







"Persoane cu dizabilități - tranziția de la servicii rezidențiale la servicii în comunitate", Cod SIPOCA/SMIS2014+: 618/127529

Reimbursable Advisory Services Agreement on Support for Speeding up the Transition of Persons with disabilities from Residential Institutions to Community-based Services (P168518)

Complex diagnosis report of the services for adult persons with disabilities at the community level

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# Contents

Introduction	8
1. Assuring quality services	18
1.1. Quality standards in the local context: legislative and institutional	18
A. Legal framework for quality assurance in disability services	18
B. Institutions involved in quality assurance in disability services	22
C. Romania's quality assurance system for disability services	23
1.2. Evaluating Romanian quality standards	29
A. General description of quality standards in social services	29
B. Romanian standards in the context of international approaches standards in social services: An overview	
1.3. Implementation of quality standards	38
1.4. Discussion and conclusions	44
Analysis of community services	47
2.1. Sheltered Houses	47
2.1.1. Legal and institutional framework	47
2.1.2. Description of services	50
2.1.3. Standards compliance and implementation analysis	62
2.1.4. Conclusions and recommendations	106
2.2. Crisis and Respite Centers	114
2.2.1. Legal and strategic framework	114
2.2.2. Description of services	117
2.2.3. Standards compliance and implementation analysis	120
2.2.4. Conclusions and recommendations	143
2.3. Home Care Services	148
2.3.1. Legal and institutional framework	149
2.3.2. Description of services	150
2.3.3. Standards compliance and implementation analysis	155
2.3.4. Conclusions and recommendations	168
2.4. Mobile Teams	172
2.4.1. Legal and institutional framework	172
2.4.2. Description of services	173
2.4.3. Standards compliance and implementation analysis	178

2.4.4. Conclusions and recommendations	191
2.5. Day Centers and Outpatient Neuromotor Recovery Service Centers	194
2.5.1. Legal and institutional framework	194
2.5.2. Description of services	196
2.5.3. Standards compliance and implementation analysis	205
2.5.4. Conclusions and recommendations	242
2.6. Personal Professional Assistance	246
2.6.1. Legal and strategic framework	246
2.6.2. Assessment of personal professional assistance	249
2.6.3. Standards compliance	250
2.6.4. Conclusions and recommendations	264
3. Developing community-based services - challenges and future directions $\dots$	266
3.1. Models of service development	266
3.2. Service development - relevant aspects and barriers	274
3.3. Conclusion and recommendations	302
References	304
Annexes	312

# **List of Acronyms**

CAbR Habilitation and Rehabilitation Center

CAPSI County Agency for Payments and Social Inspection

CEA County Employment Agency
CIA Care and Assistance Center

CITO Integration center for occupational therapy

CPRRPH Recovery and rehabilitation pilot center for adults with disabilities

CPVI Center for Independent Living

CRPD UN Convention on the Rights of Persons with Disabilities
CRRN Neuropsychiatric recovery and rehabilitation center

DC Day Center

DPH Directorate of Public Health
DSA Directorate for Social Assistance
EQUASS European Quality in Social Services

EU European Union

GA Guardianship Authority

GDSACP General Directorate for Social Assistance and Child Protection

GP General Practitioner

ILO International Labor Organization

ISU Inspectorate for Emergency Situations

MMPS Ministry of Labor and Social Protection

MO Official Gazette

mSH Minimum Sheltered House
MSH Maximum Sheltered House

MT Mobile Team

NAEO National Agency for Equal Opportunities for Women and Men

NAPSI National Agency for Payments and Social Inspection

NARPDCA National Authority for the Rights of Persons with Disabilities,

Children and Adoptions

NGO Non-governmental organization

ONRSC Outpatient Neuromotor Recovery Service Center

PIRIS Individual Program for Rehabilitation and Social Integration

PIS Individual Service Plan

PNI Program of National Interest
PPA Personal Professional Assistant
PSAS Public Social Assistance Service

RC Residential Center

ROF Regulation of Organization and Functioning

SCAAD Service for Comprehensive Assessment of Adults with Disabilities

SH Sheltered House

SID Home-based Care Service SSP Social Service Provider

UN United Nations

WHO World Health Organization

# Introduction

# Objective and context of the report

This report offers a comprehensive diagnosis of the situation at the community level in Romania of services for adult persons with disabilities. Community-based services are essential for ensuring the right to independent living and community inclusion for all persons with disabilities. As a state party to the UN Convention on the Rights to Persons with Disabilities (CRPD) since March 2, 2011, Romania has assumed the obligation to take necessary steps to implement all articles, including Article 19 on Living independently and being included in the community that requires state parties to ensure that persons with disabilities have access to a diversity of community services. This diagnosis is the first comprehensive analysis of the performance of service delivery and of its alignment with CRPD obligations that also provides necessary policy guidelines for improving the quality and access to community-based services for persons with disabilities. The diagnosis will also ground the post-2020 national strategic framework for the prevention of initial or repeated institutionalization.

The process of developing community-based services in Romania so far has led to relatively few and not diverse enough services to address the needs of persons with disabilities. There are currently only 204 community-based services<sup>2</sup> for 2,672 beneficiaries. Most services are sheltered houses (SHs) and day centers (DCs), while only very few crisis and respite centers, mobile teams, and home-based care services were developed in the past years.<sup>3</sup> The insufficient provision of appropriate community-based services is emphasized by the current EU Disability Strategy as one of the causes of segregation of persons with disabilities and the loss of control over their daily lives.<sup>4</sup> The Romanian National Disability Strategy 2022-2027 is committed to improving the access to services necessary for independent living by further increasing the number of beneficiaries and of different types of community services available to them.<sup>5</sup> This report offers an analysis of the barriers and opportunities encountered so far in the

<sup>&</sup>lt;sup>2</sup> Law no. 292/2011 on social assistance defines community services as "social services organized in an administrative-territorial unit, at the level of commune, city, municipality, that concern the services provided at home and in day centers, as well as residential services addressed exclusively to citizens from the respective administrative-territorial unit; they are similar to the social services provided in the community" (Art. 6, ii).

<sup>&</sup>lt;sup>3</sup> According to NARPDCA data, on March 31, 2021, there were 144 sheltered houses, 3 respite care centers, 2 crisis centers, 24 day care centers, 2 services with occupation profile, 24 centers for outpatient neuromotor recovery services, 1 mobile team service, 2 home care services and 2 centers for psychosocial counseling for persons with disabilities.

<sup>&</sup>lt;sup>4</sup> European Commission (2021: 8).

<sup>&</sup>lt;sup>5</sup> Operational Plan for the implementation of the National Strategy on the rights of persons with disabilities 2022-2027. Specific objective 5.3. Improving the access to social services in the community necessary for independent living. The targeted services are centers for independent living, centers for community services and training, respite/crisis centers, home-based care services, mobile teams, day centers, and outpatient neuromotor recovery service centers, as well as personal assistance services. Currently in the consultation process.

process of developing the current services that must be considered in the future to ensure access to more and diverse services for persons with disabilities.

The report includes the analysis of six types of community-based services. The services evaluated are those licensed in compliance with the mandatory minimum specific quality standards for social services for adults with disabilities stipulated by Order no. 82/2019: (i) sheltered houses; (ii) respite care and crisis centers; (iii) home care services; (iv) mobile team services; and (v) day centers and outpatient neuromotor recovery service centers. In addition, the assessment covers professional personal assistance services stipulated by Order no. 1069/2018.

# Relevance and aspects of assessment

Independent living and inclusion in the community is a basic dimension of human living that entails freedom of choice and control over all aspects of life. The right to live independently is stipulated by the CRPD ratified by Romania in 2011.<sup>6</sup> Article 19 of the CRPD specific to this right requires States Parties to take all measures to protect, promote and ensure this right, mainly to ensure that persons with disabilities: (i) have the opportunity to choose the type and location of their home, as well as the persons they wish to share it with, on an equal footing with other persons; (ii) have access to a wide range of support services that allow them to live independently in the community; and (iii) may use services intended for the general population which must be accessible and meet their needs.

According to the CRPD, everyone can live independently and included in the society provided they can exercise choice and control in all areas affecting their life. Choice and control as key dimensions of an independent life cannot be exercised in the absence of support and access to goods and services necessary for carrying out daily tasks and maximizing human potential. Persons with disabilities must have access to a wide range of support services for facilitating personal autonomy, self-determination, and interdependence in all areas of life and community living, including inter alia: transportation, information, communication, housing, a decent workplace, education, religious activities, cultural activities, participation in public and political life, personal

<sup>&</sup>lt;sup>6</sup> Law no. 221/2010.

<sup>&</sup>lt;sup>7</sup> CRPD Committee (2017: para. 8). The CRPD Committee is the UN body responsible for monitoring the implementation of the provisions of the CRPD in States that have ratified the CRPD.

<sup>&</sup>lt;sup>8</sup> "Support for persons with disabilities encompasses a wide range of formal and informal interventions, including live assistance and intermediaries, mobility aids, and assistive devices and technologies. It also includes personal assistance; support in decision-making; communication support, such as sign language interpreters and alternative and augmentative communication; mobility support, such as assistive technology or service animals; living arrangements services for securing housing and household help; and community services. Persons with disabilities may also need support in accessing and using general services, such as health, education and justice." (Special Rapporteur on the Rights of Persons with Disabilities, 2017: para. 14).

relations, daily routine, habits, clothing, food, hygiene and medical care, family life, and sexual and reproductive rights.

Community-based services are essential for ensuring the right to live independently and included in the community for all persons with disabilities. The implementation of CRPD Article 19 on Living independently and being included in the community requires state parties to ensure the right of all persons with disabilities to live in the community. Currently, 15,7239 institutionalized adults with disabilities live in residential centers throughout Romania. Deinstitutionalization is a complex and multilayered process that requires, among other things, a clear and targeted strategy for the development, improvement, and integration of community-based services tailored to the specific needs of all persons with disabilities and responsive to all their life requirements. Currently, persons with disabilities already living in the community have limited access to a relatively small number of services for facilitating their full inclusion and participation in society as equal citizens.

Community-based services must be diverse enough to ensure support for all persons with disabilities irrespective of their level and type of disability. Article 19 of the CRPD requires state parties to ensure that "persons with disabilities have access to a range of in-home, residential, and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." A diversity of services must be developed in order to ensure tailored support for any persons with disability to live in the community. According to the CRPD Committee, persons requiring high levels of support, especially those with intellectual disabilities are oftentimes accommodated in institutions or in other residential services, after having been assessed as "unable to live in the community". This is contrary to the CRPD, which recognizes the right of all persons with disabilities to live in the community regardless of their level of intellectual capacity, self-functioning, or support requirements. Currently, there is little diversity among existing services, and information about the barriers to the process of developing community-based services is limited.

Ensuring independent living and inclusion in the community also requires adequate access for persons with disabilities to services and facilities for the general population. Article 19 stipulates that community inclusion and independent living require the availability and responsiveness of community services and facilities for the general population on an equal basis to persons with disabilities. Equally essential is the exercise of the right to inclusive, accessible employment, education, and health

<sup>&</sup>lt;sup>9</sup> NARPDCA (2021).

<sup>&</sup>lt;sup>10</sup> CRPD Committee (2017: para. 21).

<sup>&</sup>lt;sup>11</sup> CRPD Committee (2017: para. 21).

care. The CRPD UN Committee notes that "[s]tructural reforms designed to improve overall accessibility within the community may reduce the demand for disability-specific services," since often inaccessibility and unavailability of certain general services may lead to initial or repeated institutionalization or the pressure to accept only the available disability-specific services. This is particularly problematic in the case of beneficiaries of community-based services located in rural areas, where access to employment, education, housing and health services is even more limited.

In order to support independent living and full inclusion in society, community-based services must be designed and provided according to specific principles and must have certain characteristics. Community-based services must be developed in a way that prevents isolation and segregation and ensures a continuous person-centered delivery that is freely chosen and under the control of the person with the disability (see Box 1). At the same time, services must be: (i) universally accessible and in the proximity of the person's residence; (ii) acceptable with regard to compliance with quality standards<sup>13</sup> as well as gender, age, and culturally sensitive; (iii) affordable, taking into account persons with low incomes; and (iv) adaptable, by ensuring necessary flexibility to the individual needs of each person.

#### Box 1: Principles of community-based service provision

- Services must facilitate the full inclusion and participation in the community, and not merely provide residence, while preventing isolation and segregation from or within the community.
- Services must be chosen and controlled by the person with disabilities, who must be provided with access to information, advice, and advocacy to be able to make informed decisions about the type of support needed.
- Services must be provided in a person-centered way tailored to the needs, will, and preferences of the person with disabilities, who must also be involved in the design and evaluation of services.
- Services must ensure continuous support for the duration of the need and must be amended as a response to the changing needs and preferences of the person with disabilities.
- Service provision should not be conditioned by the person with disabilities' home or residence, but by their needs and requirements. The residence may be changed without losing access to services, while high-level support may at any time be provided in ordinary housing.
- Living alternatives to institutionalized life must be spread out within the community and cannot be clustered on the same street or in residential buildings hosting groups of persons with disabilities.

<sup>&</sup>lt;sup>12</sup> CRPD Committee (2017: para. 33).

<sup>&</sup>lt;sup>13</sup> CRPD Committee (2017: para. 35).

Source: European Expert Group on the Transition from Institutional to Community-based care (2012: 83-84).

Even though freedom of choice in relation to services provided is essential to self-determination and control over one's life, persons with disabilities are rarely able to exercise it. Service provision for persons with disabilities is rarely self-directed. This situation is a consequence of multiple factors, such as:

- The lack of diverse alternatives from which a person may choose according to their own needs and preferences, which forces persons to accept available options.
- The lack of legal capacity (de jure, when the person is placed under guardianship, or de facto, when somebody else decides for the person with disabilities; that is, the family, the authorities, and so on).

In Romania, deprivation of legal capacity has been recently declared unconstitutional<sup>14</sup> as a practice that harms human dignity and affects the autonomous development of human personality, and is contrary to the equal right of persons with disabilities to be recognized in front of the law as stipulated by the CRPD.<sup>15</sup> In practice, deprivation of legal capacity occurs in any situations when persons with disabilities are denied the possibility to take one's own decisions, such as the administration of any medical treatment, or their involvement in any activities without their full and informed consent.<sup>16</sup>

# Methodology

#### **Data collection instruments**

The evaluation of services for adults with disabilities at the community level was based on both quantitative and qualitative data on four main aspects: (i) service compliance with mandatory minimum specific quality standards stipulated by national legislation; (ii) service compliance with quality standards' requirements regarding independent living; (iii) compliance with independent living requirements; and (iv) barriers encountered to developing and maintaining community-based services. In terms of methodology, the evaluation involved the development of specific tools for collecting data subsequent to each of these four dimensions and also took into account the nature of each social service that fell within the scope of this evaluation (see

<sup>&</sup>lt;sup>14</sup> Decision no. 601 from July 16, 2020, regarding the exception of unconstitutionality of the provisions of Art. 164 (1) Civil Code (CC), published in the Official Journal No. 88, January 1, 2021. The CC holds that guardianship in the absence of safeguards for ensuring the exercise of legal capacity infringes on the provisions of constitutional provisions of Art. 1 (3), Art. 16 (1) and of Art. 50, in its interpretation in view of Art. 20 (1) and in view of Art. 12 of the CRPD.

<sup>&</sup>lt;sup>15</sup> CRPD (2014: Art. 12).

<sup>&</sup>lt;sup>16</sup> See (World Bank, 2021), Ch. 2.1. Limited possibility of persons with disabilities to make decisions.

#### Box 2: Data collection instruments

- Questionnaires for checking the compliance of community-based services with quality standards for each type of service. These instruments measure the degree of compliance with all mandatory requirements provided by the standards, which are grouped in specific modules regarding the management of the social service, accessing the service, needs assessment and service planning, and activities provided, as well as beneficiaries' rights. In addition, the instruments also collected administrative data related to the profile of beneficiaries (by sex, age, type, and degree of disability; legal ability; family situation; residence; history of institutionalization; duration of use of the service; and so on). The questionnaires also covered material and human resources, activities carried out within the service, mechanisms for filing complaints, and protection of rights.
- o Instruments for the external evaluation of community-based services for each type of service. These instruments measure the services' compliance with various dimensions relevant for ensuring independent living, such as the location of the service in the community; adequate standard of living; choice and control of the service; access to mainstream services in the community; health status; involvement and participation in civic, political, and cultural life; intimacy and dignity; daily life; personal relations and social contacts; The instruments also measured family life, service staff, needs-assessment and service planning and monitoring, independent living skills, informed consent, access to information, protection against violence and abuse, and complaints and feedback procedures.
- A questionnaire for beneficiaries who live in sheltered houses. This instrument collects data regarding beneficiaries' satisfaction, inclusion, and participation in the community; services and support for independent living; choice and control over daily life and services provided; rights; and material well-being.
- o Interview guides with beneficiaries from other types of community-based services. These guides collect data on aspects similar to those assessed by the instruments for the external evaluations.
- o Interview guides with social service providers (SSP) directors, service coordinators, and NGO representatives. These guides collect data on types of services developed at the local level as well as barriers in the process of development, needs for services at the local level, collaboration with relevant stakeholders, ensuring access to services for persons with disabilities, and assessment and monitoring of services. They also collected data on the implementation of quality standards, service integration, access to mainstream services, compliance of services with independent living principles, consciousness-raising campaigns, and so on.

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## Data collection process

The universe of the evaluation consisted of all public community social services approved by NARPDCA, more precisely those under the administration of GDSACP or local public authorities, and which at the time of data collection (March-May 2021) had a valid operating license or were in the process of licensing or relicensing. The analysis excluded the services of private providers as well as those not licensed, based on specific minimum quality standards for services for adults with disabilities. The following categories of services were included in the evaluation scope: (a) sheltered housing; (b) respite and crisis centers; (c) day centers and outpatient neuromotor recovery service centers; (d) mobile teams; (e) home care services; and (f) personal professional assistance.

Data collection took place between March and May 2021, in three distinct stages. First, interviews were conducted with representatives of public social service providers (GDSACP and PSAS) from 20 counties and coordinators of community services in these counties, as well as with representatives of NGOs active in the field of protection of the rights of persons with disabilities. The data collected through these interviews focused on the process of developing and ensuring quality services at the community level to guarantee an independent life for adults with disabilities. A total of 49 interviews were conducted. Their distribution by type of institution is presented in the following table (Table 1).

Table 1. Distribution of interviews with public SSPs and NGOs

Interviewees	terviewees Counties	
Representatives of GDSACP (directors, deputy directors, coordinators of service departments for adults with disabilities)	(sector 3), Călărași, Constanța, Dâmbovița, Dolj, Gorj,	18*
Coordinators of community services (SH, DC, SID, MT, crisis center)	Alba, Bihor, Bucharest (sector 3), Constanța, Dâmbovița, Dolj, Hunedoara and Iași	11
Representatives of PSAS that have community services for adults with disabilities	Alba, Argeș, Brașov, Călărași, Constanța, Maramureș, Timiș and Tulcea	8
Representatives of NGOs, service providers or active in the field of protection of the rights of persons with disabilities	Harghita, Iași, Satu Mare, Sibiu	12

*Note*: \* 18, of which 10 with GDSACP who have no or very few services at the community level.

A second stage was to collect data to assess the compliance of services at the community level with specific minimum quality standards. At this stage, an exhaustive survey was conducted through online questionnaires and administrative data were collected from all services in the community for adults with disabilities. For each of the six types of services there was a specific data collection tool, which was filled in by the service coordinator. In total, data were collected from 142 public social services, licensed or in the process of licensing, for adults with disabilities at the community level from 28 counties (100 sheltered houses, 22 day centers, and 12 outpatient neuromotor recovery service centers, 2 crisis centers, 2 home care services, 2 mobile teams, and 2 professional personal assistance services). Out of 142 services, 140 being under the administration of GDSACP and only 2 belonging to some PSASs.

The third stage was the external evaluation of the 142 services mentioned above, aimed at assessing how community services meet the requirements for ensuring an independent life for adults with disabilities. This stage had two data collection components.

- The first component was an external evaluation carried out through "virtual" visits to each of the 142 services conducted by experts specially trained for this purpose. The virtual visits within the services were carried out through video-calling applications and used as methods of data collection observation interviews with coordinators and employees of the services and document analysis, using as a tool for data collection a standardized evaluation form, still specific to each type of service. Among the analyzed documents were the specific regulations and procedures, and a number of 2 to 7 files of the beneficiaries for each service included in the evaluation were also consulted through a survey.
- The second component was aimed at evaluating the provision of services from the perspective of beneficiaries. To capture this, World Bank experts conducted questionnaires with a sample of beneficiaries of sheltered housing and semi-structured interviews with beneficiaries of other types of community services. All questionnaires and interviews were conducted by video calls, trying as much as possible to carry them out in the absence of third parties who could have influenced the responses of the beneficiaries (Table 2). There were differences between the designed and the completed sample because in some services there was no beneficiary with the necessary level of understanding and communication to be able to participate in the interview.

In the case of SHs, the sample of beneficiaries was probabilistic, proportional to the capacity of all 100 SHs in the evaluation universe. The selection of beneficiaries in the sample was also probabilistic, using random numbers, with the possibility to replace a person in case of refusal. At the same time, the data collection methodology allowed the completion of questionnaires through a proxy respondent (another person, usually among SH employees, who knew the respondent very well) if the selected person did not have the ability to understand the questionnaire. Out of 194 filled-in questionnaires, 41 were administered to a proxy respondent. It

should be noted that in 38 cases, the respondent was assisted during the interview by one of the SH employees.

The external evaluation sheets for day centers, outpatient neuromotor recovery service centers, and SHs, as well as questionnaires with beneficiaries of SHs, were filled in by World Bank experts in an online application specially developed for this purpose, which allowed very good control from the perspective of data entry and validation errors.

Table 2. External evaluation of public social services, licensed or in the process of licensing, for adults with disabilities at the community level

Type of service	No. of services evaluated	Number of questionnaires/interviews conducted with beneficiaries	
Sheltered houses	100	194	
Day centers	22	19	
Outpatient	12	20	
neuromotor			
recovery service			
centers			
Crisis/respite	2	5	
centers			
Mobile team services	2	6	
Home care	2	4	
services	-47		
Personal	5 <sup>17</sup>	5	
professional			
assistance services			
Total	145	253	

# Structure of the report

Besides the introduction, the report is structured in **three parts**.

- The first part offers a description of the quality assurance system of community services for persons with disabilities in Romania, by assessing the legal and institutional framework, while also providing an in-depth analysis of quality standards for community services, both in terms of content (indicators, forms, person-centeredness, etc.) and in relation to international standards, to determine whether they can provide a minimum quality framework tailored to the individual needs and preferences of persons with disabilities.
- The second part contains six chapters of a comprehensive analysis of each type of service evaluated. Each chapter can be read on its own, as it offers an analysis of the degree of service compliance with mandatory quality standards in addition to

<sup>&</sup>lt;sup>17</sup> In the case of PPA, administrative evaluation of compliance with the minimum quality standards involved the evaluation of the service within the GDSACP dealing with the management of personal assistants, while the external evaluation was performed directly at the homes of professional personal assistants.

- an assessment of aspects relevant for ensuring independent living, as well as a series of recommendations considering the value and success of the service.
- The third part is an analysis of the process of developing community-based services so far, by assessing various approaches to development as well as barriers encountered in terms of access to financial, human, and material resources; collaboration between stakeholders; service integration and case management; person-centered aspects of service delivery; and working with families and communities.

This chapter analyzes the minimum quality standards for social services for persons with disabilities. The analysis is intended to serve as an overall introduction to the Romanian system of quality assurance, and offers a foundation on which to evaluate the services discussed in subsequent chapters. To this end, this chapter: (i) outlines the legal and institutional framework for Romania's quality standards for disability services; (ii) presents and evaluates the standards and the national quality assurance system; and (iii) discusses the standards' implementation from the perspective of service providers and coordinators.

# 1.1. Quality standards in the local context: legislative and institutional A. Legal framework for quality assurance in disability services

#### Law no. 197/2012 regarding quality assurance in the field of social services

Romania's quality assurance system for social services is based on a 2012 law (Law no. 197/2012)<sup>18</sup> that was modified in 2019 (Law no. 177/2019).<sup>19</sup> Law no. 197/2012 establishes the broader framework for assuring quality in social services, articulates the main approaches and instruments, nominates the institutions and governmental bodies to be in charge of implementing the laws, and describes the main procedures involved in assuring quality; namely the processes of accreditation and licensing, issuing a quality class certificate, and conducting inspections. The purpose of the law is to offer a unitary, standardized, quality assurance system (defined as a set of procedures for evaluation, certification, monitoring, and quality control) that applies to *all* social service providers (SSPs), both private and public, in Romania. Law no. 177/2019 brought changes to the original law both in substance and language with the purpose of clarifying some of the procedures and bringing them in line with other legislative and institutional changes. These laws are supported by a set of methodological norms<sup>20</sup> that lay out concrete procedures for implementation.

The law's conceptual framing, language, and objectives, especially after the 2019 modifications, are in line with a more modern, progressive approach to social services. The law offers an approach that is rooted in a commitment to human rights and non-discrimination. The legislation also: (i) proposes a person (beneficiary) centered approach (tying quality to beneficiary satisfaction); (ii) lists beneficiary involvement and input as an essential aspect of the system and how standards and criteria are defined; (iii) views quality assurance as a continuous process driven by improvement and striving for excellence; and (iv) aims to promote partnerships and cooperation between all stakeholders, with a focus on developing a community service-

<sup>&</sup>lt;sup>18</sup> Law no. 197/November 1, 2012 regarding quality assurance in the field of social services, published in Official Journal no. 754/November 9, 2012.

<sup>&</sup>lt;sup>19</sup> Law no. 177/October 10, 2019 for the modification of Law no. 197/2012.

<sup>&</sup>lt;sup>20</sup> Methodological norms for the application of Law no. 197/2012, adopted through Government Decision no. 118/February 19, 2014. It is interesting to note that the methodological norms were published two years after the law was published, making the law impossible to apply until then.

The quality assurance system is defined in terms of "standards, criteria, and indicators" to be used in all processes within the scope of the law. These should be complex and contain measurable criteria on the structure, process, and results of the services being offered.

However, the processes, procedures, and instruments defined in the law and methodological norms do not fit the promise laid out in the law's first chapter. The legislation *only* offers minimum quality standards; the entire system is built around them as both a threshold to be passed to legally offer social services and to trigger sanctions, in case a certain level of quality is not met. A second set of instruments is mentioned, namely classes of quality to be granted to providers that exceed these minimum standards. This last procedure is left vague, with an evaluation team to be assembled on request, and quality indicators to be produced (although it is unclear when or how) in relation to the minimum standards. The forms and instruments for these quality classes presented in the methodological norms are equally vague and non-directive.

The law also fails to offer clear ways to improve the quality of social services, besides enforcing minimum standards. The law does not provide for any other positive, supportive measures or instruments that would help fulfill the stated commitment to cooperation, integration, and continuous quality improvement (and not just meet the bare minimum in services). Furthermore, outside of the law's first, more general chapter, any concerns regarding beneficiaries (the person-centered approach, beneficiary involvement, beneficiary satisfaction) are not included at all. All provisions discuss only the various institutions involved, the services providers, and their rights and obligations.

Order no. 82/2019 regarding approval of the minimum compulsory specific standards for social services for adults with disabilities

Social services for adults with disabilities must observe a specific set of minimum quality standards. Law no. 197/2012, which regulates the quality assurance system regarding social services, references a set of minimum quality standards that all social services must implement to be licensed. Regarding services for persons with disabilities, current standards were issued and adopted through Order no. 82/2019 of the minister of labor and social justice, which provides, in its annexes, specific standards for both residential and community services. The community services mentioned in the law and the standards are sheltered houses, crisis centers, respite centers, day centers, home care services, and mobile services. In line with the main law, the order explicitly indicates that Social Inspection is the institution responsible for evaluating social services (verifying compliance), using the standards that were provided.

<sup>&</sup>lt;sup>21</sup> Different types of social services must observe separate sets of minimum quality standards in accordance with their specific profile. The Ministry of Labor and Social Protection established four distinct areas of social services—Elderly Persons, Child Protection, Persons with Disabilities, and Protection of Victims of Domestic Violence. See <a href="https://www.serviciisociale.ro">www.serviciisociale.ro</a>

The current standards for services for adults with disabilities have replaced a number of other standards from 2003 and onwards that were successively repealed. The first set of standards was adopted in 2003 and was applicable to all institutions for special protections that provided services to adults with disabilities, regarding their specific profile.<sup>22</sup> The standards were further repealed in 2005, when the new standards were approved specifically for: (i) residential centers; (ii) sheltered houses; and (iii) day centers.<sup>23</sup> While the next quality standards from 2008 covered the same type of services,<sup>24</sup> a new type (home-based service) was introduced in 2015.<sup>25</sup> It was only in 2019 that quality standards were first introduced for mobile teams, crisis centers, and respite centers.

Order no. 1069/2018 regarding the approval of compulsory minimum standards for ensuring the care and protection of adults with disabilities by a personal professional assistant

Personal professional assistance is an additional service for persons with disabilities. Law 448/2006 establishes the service of a personal professional assistant (PPA) who can provide care and protection for adults with accentuated or high degrees of disability, who do not have access to housing, lack income, or have income less than the medium national net wage. While provision for this service was set out in the first version of this law, the law that provided conditions for obtaining a certificate as a PPA was only passed in 2017. Finally, the minimum quality standards were passed in 2018, along with the law regarding monitoring and controlling PPA activity.

#### Other laws

Several other laws are relevant to quality assurance in disability services. Government Decision no. 1002/2019 offers a framework for the organization, functioning, and attributes of the National Authority for the Rights of Persons with Disabilities, Children and Adoptions (NARPDCA). Some of the NARPDCA's responsibilities are directly relevant to regulating the quality of disability services. The NARPDCA is the

<sup>&</sup>lt;sup>22</sup> Order no. 22/January 29, 2003 regarding the approval of quality standards for services provided in special protection institutions for handicapped persons, Official Journal no. 139/March 4, 2003. At the time, the institutions for special protections for adults with disabilities were considered the pilot centers, centers for care and assistance, centers for recovery and rehabilitation, centers for integration through occupational therapy, family-type sheltered housing, day centers, early intervention centers, and other specific services set up under the coordination of county councils with the approval and coordination of the National Authority for Persons with Disabilities (Government Emergency Ordinance no. 102/June 29, 1999, regarding the special protection and employment of persons with disabilities).

<sup>&</sup>lt;sup>23</sup> Order no. 205/2005.

<sup>&</sup>lt;sup>24</sup> Order no. 559/2008.

<sup>&</sup>lt;sup>25</sup> Order no. 67/2015.

<sup>&</sup>lt;sup>26</sup> Law no. 448/2006, Art. 45 (1).

<sup>&</sup>lt;sup>27</sup> Government Decision no. 548/2017.

<sup>&</sup>lt;sup>28</sup> Order no. 1069/2018.

<sup>&</sup>lt;sup>29</sup> Ministry of Labor and Social Justice Order no. 1690/2018.

institution responsible for licensing social services for persons with disabilities.<sup>30</sup> Government Decision no. 1002/2019 reinforces Law no. 197/2012 in that it makes the NARPDCA responsible for quality certification and evaluation (including licensing) in the area of disability services. While the previous law that regulated the functioning of the NARPDCA<sup>31</sup> also stipulated that it was responsible for assigning quality classes to disability social services, the current law leaves out this provision altogether. As a result, there is an institutional void: the fundamental law (Law no. 197/2012) indicates that there should be a quality classification system for social services, but no current law indicates which institution should carry out this requirement.

The law that regulates the statute and activity of social inspectors (Government Emergency Ordinance no. 82/2016) indicates, among other things, that social inspectors are responsible for the following activities: (i) verifying SSPs to ensure they follow the minimum standards on which their accreditation and licensing were based; (ii) evaluating quality of services; and (iii) advising and providing guidance for improving service delivery, particularly to meet minimum quality standards. Overall, the language and framing of the activity required of social inspectors defines them as a type of social services and benefits police, based on the premise that both beneficiaries and service providers break laws and regulations, and it is social inspectors' duty to catch and investigate these instances.<sup>32</sup>

Romania's fundamental piece of legislation in the area of social services is the social assistance law (Law no. 292/2011). It lays out the general approach of the Romanian state in the field of social assistance, defines the scope of social services and benefits, and describes their provision and institutional framework (centrally, through the Ministry of Labor and Social Protection, and locally through the local administration). The law also defines the minimum acceptable level of performance for SSPs. <sup>33</sup> The law establishes the Ministry of Labor and Social Protection as the institution responsible for: (i) developing criteria, performance indicators, and quality standards for social services, including those for persons with disabilities, <sup>34</sup> and (ii) monitoring and supervising their observance by public and private service providers <sup>35</sup> and the local public administration authorities.

<sup>&</sup>lt;sup>30</sup> To obtain the notification of acceptance from NARPDCA, the SSP must file in: (i) a request for the notification; (ii) the draft decision of the county council, respectively local of the sector Bucharest municipality or the decision of the governing body of its association the foundation, as appropriate; (iii) a substantiation note; and (iv) the draft organizational chart. (Government Decision no. 268/2007).

<sup>&</sup>lt;sup>31</sup> Government Decision no. 50/2015, Art. 4, para. dd.

<sup>&</sup>lt;sup>32</sup> For example, in Art. 5, para. 3, the activity of social inspection is defined as "the activity through which [social inspectors] identify the cases of fraud, abuse, and negligence that have generated material and financial prejudices to the state, as well as serious violations of the social rights of the beneficiaries and transmit the data and the information to the appropriate institutions."

<sup>&</sup>lt;sup>33</sup> Law no. 292/2011, Art. 6 (mm).

<sup>&</sup>lt;sup>34</sup> Law no. 292/2011, Art. 112 (3) m).

<sup>35</sup> Law no. 292/2011, Art. 105 (n).

The main law regarding protecting and promoting the rights of persons with disabilities (Law no. 448/2006) establishes the observance of mandatory standards by SSPs for persons with disabilities, and the role of national and local agencies for payments and social inspections to evaluate, monitor, and control the observance of standards. 36 The law also stipulates the types of sanctions and fines for failing to comply with the standards.<sup>37</sup>

#### B. Institutions involved in quality assurance in disability services

The NARPDCA is an institution subordinated to the Ministry of Labor and Social Protection. It is responsible for ensuring compliance with both the treaties Romania has signed and ratified in the area of rights of persons with disabilities-including the CRPD-and national legislation. The NARPDCA elaborates the minimum standards and issues accreditations and licenses for all disability social services. It is also the main entity responsible for developing and proposing strategies, projects, and measures for public policy and legislation in the area of protecting and promoting the rights of persons with disabilities, including the quality assurance system to be used in evaluating disability services.

The National Agency for Payments and Social Inspection (NAPSI) is the main public institution mandated to ensure quality in the area of social services in Romania. NAPSI is a large institution, under the jurisdiction of the Ministry of Labor and Social Protection, with branches in all counties (called the County Agency for Payments and Social Inspection, CAPSI). NAPSI has a wide array of responsibilities, including: (i) administering social assistance benefits, including public social services; (ii) evaluating and monitoring social services and various social protection measures; and (iii) verifying the way disability certificates have been issued.<sup>38</sup> The declared mission is to ensure that all those entitled have access to social benefits and services, but most of the obligations and expressed activities are related specifically to protecting state (financial) resources.

The Directorate of Social Inspection is a branch of NAPSI, and is the main body responsible for carrying out social inspections. The Directorate is responsible for monitoring and supervising how quality criteria, standards, and indicators are followed by service providers. While accreditations and licenses are offered by a different institution, the Directorate of Social Inspection is responsible for monitoring continued compliance with the conditions included in those accreditations and licenses. The Directorate performs its responsibilities through three types of missions. Thematic inspection missions are planned, thematic, nationwide inspections that look at social services as a whole and lead to national reports aimed at improving the legislative and institutional framework. Evaluation/monitoring missions are announced visits that verify compliance with standards. SSPs are notified 15 days prior to the visits. Finally, unannounced inspection missions are visits that follow up on complaints or internal

<sup>&</sup>lt;sup>36</sup> Law no. 448/2006, Art. 34 (2).

<sup>&</sup>lt;sup>37</sup> Law no. 448/2006, Art. 100 (e).

<sup>&</sup>lt;sup>38</sup> Government Emergency Ordinance no. 113/2011.

decisions and examine compliance with quality standards as well as other kinds of problems or violations.

#### C. Romania's quality assurance system for disability services

Romania's quality assurance system for disability services is based, in practice, on: (i) a process of accreditation and licensing; (ii) conducting inspections; and (iii) awarding quality classes. It relies on establishing minimum standards and guarding against failure to meet them, rather than encouraging improvement and excellence.<sup>39</sup>

#### Accreditation and licensing

Only accredited SSPs can apply to have their services licensed. Accreditation is the process of authorizing a private or public entity to function as a provider of social services for persons with disabilities. Accreditation is offered indefinitely, as long as certain standards and criteria are met. One of the criteria is that within three years of accreditation, the provider will have at least one licensed social service. Licensing 40 is offered to SSPs with accreditation for particular social services, and is valid for five years, after which the service has to be re-licensed. Licenses must be obtained for each service offered and for each location. For disability services, licensing is offered by NARPDCA, after an evaluation of the application in reference to the set of minimum quality standards (discussed in a separate section), as well as of other documents. Compliance with minimum standards is based on a self-evaluation carried out by the social service, using a special form. 41 A provisional license is granted until Social Inspection carries out its assessment, and a definitive license may be issued for five years.

The process of obtaining a license can be a demanding process for SSPs. Licensing is a multi-phase process that involves multiple state actors, an elaborate sequence of actions and activities, and reassessments of minimum quality standards as reference quality indicators (see Figure 1). This is a bureaucratic process that, as many SSP representatives interviewed for this report pointed out, has little to do with the actual objective of providing quality services to persons with disabilities. The process of applying for the license requires assembling over 30 separate documents that must be sent to the Ministry of Labor and Social Protection by regular mail. The process could be simplified by consolidating some of the documents and digitizing at least part of the procedure. 42 In the process of licensing services, the providers received methodological

<sup>&</sup>lt;sup>39</sup> Attempts exist, but they are not actually integrated into any systematic or intentional approach for using best practices to promote quality improvement. For example, in 2018, the Ministry of Labor published a collection of the best 100 social services in Romania, a booklet with brief information about the service and what makes it special. The booklet was meant more like a celebratory effort, to mark 100 years from the Great Union, considered the founding of Great Romania. Ministry of Labor and Social Protection (2018).

<sup>&</sup>lt;sup>40</sup> Although the distinction between accreditation and licensing is drawn in the text of the main law (Law no. 197/2012), the methodological norms use both terms to refer to the process of licensing a social service (as a qualifier to different other terms, like "commission," "application," and "certificate").

<sup>&</sup>lt;sup>41</sup> Included in the standards for each type of social service for persons with disabilities provided by Order no. 82/2019.

<sup>&</sup>lt;sup>42</sup> World Bank (2021: 167).

support from NARPDCA, however, some complained about not receiving proper guidance from state authorities.

Figure 1. Process for licensing social services



Submitting the file for social service licensing to MLSP headquarters (including the application form for social service licensing, the decision of establishment, the ROF, the commitment, the selfevaluation form, etc.)

Settlement deadline: 60 days - during this time the evaluator (MLSP/NARPDCA/NAEO) can request clarifications and/or additional supporting documents

Within a year, the social inspectors within CAPSI carry out a field inspection of the fulfillment of minimum quality standards of the social service in order to issue the 5-year Operating License.

CAPSI sends to the MLSP, respectively to the institutions evaluating the licensing file, the notification of granting/withdrawing provisional operating license.

MLSP/NARPDCA/NAEO issues the 5-year Operating License or the Decision for withdrawing the provisional operating license.

Source: Ministry of Labor and Social Protection, Accreditation of public social service providers and licensing social services: of http://mmuncii.ro/j33/images/Documente/Familie/Acreditarelicentiere PublicMMPS.pdf

Besides the bureaucratic intricacies of applying for and obtaining the license, the process is fraught with difficulties related to meeting the minimum standards as a condition for obtaining the provisional or permanent license. Interviews with SSP representatives indicated a variety of difficulties with the process of licensing, such as the impossibility of ensuring infrastructure aspects as required by standards (accessibility, bathrooms, etc.), mandatory approvals from other state institutions (such as the Directorate for Public Health) that take time and resources and may delay the process of licensing, the requirement to ensure access to a day center for beneficiaries of sheltered housing, etc. While minimum quality standards constitute the basis for licensing, their level of detail concerning certain requirements can sometimes be invoked to halt or delay the process. There is tension, as evidenced by interviews with SSP representatives, between the authorities' attachment to the letter of the law and their invested attribution to interpret it and the service providers' own interpretation.

Box 3: Barriers to the process of licensing community-based services for persons with disabilities

"In the process of getting the license, you often come across rigid terms that lead to endless paperwork changes (for example, the center is under the subordination of GDSACP or the center is in the structure of GDSACP; why do we have specialized inspectors although in the organizational charts we only have one type of personnel, we really turn into bureaucrats, this is the problem with the standards." -GDSACPDirector

"Extremely bureaucratic licensing process... Too much distance between the people in the offices who set the laws and give licenses, and the frontline people, who actually work in the field... It's a bureaucratic process torn from reality." —Private SSP

"The bureaucratic part, you can ask any SSP, is so horrible that you feel guilty for providing services, you are nearly punished for providing services, for daring in a country like Romania run by public authorities to provide services." —Private SSP

"The sheltered houses are located in blocks of flats, but we need approvals from DSP, DSV, firefighters, ISU, etc. They did not have buildings specifically designed for sheltered houses, and obtaining permits means a lot of time and money. Moreover, DSP does not give approval without the consent of the neighbors (50 percent of neighbors in the block of flats), there were problems with one of the neighbors and for this reason, DSP does not give approval for one of the apartments." -Private SSP "I submitted the paperwork for obtaining the license, after the approval from NARPDCA, you have to respect ad litteram everything in standards, some unimaginable requirements, after you submit the file to MLSP, then the file goes to NARPDCA, another office deals with the license, they send you to MLSP, they contradict MLSP and it's something... It is understandable why there are few suppliers, you are held accountable for having public-private partnerships in order to survive, we were told that NGOs are rich, they have to have private sponsors... Consequently, there are many companies that provide only care services (accommodation) so as to circumvent the accreditation as SSP." —Private SSP

"Matters of detail - standards for sheltered houses require that the surveillance cameras should be in the common spaces and in the yard, but it does not say that SSP has the obligation to install cameras. On this subject, we throw the cat from one to another. We do not want to put rooms in the beneficiaries' homes. If things are not required as such, then it is not an imperative, we interpret it as a possibility, but the Authority says otherwise." —Private SSP

Source: World Bank interviews with GDSACP representatives and private SSPs (March-April 2021).

## **Inspections**

Inspections are the main way to evaluate and monitor quality. The purpose of inspections is both to verify compliance with minimum quality standards (as well as other laws and regulations), and issue fines and other punitive actions (withdrawing accreditation or licensing) if problems are found. In addition, the inspection teams will provide concrete indications for how to remedy the problem and improve quality, so the minimum standards are met.<sup>43</sup> The inspections are carried out by social inspectors, a type of public servant with experience in the general field of social inspection. The frequency of CAPSI monitoring varies greatly; some of the SSP representatives interviewed confirmed that CAPSI monitoring CAPSI takes place at least once a year (and in some cases up to four times a year), while some coordinators suggested that social inspectors only come when the service needs to be relicensed—every five years, or whenever there are various notifications or complaints.

Although inspections should have an evaluative component aimed at continuously improving the service being offered, they are mainly oriented towards control. The promise and basis for a different approach exist in the law (Law no. 197/2012), but unfortunately, there is a lack of specially trained personnel, concrete instruments and procedures, and a general framework for cooperation, communication, and promotion of best practices between service providers. 44 According to their last annual report (2019), the Social Inspection uses "evaluation" to refer to the process of evaluating a service in order to license it, and "monitoring" to the process of verifying compliance with the minimum standards, once a service has been licensed. 45

The procedure of inspection requires a unitary framework with measurable indicators and common guidelines, as well as adequate training. While social inspectors are expected to participate in annual training sessions in the field of social inspection, social protection, and other related fields, 46 there is no explicit requirement that they should be specialized in a particular type of social service or benefit. In fact, as some SSP representatives interviewed pointed out, social inspectors do not seem to have professional competencies or relevant knowledge about the purpose of social services for persons with disabilities, and particularly about independent living. Rather, in the absence of specific indicators and methodologies, social inspectors tend to pursue missions as needed, mostly by checking the service documents. This results in divergent local inspection practices. In addition, inspections as regulatory practices could be regularly evaluated to ensure that responsible local institutions fulfill their responsibilities to adequately control the provision of social services. 47

# Box 4: SSPs' experiences with social inspection

<sup>&</sup>lt;sup>43</sup> Government Emergency Ordinance no. 82/November 16, 2016 for the approval of the Special Statute of the specific public position of social inspector and for the amendment and completion of some normative acts. Art. 7 (e)

<sup>&</sup>lt;sup>44</sup> World Bank (2020: 170).

<sup>&</sup>lt;sup>45</sup> For example, NAPSI (2019: 20–21, 24–25).

<sup>&</sup>lt;sup>46</sup> Government Emergency Ordinance no. 82/2016, Art. 9 (1) (j).

<sup>&</sup>lt;sup>47</sup> Chiriacescu (2008: 42).

"At the level of authorities, what I can see is that the law appears, and they come and hit you with the law over the head, like, look, the standard was modified and you're not complying now, and that's it, you get a fine, you do not get the license, and nothing else. No sending the information so you can see that the standard has changed. There is no mutual support. There should not be just fines, directly. There should be 10-15 days given after identifying the problems, so they can be fixed, [there should be a collaboration. Because the purpose should not be just to not do well so you can give me a fine." —Private SSP

"We are not upset that [CAPSI] come, we are upset that they only look at papers... they tell us that they do not have time, they do not have methodologies." -Private SSP

"[We] offer services in 3 counties. The difference between the counties is like they were in different countries... You read the standard and when I go to Petrosani the lady there tells me, what is this, then I go with the same thing in Miercurea Ciuc and they congratulate me, well done, you did really well and in Gheorgheni they ask me, what in the world is this? And I sit dumbfounded and look. And they tell me, you see, if you read it backward it's not like that, and the one in Miercurea Ciuc tells me, see, if you read every other word is something different and the one in Gheorgheni tells me, translate it to me in Hungarian." -Private SSP

"It is very hard to explain to people [CAPSI—the control] that you do not lock up the [beneficiaries]. Every person in the sheltered housing has his/her own room and is 'allowed' to have a private life. 'What is the time of day when you check off and sign, that the person came home?' Well, nobody checks, because we are a minimally sheltered housing, we are building a relationship of trust, they support each other, we have an emergency number, 'but someone has to sign, a designated person has to lock the door!' [CAPSI inspectors do not understand the right of the people to take independent decisions]. 'What do you mean they should buy their own food? What if they buy poison? You will be responsible!" —Private SSP

"The institutions in charge of control and licensing place many and petty barriers the evaluation forms need to have I do not know what extra point,... insignificant things without which we could work extraordinarily well and we wouldn't have any complaints." —Services coordinator, day center and sheltered houses, public SSP Source: World Bank interviews with service coordinators and private SSPs (March-April 2021).

#### Awarding quality classes

A promising component of the quality assurance system, as presented in the main law (Law no. 197/2012) is the option to award a quality class (I or II) for those services whose quality exceeds the minimum standard. The evaluation to receive one of the quality classes is to be done upon request, by a team assembled just for this purpose, and will be based on a specially developed set of criteria and indicators. The methodological norms offer some details on the process, including a (mostly open) form to be used by the team, but many aspects are left vague, including exactly how the

#### Internal evaluations

In addition to social inspections, service providers organize their own evaluation of the services they coordinate. Law no. 197/2012 also stipulates, without much detail, that service providers are legally obligated to have their own internal evaluation procedures for: (i) making sure that the minimum standards are observed, and (ii) continuously improving the quality of their services. The methodological norms for the law do not offer any other detail on the matter. In practice, not all SSP representatives interviewed indicated the existence of a functional internal evaluation framework, while the frequencies of evaluations—when these are carried out—vary from monthly to yearly. In general, GDSACPs have control bodies that evaluate both technical and financial aspects of the services they coordinate, conduct evaluations that are sometimes unannounced, and report the evaluation results to the management. In addition, the NARPDCA's control body also carries out monitoring visits to services. Also control body also carries out monitoring visits to services.

Social services are also internally evaluated by assessing beneficiaries' feedback. Minimum quality standards require that all types of services must measure beneficiaries' satisfaction regarding service provision. Beneficiaries can express their opinion regarding service activities or any other issues via anonymous questionnaires that they fill out annually; these are subsequently analyzed by the service coordinator and other staff members. The standards do not make clear the obligation to translate beneficiaries' feedback into measures that will improve the quality of service provision, or how this should be done, although they comprise the obligation to include any measures required by the analysis of the questionnaires in the annual activity report prepared by the head of the residential center. In practice, not all GDSACPs and SSP

<sup>&</sup>lt;sup>48</sup> Methodological norms for the application of Law no. 197/2012, adopted through Government Decision no. 118/February 19, 2014. Art. 38, paras. (3), (4).

<sup>&</sup>lt;sup>49</sup> Law no. 197/2012, Art. 3, para. (2).

<sup>&</sup>lt;sup>50</sup> European Commission (2018).

<sup>&</sup>lt;sup>51</sup> Law no. 197/2012, Art. 34.

<sup>&</sup>lt;sup>52</sup> Order no. 136/2020. Regulation of organization and operation of the NARPDCA, Section 3. (NARPDCA, 2020).

<sup>&</sup>lt;sup>53</sup> The standard regarding beneficiaries' satisfaction is included in Module V – Protection and rights in all annexes of Order no. 82/2019.

<sup>&</sup>lt;sup>54</sup> Order no. 82/2019, Annex 1, Module I, Standard 1, Minimum Requirement 9.

representatives interviewed indicated that the questionnaire is administered annually. For beneficiaries with high communication support needs, service coordinators sometimes administer the questionnaire to family members. In other cases, beneficiaries can provide regular feedback through daily interactions with staff and service coordinators, but what interviewees call feedback appears to be more like a responsiveness that staff should be expected to have as part of regular service provision. It is also unclear how this informal feedback is used to improve services.

# 1.2. Evaluating Romanian quality standards

#### A. General description of quality standards in social services

In the area of social services, Romania currently maintains a set of minimum quality standards for both licensing and monitoring. Every type of service has its own standards, which contain both general and specific criteria (and many of these overlap). The standards are organized into modules, 55 and each module has a set of standards that contains a set of narrower standards, some of which are operationalized, minimum requirements (see Box 5).

# Box 5: The structure of minimum quality standards

Module V - Protection and Rights

Standard 1 - Respecting beneficiaries' rights

Standard 2 - Management of risk situations

Standard 3 - Code of ethics

Standard 4 - Protection from negligence, exploitation, violence, and abuse

Standard 5 - Protection from torture and cruel, inhuman, and degrading treatment

Standard 6 - Assistance in the event of death

Standard 7 - Notifications and complaints

Standard 8 - Beneficiary satisfaction

#### Minimum requirements for Standard 8

- 1. SSP/Respite center/Crisis center administers questionnaires for registering beneficiaries' opinions regarding activities/services/general views.
- 2. Beneficiaries may request support to fill in the questionnaires from staff, a legal representative, or a family member.
- 3. Beneficiaries submit the filled-in questionnaires to a special box that is easily accessible.
- 4. The respite/crisis center coordinator, the case manager, and a staff representative analyze the questionnaires, and the results will be included in the annual report.

Source: Order no. 82/2019, Annex 3, Minimum mandatory quality standards for respite and crisis centers.

<sup>&</sup>lt;sup>55</sup> Such as Management of the social service; Accessing the social service; Evaluation and planning; Activities and services; and Protection of rights.

The current standards (published in 2018 and 2019) are far more detailed than the first quality standards legislated in 2005 and only measure compliance/noncompliance with minimum quality requirements, but not the degree or form of compliance. In contrast, the 2005 standards<sup>56</sup> were organized around several principles<sup>57</sup> that were not clearly operationalized (the task was left to the evaluation team), and the final score reflected the degree to which a criterion was fulfilled, helping better identify strengths and weaknesses, and even points of excellence. The standards for the PPA were adopted separately, in 2018, and fall somewhere between the principle-driven standards of 2005 and the more detailed and operationalized ones of 2019.

In applying for a license other than the PPA, providers must fill out a self-evaluation form, which contains a reduced set of criteria, organized around the same modules and standards. Each criterion is assigned one point if fulfilled, or zero, if not; these numbers are then totaled for a final score. The exact role of the complete list of minimum requirements is unclear, as the criteria for licensing seem to be a subset of this extended list. The set of criteria used in the evaluation is less than a quarter of the set of the minimum requirements published in the standard (see Table 3, also Annex 1-6). This process is similar to obtaining the PPA license: a self-evaluation form is filled out, but the total score is computed differently: each standard is assessed globally and awarded 1 point if fulfilled, regardless of how many requirements it might contain.

The minimum quality standards also contain a number of control and monitoring indicators to assess how the standards were implemented. Each standard under each module is assigned a number of indicators marked as control indicators and monitoring indicators. The standards define the monitoring indicators as indicators to be used for monitoring the regulations from the domain under the jurisdiction of NARPDCA. However, there is no information as to how they are to be used. In 2003, NARPDCA carried out the only comprehensive assessment of how standards are implemented, aimed at improving the standards and strengthening their institutional role.<sup>58</sup> The control indicators are not defined, nor are there any provisions for their use.

<sup>&</sup>lt;sup>56</sup> Order no. 383/2005 for approving general quality standards regarding social services and the procedure for evaluating their fulfillment. These standards were repealed in 2014 and replaced with specific standards for the elderly, homeless, youth who have left the social protection system, and other vulnerable persons. (Order no. 2126/2014 regarding the approval of minimum quality standards for the accreditation of services for the elderly, homeless, youth who have left the child protection system, and other categories of persons in difficulty, as well as for community-based services, integrated services and social canteens, published in Official Journal Part I no. 874/December 2, 2014, repealed by Order no. 29/2019.)

<sup>&</sup>lt;sup>57</sup> Organization and Administration, Rights, Ethics, Comprehensive Approach, Person-centered Service Provision, Participation, Partnership, Results-oriented Service Provision, Continuous Improvement of Service Provision.

<sup>&</sup>lt;sup>58</sup> National Authority for Persons with Disabilities (2003). Monitoring and methodology office. The report presents an analysis of the implementation of quality standards in 146 services under the subordination of the national authority at the time. The assessment was carried out through the self-administration of a questionnaire with 320 questions that overlapped with items from the quality standards in force at the time, that could be answered YES/NO, as well as with fields for any observations related to the implementation of standards, observations that were not subsequently included in the analysis. The assessment results showed that the level of standards' implementation was 55.27 percent, with no institution fully observing the quality standards.

Table 3. Minimum requirements and criteria used in the evaluation, by type of service

Type of servi	ce	No. of minimum requirements	No. of criteria used in the evaluation
Sheltered hou	ısing	331	54
Respite and c	risis centers	196	54
Home care se	rvices	146	38
Mobile team		139	38
Day neuromotor centers	centers/outpatient recovery service	227	54
PPAs		120	1 point per standard = 22 points

Source: Order no. 82/2019 regarding the approval of mandatory minimum quality standards for social services for adults with disabilities.

The minimum quality standards are the state's most important instrument for assuring quality in disability services and protecting their users; however, there is work to be done in terms of how they are used to measure the quality of service delivery. Quality standards function on the assumption that if the service provider complies with the standards and requirements, as shown by the self-evaluation form and the inspection (organized around the same form), then users will receive at least the minimum quality of service they are entitled to as per national law and the international conventions to which Romania is attached (particularly the CRPD). Looking more closely at the actual standards (Annexes 2-6, plus the PPA standards), however, challenges this assumption. There are several problems, including the way results are defined, what constitutes a desirable result, the relationship (or lack thereof) between results and standards, the lack of (clear) operationalization of the indicators used to measure the results, and the fact that the standards and requirements are vague and imprecisely worded. More generally, the standards and indicators are primarily input-based, and therefore cannot be used to measure results. For a more detailed explanation, see Box 6.

# Box 6: Evaluation of minimum quality standards (the self-evaluation form)

Romanian minimum standards are broadly organized into modules, which are broad areas of evaluation (for example, Evaluation and Planning or Activities and Services). Each module consists of one or several standards, which are statements that represent the standard of service quality that each provider should offer; for example, "Sheltered housing is concerned with maintaining the psycho-emotional balance of the beneficiaries." The assumption is that attaining this standard will lead to the desirable result; for example, "The beneficiaries are ensured conditions for psycho-emotional balance and personal optimization." The requirement is used as an indicator for attaining the standard and ensuring the stated result; in this case, "Psychological counseling is recommended by the evaluation team in the Personal Life Plan, is done according to planning, and is monitored by the sheltered housing coordinator in terms of completion, and by the case manager in terms of the beneficiary's progress." (All examples were extracted from Order no. 82/2019, Annex 2, the standards for Sheltered Housing).

Most of the standard result indicator triads present some major problems:

- Most of the standards and indicators are input-based. They refer to existing physical infrastructure, staff executing tasks, and documents being created or filled out. They do not refer to actual outcomes for the service or the beneficiary. For example, in the case of Day Centers, Module IV, Standard 7, Neuro-motor recovery, the result is that users are offered conditions to maintain their functional potential, and the criteria used in the evaluation are that the recovery services are planned, offered, and monitored, which is all evidenced by the appropriate paperwork.
- o For some of the standards, what is presented as a result is not exactly an outcome for the user, and does not indicate the results presented in the actions or conditions of the standards. In some cases, it only shows their completion. The results thus presented do not at all describe the content or quality of service that was received or the impact on the user's quality of life; just that a service was offered. For example, in Sheltered Housing, Module IV, Standard 5, the result is: "Beneficiaries receive support for developing/consolidating their cognitive skills." A more appropriate definition of the result would indicate the beneficiary's outcome, the quantity or kind of support received, and whether it was appropriate for the user's needs.
- o The criteria listed are vague, and not measurable or verifiable. They do not actually operationalize compliance with the standard, nor do they guarantee the indicated result. For example, in the case of the standards for preventing torture and degrading treatment (which are common to all standards), the criteria indicate having a procedure, a register, and holding annual training sessions with staff to recognize such cases. These requirements should guarantee the result of "Beneficiaries are protected against torture and cruel, inhuman, and degrading treatments." Yet having a written procedure, a register, and training sessions says nothing about how many such cases occurred, how they were handled, if staff knew what to do, and what the outcome was for users. A more useful way to evaluate this item would be to report the number of cases, how many were satisfactorily resolved, the staff's level of knowledge and respect for human rights principles, whether the procedure is adequate, if it respects particular international standards, etc.

Moreover, the standards, as they are presented in the requirements and especially the self-assessment form, require a mostly paper-based evaluation and, at best, an inspection of the premises. No evaluation of the actual services or the impact on users is necessary. This opens the possibility for providers to "game" the system, by providing flawless paperwork and minimum infrastructure, without offering the necessary level of service.

None of the provisions in the self-evaluation form mention user involvement or participation as a requirement/criterion for any standard, which further indicates that user involvement is not really a part of how the quality of service is defined.

#### B. Romanian standards in the context of international approaches to quality standards in social services: An overview

To get a broader perspective on the form, content, and significance of the minimum standards used in the Romanian system, we briefly assessed these standards in the context of two different approaches, using particular standards that pertain to disability services: (i) an independent certification system, used internationally (EQUASS), and (ii) the Voluntary Quality Framework for Social Services, proposed by the European Commission. We also included two guides for quality assurance and improvement that approach services from a consumer and a person-centered approach, respectively.

#### **EQUASS**

EQUASS (European Quality in Social Services)<sup>59</sup> is an initiative of the European Platform for Rehabilitation. It offers, among other things, a recognition and certification program that shows compliance with the European requirements for the provision of social services, as well as the commitment to social justice, excellence, and continuous quality improvement. So far, SSPs in eight European countries have been awarded EQUASS Assurance and Excellence certifications. Regarding the audit process, two different perspectives are used: one that focuses on implementing the approaches detailed in the EQUASS principles and criteria, and one that focuses on the results obtained. The system is based on 10 principles, each detailed through criteria and indicators showing the degree to which the criteria are fulfilled (in five certification classes): Leadership, Staff, Rights, Ethics, Partnership, Participation, Person-centered Approach, Comprehensiveness, Results-orientation, and Continuous Improvement.

The Romanian standards adopted in 2005 were developed following the framework offered by the EQUASS principles. 60 The 2005 standards are general to all social services and organized around nine principles: organization and management, rights, comprehensive approach, person-centered approach, partnership, orientation towards results, and continuous improvement. While their general wording and lack of operationalization were certainly a problem, the standards communicated a commitment to person-centered services, beneficiary involvement, partnership with the community, and a focus on quality improvement. Moreover, the evaluation system allowed authorities to assess the degree to which the service complied with particular criteria by scoring it from 0 to 5, with 5 representing best practices.

Both the current Romanian and EQUASS standards and criteria show partial convergence in a few areas, at least in spirit and intention:

<sup>&</sup>lt;sup>59</sup> European Quality in Social Services (2017).

<sup>&</sup>lt;sup>60</sup> Order no. 383/2005 for approving general quality standards regarding social services and the procedure of evaluating their fulfillment by providers.

- o There are explicit references to ethics codes and preventing negligence, exploitation, violence, and abuse, torture, and cruel, inhumane, or degrading treatment, in both the standards and the criteria used for licensing and control.
- o The standards include principles pertaining to person-centeredness and comprehensiveness, even if they are not satisfactorily operationalized or approached through their actual implementation (rather than creating the framework through rules and forms that exist in the service provider's documentation).

# The current, 2019, and 2018 standards, however, stray from the EQUASS framework in several significant ways:

- o The Romanian standards are compulsory minimum standards and do not allow for differentiation between services that offer the bare minimum and those that show commitment to beneficiaries' needs and quality of life.
- The Romanian standards are not results-based; they only acknowledge the creation of the framework for, and the partial implementation of, particular standards and requirements. The only (partial) approach to incorporating results is the beneficiary satisfaction questionnaire mentioned at the end of the standards.
- o The Romanian standards do not have provisions for continuous quality improvement, innovation, encouraging excellence (in the field of management, staff, services), and incorporating best practices. This, coupled with the tedious system of licensing and inspections, is very likely to keep providers focused on meeting the legal minimum requirements instead of pursuing improvement.
- There is no explicit focus on social justice as part of service providers' mission.
- o The Romanian standards do not include any way to encourage or verify real partnerships or collaboration with all relevant stakeholders, and particularly users and their organizations.
- o The Romanian quality standards lack provisions for empowering users and ensuring their full participation in service planning and provision. 61
- o The only person-centered elements of the Romanian standards refer to individual, personal files and personal service plans, but no provisions are made to actually verify that the approach is truly person-centered.

#### The Volunteer Quality Framework for Social Services

The Volunteer Quality Framework for Social Services is a framework developed by the Social Protection Committee at the European Commission with the purpose of offering principles and methodological guidelines that Member States can use to develop tools to define and measure the quality of social services. 62 The framework offers both a set of overarching quality principles, as well as more specific principles organized around three dimensions: the relationship between service providers and users; the relationship between service providers and public authorities, social

<sup>&</sup>lt;sup>61</sup> For example, the standard for Sheltered Housing (Annex 2), Module III has several provisions that make reference to the beneficiary's involvement in the planning of the services, but the language is vague and non-committal ("the multidisciplinary team is preoccupied with actively involving the beneficiary and actively listening to his [sic] opinion") and none of these requirements are operationalized or included in the actual criteria for licensing and evaluation.

<sup>&</sup>lt;sup>62</sup> The Social Protection Committee (2010).

partners, and other stakeholders; and human and physical capital. The principles are detailed through specific operationalizable criteria.

The Romanian standards are structured in a way that acknowledges many of the key concepts and concerns presented in the framework. Yet the details, explanations, and particularly the minimum criteria point to a rather superficial approach, substituting a formal document that communicates an intention or an unverifiable gesture for the actual application of the principle. The result is that the principles and approaches that can be checked off by adopting and presenting a document are more likely to be represented in the standards. For example:

- o The general principle of comprehensiveness is included through the involvement of a multidisciplinary team both evaluating the needs and implementing a personalized plan, without the possibility of verifying the user's involvement or including his/her needs, capacities, and preferences.
- At the same time, the extent to which the service is person-centered is shown only through personal evaluations and plans, the twice-yearly evaluation of users, and vague mentions of how users will be involved. However, the entire system of standards is developed not from the perspective of an actual user, who has changing needs and life circumstances, but rather from the perspective of the encounter between control teams and service managers who need to communicate through documents. Users are only "involved" in the evaluation through annual user satisfaction questionnaires.
- o The provisions regarding users' rights and prevention of abuse, torture, negligence, etc., are all addressed through formal documents that exist somewhere in the service's files (rules, registers to be filled out if needed), along with proof that staff was trained on these topics (attendance sheets, for example). However, there is no documentation that shows whether staff learned, internalized, or otherwise applied any knowledge they received in an afternoon training, for example.

At the same time, other key aspects, principles, and methods seem to be outside the scope of the standards and their application. For example:

- The framework recommends using a mix of input, process, and outcome-based standards, but the Romanian standards are mostly input- and process-based (although superficially), verifying the physical and institutional framework and the use of documentation rather than the actual quality of service provision and the impact on users.
- Although quality of service is clearly tied to staff skills and working conditions, there are no provisions for this outside of compliance with the legal requirements for holding particular positions (as evidenced, again, through documentation).
- o In the Romanian standards, a service seems to be defined mostly as a relationship between the state (regulator) and the provider, with the user defined as a recipient of the service, and not as a partner. There are no provisions for including other partners (for example, community stakeholders, users' organizations, etc.) or for considering the service and integrating it into a network of other services that comprehensively contribute to users' well-being.

Person-centered approaches to assessment

Personal Outcome Measures is an assessment methodology created by The Council on Quality and Leadership that defines quality in terms of person-centered services and support. The system is meant to help organizations improve the quality of their services, especially in the field of behavioral health services and support. The Council on Quality and Leadership also published a guide<sup>63</sup> that can be of use both in the organizations' internal quality assessment and in designing quality assessment that can work on a large scale. The guide identifies eight factors for successfully planning and delivering a person-centered service (see Box 7).

Using the guide as a reference point, a global evaluation of Romania's current standards reveals several areas that are either lacking or could be improved:

- o Users should be the focus of the entire assessment system. All other elements should be defined and approached through their relationship and impact on users.
- o Evaluations should gauge not just users' involvement/participation in a service's planning and provision, but also their autonomy, empowerment, and authority in terms of defining their vision of what they need and their desired quality of life. Users should also be actively involved in evaluating the service that is delivered to
- The evaluation should also pay attention to how dynamic and responsive the service is to changing priorities, opportunities, and needs.

#### Box 7: Key factors and success indicators in person-centered supports

Factor 1: Person-centered Assessment and Discovery

#### Indicators:

- 1a. People\* feel welcomed and heard.
- 1b. People have authority to plan and pursue their own vision.
- 1c. Assessment of needs is fair and accurate.
- 1d. Assessment and discovery should identify personally defined quality of life.

### Factor 2: Person-centered Planning

#### Indicators:

- 2a. Planning is person-centered.
- 2b. The plan identifies and integrates natural supports and paid services.
- 2c. Informal community resources are used.
- 2d. Planning is responsive to changing priorities, opportunities, and needs.
- 2e. Planning and funding are connected to outcomes and supports, not programs.

#### Factor 3: Supports and Services

#### Indicators:

- 3a. People have the authority to direct support and services.
- 3b. Supports are flexible.
- 3c. Support options are accessible.
- 3d. People manage supports and providers.
- 3e. Supports are available in an emergency or a crisis.
- 3f. People can identify personal champions.

<sup>&</sup>lt;sup>63</sup> The Council on Quality and Leadership (2010).

Indicators:

- 4a. Community membership facilitates personal opportunities, resources, and relationships.
- 4b. Peer support/mentoring is available.
- 4c. People receive information and training.

Factor 5: Workforce

Indicators:

- 5a. The workforce is stable and qualified.
- 5b. Practices are culturally competent.
- 5c. Personnel have the flexibility and autonomy to support people.
- 5d. Support for cultural/organizational change is provided.
- 5e. Advocacy efforts promote fair and affordable provider rates and responsive payment systems.

Factor 6: Governance

Indicators:

- 6a. Organization mission, vision, and values address person-centered supports.
- 6b. Organizational practices are both person-centered and system-linked.
- 6c. People and families play meaningful leadership roles.

Factor 7: Quality and Accountability

Indicators:

- 7a. Quality management systems are integrated.
- 7b. Quality of support is measured.
- 7c. Participants, families, and advocates evaluate supports and providers.
- 7d. The public is kept informed.
- 7e. Personal information remains confidential.

Factor 8. Emerging Practices in Individual Budgets

Indicators:

- 8a. People control their budget allocations.
- 8b. Individual budgets are both fair and ample.
- 8c. Budgets, money, and services/supports are portable.

\*The terms "people" and "person" refer to service users. All others are defined through their relationship to the users.

Source: The Council on Quality and Leadership (2010).

#### **User organizations**

Inclusion Europe, a larger, pan-European organization comprised of organizations that represent persons with intellectual disabilities from 39 European countries, proposes an approach to evaluating the quality of disability services through the paradigm of consumer satisfaction.<sup>64</sup> One of their most important recommendations

<sup>&</sup>lt;sup>64</sup> Inclusion Europe (2003).

is that evaluation systems should be independent; or at least, there should be a system independent of the ones set by service providers and the state, which tend to focus on minimum requirements and structural measures.

When comparing the current Romanian standards to the principles proposed in the report, several opportunities for improvement emerge:

- Treating users as clients65 can help them avoid being seen as dependent recipients of care and services, but rather as active consumers, with rights that result from this relationship (in addition to their human rights).
- o The input, opinions, and involvement of advocates (family members, guardians, organization representatives) are valuable in the context of the quality of service planning and provision; they should complement but not replace those of the actual service users.
- Quality of life outcomes should be important in the process of quality assessment.
- o Evaluation using standards, uniform measurements, and assessments might not accurately indicate the quality of a service, as this is to be judged through means and instruments that take into account the service user's preferences, needs, and
- The assessment should be multidimensional and not address users as mere persons with disabilities in need of a specialized service; it should take a more complex approach that considers multiple aspects of quality of life.

#### 1.3. Implementation of quality standards

Any service must implement minimum quality standards to obtain a license and meet the control and monitoring indicators. In practice, implementing the standards is a challenge for many SSPs and coordinators. In some situations, licensing a service entails meeting certain requirements that are not always provided by the legislation. For instance, while standards do not impose a minimum number of staff or activities that a day center must provide to its beneficiaries—such as psychological counseling, kinesiotherapy, or social assistance—in practice, failing to do so may be reason to not license a service. This might result in offering services that are not necessarily needed, to the detriment of other services and activities that could better address the beneficiaries' needs. Conversely, the fact that the standards don't stipulate a minimum mandatory number of services or staff to be provided by a day center can sometimes be an argument for local authorities to dismiss requests to allocate budget to hire the necessary staff or direct the necessary resources.

In general, standards are often not implemented due to a combination of material, financial, and human resources-related reasons, according to SSPs. Standards implementation challenges often involve:

• Service accessibility. It can be difficult for SSPs to ensure that a service is physically and informationally accessible (for instance, making sure information about service provision is available in accessible formats). Often times, service infrastructure is either old or was not built-in line with universal design principles, and consequently

<sup>&</sup>lt;sup>65</sup> The authors of the report use "consumer," "client," and "user" interchangeably.

requires additional financing from local authorities to make adjustments or build new structures that comply with standards. These resources are not always readily available.

- The lack of adequate infrastructure. Besides ensuring accessible infrastructure, simply keeping the service buildings up to standards is also a challenge, particularly for smaller SSPs (such as NGOs), and/or in the case of services that were set up as part of projects with limited funding. In addition, minimum standards for some types of services, such as sheltered housing or respite centers, require that each beneficiary has access to her or his own room. In effect, some SSPs were forced to terminate the service contracts for beneficiaries of sheltered housing that did not comply with this requirement.
- o The lack of financial resources. In addition to the needs regarding infrastructure accessibility and maintenance the at the level of mandatory standards, the lack of financial resources needed for standards implementation was also indicated in cases where cost standards were not enough to ensure certain mandatory aspects of service provision (for instance, providing adequate clothing for beneficiaries).
- The lack of specialized staff to provide services in a person-centered manner that does not reproduce a medicalized institutional practice of care has also been indicated as a barrier to offering necessary services and activities.

The large volume of paperwork may deter staff from offering services to beneficiaries according to their personalized plans. Minimum quality standards cover a combination of service aspects that require both administrative and specialized work. For instance, all services are required to register and file the evaluated needs of beneficiaries, the activities provided, and their respective scheduling and staff. This activity often takes a lot of time that can be better allocated, as service coordinators pointed out, toward activities that engage beneficiaries directly. In addition, in terms of registering beneficiaries' progress on specialized activities (for example, rehabilitation or maintaining/developing independent living skills), some service coordinators pointed out that the standard requirements to register any change in beneficiaries' progress, as well as shortening the time between evaluations, are often redundant since visible progress occurs after a longer period of time.

At the national level, the practice of implementing quality standards varies greatly and illustrates an apparent tension between rigidity and vagueness. Some service providers report their preference to use the standards as a minimum framework that they can develop or augment through their own internal procedures. 66 In other cases, services providers expressed that they need guidance regarding, for instance, certain procedures that must organize the service activities according to standards or type of staff that is expected to implement these procedures. This tension is arguably a result of the difference between services' organizational capacity, as well as past and current access to resources; for instance, some service providers have previously had or have access to both knowledge or expertise, as well as material, financial, and human

<sup>&</sup>lt;sup>66</sup> In other situations, for instance, in the case of mobile team services, coordinators suggested that current minimum standards for this specific type of service covers aspects that their services had already been implementing.

resources that have enhanced their capacity to meet quality standards to best suit their objectives. This issue can be addressed by making sure service providers have adequate guidance, supervision, guidelines, and in-person support, rather than exclusively controlling and monitoring their activities, as some expressed during the interviews.

The implementation of standards is sometimes hindered by licensing requirements. Some aspects of service provision covered by standards are also subject to clearance from various public institutions, such as obtaining a sanitary authorization to prepare and serve food to beneficiaries. For instance, in the case of sheltered housing, the Directorate of Public Health (DSP) may require the presence of a cook or a fully equipped kitchen to comply with health and safety regulations that pertain to activities that support beneficiaries to learn how to prepare their meals. Some service coordinators indicated that these requirements are excessive, costly, and unnecessary to ensure a living environment for beneficiaries of sheltered housing that resembles any other home in which people live independently.

Implementing quality standards may lead to the conversion or development of community services not otherwise planned or that are not needed to respond to identified needs of persons with disabilities locally. In some situations, according to interviews with SSP representatives and coordinators, services were developed according to aspects of quality standards that require the integration of certain services. For instance, sheltered housing is defined by law as the social service that provides housing to persons with disabilities who also benefit from services and activities offered mostly in a day center.<sup>67</sup> Thus, no sheltered housing unit can be licensed as a service if residents do not have access to a day center. In some situations, SSPs had to also set up a day center, even if residents of sheltered housing did not need it, or SSPs thought day center services and activities could be offered in the sheltered housing.<sup>68</sup> This requirement also led to the proliferation of service hubs<sup>69</sup> - several protected housing units and a day center established close together (often in the same courtyard or as neighboring residential centers), 70 which reinforced the seclusion of beneficiaries of protected houses and may have acted as disincentives for local authorities to set up day centers in the community. In one situation, a private service provider was forced to convert a sheltered house into a residential center (Center for Recovery and Rehabilitation for Adults with Disabilities, or CAbR) since it could not meet the requirement to also provide beneficiaries with services in a day center. In another situation, a service provider could not secure public funds to hire a psychologist to provide services in a sheltered house due to the minimum standards requiring sheltered housing to provide beneficiaries with specialized services in a day center only.

<sup>&</sup>lt;sup>67</sup> Order no. 82/2019, Annex 2.

<sup>&</sup>lt;sup>68</sup> Such as psychological counseling.

<sup>&</sup>lt;sup>69</sup> According to the World Bank survey of sheltered housing carried out for this report, 43 percent were part of service hubs ("complex de servicii").

<sup>&</sup>lt;sup>70</sup> Since, in some situations, setting up protected houses was the main transfer option for beneficiaries of residential centers that had been sized down.

The lack of access to mainstream services in the community can mean that minimum standards are not met. The standards for sheltered housing, for instance, limit the maximum period for a service contract to five years.<sup>71</sup> In practice, this requirement is not always met because of the community's lack of social housing or because beneficiaries do not earn enough to rent their own place in the community, leading their service contract to be prolonged indefinitely. In addition, standards require beneficiaries of minimum sheltered houses to find and maintain employment for the time of their residence. 72 However, in many situations, sheltered housing is situated in areas with few accessible jobs, which may lead service providers to convert protected houses into residential centers.

The implementation of quality standards can only be a baseline for ensuring quality services. Minimum quality standards are seen as the reference level for the quality of social services;<sup>73</sup> consequently, any monitoring and evaluation activity that measures standards implementation is limited to actions that identify non-compliance, and cannot encourage quality improvement, excellence, or best practices. In fact, some GDSACP directors emphasized that a service that observes the standards can be further improved, since standards implementation is a legal obligation that has nothing to do with good practices.

Box 8: Difficulties implementing minimum quality standards for SSPs

"[The standards] are rigid in the first place, and not only concerning their language, but problems arise whenever certain authorities or persons who are very rigid pay attention only to the letter and never to the spirit of the law. We've had worse standards, that one that required reevaluations every 3 months has changed to every 6 months. I do not think that we acquire much as adults every 6 months, and even less so when it comes to persons with disabilities. We have implemented as part of our own procedure a minimum discussion based on an interview guide [with beneficiaries] and at the minimum an individual's discussions with caretakers following an interview grid, whereby we ask what wishes, needs they have, and how we can pursue them. So in my opinion [the standards] are rigid; they provide us with a framework but I relate to it as to a minimum framework." -NGO, service provider "[The standards] are not as rigid as the management initially perceived them, but they are slightly idealistic, there is a lot of paperwork and we lose a lot of time with forms and standard documents that need to be signed by the beneficiary, and that time could be dedicated to the beneficiary (for instance, the beneficiary benefitted from counseling, kinesiotherapy, and you go around with a sheet of paper and you end up confusing the beneficiary)." —GDSACP Director

"The standards were implemented, these Personalized Plans were introduced, and it took us some time to figure out how to plan them, how to approach them, we could have used some guidance, someone who would tell us what to do, and not only an

<sup>&</sup>lt;sup>71</sup> Order no. 82/2019, Annex 2, Module 1, Standard 2, Minimum requirement 8.

<sup>&</sup>lt;sup>72</sup> Order no. 82/2019, Annex 2, Module 1, Standard 2, Minimum requirement 8.

<sup>&</sup>lt;sup>73</sup> Law no. 197/November 1, 2012 regarding quality assurance in the field of social services, Art. 5 (3).

authority that controls us." —Service coordinator, currently CIA, previously CPVI and SH+DC.

"I do not think it's quite useful to make licensing mandatory, since it is this licensing that makes the process of service development difficult. And this does not concern the Directorate for Social Assistance, since we had the necessary capacity, we have a social worker, we hired a kinesiotherapist, a psychologist. But in case I have a small NGO, I wouldn't have the capacity to offer kinesiotherapy. But perhaps I have an excellent psychotherapist that would be enough to provide services to a certain segment on the market, to some children for instance, I would relieve the pressure that is on the family through these services. Why should I be required to offer 3 social services? Maybe the person does not need them all." -DSA Director

"It is up to each Directorate how it implements or takes on the standards, but then there is CAPSI which has a different approach or interpretation, that even differs among counties, and this is why certain aspects should be spelled out. [...] clarifications in the law and in standards concerning the staff in each type of center (GDSACP's interpretation is that both LP and CZ can employ social workers and psycho-educators while NARPDCA claims these positions cannot exist in both LP and CZ." —Head of case management service, GDSACP

"It is not clear what the vision of persons who elaborated the standards was: we would've needed more help to understand what to do and how. Each Directorate has a different approach and we would've needed more support to define the procedure [concerning Neglect, exploitation, abuse, cruel, inhuman and degrading treatment." -Head of case management service, GDSACP

"[Regarding the case management standard in the case of externalized or private service, who should provide case management] we understood this in one way, the Directorate from [county X] in a different way and so we cannot know who is right. Who should we ask an opinion on this?" —Head of case management service

"[In the standards] for sheltered housing the number of beneficiaries has been modified, so now we need to take out 3 persons." -GDSACP director

"Quality standards require that they should have good clothing, cost standards limit the spending to a maximum of 300 RON/year. It happens that sometimes the expenses exceed the standard cost and in that situation we have to appeal to the County Council to cover the difference." -GDSACP director

"We have employees who need from time to time to get out of their routine—nurses, caretakers, once you enter a residential center, you somehow internalize those habits, practices, they do not pay attention to a person's life history, that perhaps that person is traumatized whenever is being moved from one side to another." -GDSACP director

"A smaller amount of papers, they may be useful, and now, the new standards require planning, in the case of occupation therapy we have yearly planning, annual planning that includes all evaluation fiches, but this is lost time spent in front of the computer. And it is then when the beneficiary needs you, s/he is not interested in the fiche, and sometimes you write down your objective in the fiche, and there are times when you cannot reach that objective because he/she is one day in a state, the next day s/he requires different attention from you or may get sick and you need to focus on improving his/her health and that objective automatically disappears, even though we take him/her through all the needs rubrics. They are useful, but there is also a lot of wasted time that could translate into time spent with the beneficiary. ... There are many aspects in the Personalized Plan that I must repeatedly write down because we do them repetitively, and so we miss his/her evolution at that moment in time." -Service coordinator of CIA, previously CPVI, previously LP+CZ

"[The standards] are not that different from what we usually do. Besides the monitoring in writing, which is something I need to do monthly, which I was doing anyway, but not in writing, I think they are very similar to what I had been doing. They are not an obstacle, but neither helpful." —Service coordinator, mobile team "This is a sheltered house, our purpose is to teach the beneficiary to do everything so once in the community s/he knows how to cook, clean, etc. And the legislation exists but it is not correlated, I have to cook for each sheltered house by involving the beneficiary directly in the process, s/he must know how to do these things, however, the Directorate for Public Health comes in and says I cannot involve the beneficiary since I need to have a cook because this is how things need to be done this happens everywhere where there are centers—a misalignment of DPH procedure and that of the sheltered house, we would need to be excepted from this, so that I wouldn't need to have seven fridges—for eggs, dairy, meat, chicken meat, pork meat, etc. I coordinate a sheltered house, this is a home, at home, I have a fridge where I keep whatever I need. They are making it really difficult for us, I need to size down the space the beneficiary could use for activities to place fridges instead." —Service coordinator, sheltered house

"Too much paperwork and we waste a lot of working time we could be spending with the beneficiaries. They forms have killed us, because there were none, we had to adapt them to fit the standard, for every beneficiary you have to write in a form what activity, its duration—to write every activity they do in 12 hours of program, which is a big waste of time if you take into account the number of beneficiaries, and I have to take away time from beneficiaries to write up the papers." —Service coordinator, sheltered house

"There are problems because of insufficient staff—CAPSI left a measure [recommendation] for this, but the mayor didn't want to hire the necessary staff. [the problem is that] we have legislation but we run against the will of the heads of the local administration, which know there is nothing that can happen to them, because the measures are left to the DSA [Directorate for Social Assistance] director. The challenge is to respect the law so that there are no optional articles. A day center should have compulsory standards, a certain compulsory staff, so that it is not left to the decision of the paying institution." -Day center, coordinator

"We had a sheltered house in a rural area and we transformed it into a CAbR [a residential center], not because of the needs of the beneficiaries, but because the standards should run primarily through a day center, and we do not have a day center in this rural area. And in a sheltered house we should be focusing on finding people jobs, but in this rural area we had no chance of finding jobs for not even one of our 10 beneficiaries." —Private social service provider (NGO) subcontracted by the **GDSACP** 

"According to the quality standards for sheltered housing, we have there that 5-year term after which the beneficiary should be integrated in the community. That term cannot always be respected, and, on the other hand, it would be ideal if the community supported us with social housing. The wages of these young people who work are relatively small, maybe even the minimum wage, in many cases. We try to support them to save up, but they have to pay utilities bills, and we cannot deprive them of some certain pleasures that want. The money they save is little. When we have to integrate them in the community, with rent, they are ready, but financially they cannot make it. If there was a complementary service, an integrated support service that would help them get social housing, then we could say that a community service has an actual outcome, a finality. These beneficiaries, even if they are integrated, they will need support for the rest of their lives. In the sheltered house we have young persons who came from medical-social institutions with a psychiatric profile, young persons with severe retardation, but with a lot of work we managed to integrate them in the labor market. But these people will never be able to live by themselves. They need to clarify the type of beneficiary that can access the sheltered house. Based on the initial assessment, they would belong in a CIA [care and assistance residential center], but with the work, we could integrate them in sheltered housing. This is why, that term [5 years] I think it should not exist. If you integrate them on the labor market, we really can't talk about the CIA." -GDSACPdirector

Source: World Bank interviews with GDSACP, DSA/PSAS representatives and private SSPs (March-April 2021).

#### 1.4. Discussion and conclusions

Quality standards are part of a complex system for regulating disability service provision in Romania. A fair assessment would place them in the context of that regulatory system, highlighting not only their particular contribution, but also how the system as a whole works to provide safe and adequate services that assure the wellbeing of persons with disabilities.

Romania's regulatory system is largely a top-down system, based on an approach of authority and control, focusing almost exclusively on its normative function, and to a lesser degree on its corrective function.<sup>74</sup> The state, through its specially mandated institutions and bodies, acts as the main stakeholder and decision maker, with very little or no involvement from civil society, especially users of the services. The normative function—which dominates in southeastern Europe—is what allows the state to set the "rules of the game" through standards, procedures, and instruments that

<sup>&</sup>lt;sup>74</sup> Chiriacescu (2008: 43).

assure a minimum set of standards in service delivery. This approach also offers instruments and procedures for the implementation and control of correct service delivery within the standards, imposing punitive or corrective actions on the various actors involved. The corrective function, which is characteristic to systems undergoing reform and renewal, is what allows the regulatory system to transform, encourage, and support the adoption of new practices and principles among those involved in the service provision process, from institutions to professionals to users. This is attested by the numerous changes in the laws, methodological norms, and particularly quality standards over the past 20 years, even if some of the changes were not necessarily for the better.<sup>75</sup>

There are examples of disability service systems that have worked for decades without strict state regulation or oversight. For instance, until recently, Ireland had no regulatory system that set mandatory standards, a licensing and inspections system, or uniform quality systems for service providers that serve persons with disabilities (as opposed to children or the elderly). What helps the success of such a system are local resources and interest in providing disability services, and adopting external (international) quality systems. In Ireland, massive grassroots efforts and secular community-based care voluntary organizations were able to induce reform and provide the necessary services to persons with disabilities, with minimal state support or involvement.<sup>76</sup> The danger in this option is that it can put persons with disabilities at risk of neglect or abuse, and the system could develop unevenly, both geographically and in terms of service quality.<sup>77</sup>

The role of minimum quality standards in service delivery - which seem to be the backbone of the Romanian regulatory system, as part of the licensing/accreditation, inspection, and sanction procedures - should be re-evaluated. They should be transformed and become one element in a mix of instruments and procedures that are focused on excellence in service delivery and building around best practices instead of merely guarding the system against negative examples (see the box below on the role of responsive regulation).

Box 9: Responsive regulation for services for persons with disabilities
Responsive regulation has emerged recently as the most promising option in social
services, and particularly in disability services. Responsive regulation is based on a
paradox: even though (state) regulators have the power and capacity to sanction and
impose tough punitive interventions, they will first opt for collaborative capacity
building and support, which fosters innovation, problem-solving, and disseminating
solutions to other actors.\* Punitive actions become a last resort. Emphasis is placed
on all actors' ability to self-regulate and improve their service while providing a
central framework that ensures accountability and transparency. The devolution of
authority to lower levels all the way to the service frontline, and ultimately the user,

<sup>&</sup>lt;sup>75</sup> For a review and discussion of the functions of regulatory systems in this context, see Chiriacescu (2008: 43).

<sup>&</sup>lt;sup>76</sup> Power et al. (2013).

<sup>&</sup>lt;sup>77</sup> National Economic and Social Council (2012).

also comes in response to the challenge of delivering a person-centered approach as part of a nationwide system of social services.\*\* In addition, responsive regulation:

- o Is about involving multiple key players in the regulatory process (other than the regulator and the actors being regulated), with the explicit purpose of preventing the accumulation of power while fostering accountability. In the case of disability services, in addition to the state and service providers, the process should involve service users, organizations that represent them, local communities, and service professionals.
- o Can also be a way to reconcile the apparent contradiction between the inherent power of the state over the lives and bodies of the users of social services and the moral imperative to empower and respect these users.\*\*\* This can be achieved by providing a framework for feedback and a response that is not reduced to complaints and redress but rather focuses on continuously improving the quality of services and life.
- o Is about a fair and efficient regulatory system that should make possible and encourage independent evaluators and evaluation systems. Certification systems could be a solution, as well as independent evaluators or even peer evaluations.

Source: \* Braithwaite (2011). \*\* National Economic and Social Council (2011). \*\*\* Burford & Adams (2004).

If used smartly and responsibly, quality standards remain important tools in both improving quality and assuring accountability in disability services. If this is to be achieved, the new standards should:

- o be developed through real and extensive consultations with partners from civil society, particularly users and their organizations, and should reflect their concerns, needs, and priorities;
- o be both input- and output-based, focusing primarily on outcomes for users;
- o ensure that services are person-centered;
- o have clear, measurable/verifiable criteria that clearly connects the standard to the desired results;
- o verify, measure, and encourage users' involvement and participation in service planning, delivery, and evaluation;
- o gauge the quality of the service, differentiating between providers that offer the bare minimum and those that offer a higher quality of service;
- o evaluate the use of partnerships and collaborations that can provide users with comprehensive complementary services in the community;
- o encourage service quality improvement, innovation, and adoption of best practices;
- o be conceived with a progressive approach to allow for a dynamic possibility for improvement;
- avoid excessive paperwork;
- o can ensure that social inspections are carried out with consistency and uniformity.

#### **Analysis of community services**

#### 2.1. Sheltered Houses

This chapter offers a comprehensive evaluation of sheltered housing services with regard to the compliance with the minimum quality standards provided by the Romanian national legislation. First, it introduces the legal and institutional framework that regulates the provision of this service. Second, it provides an overview of the services in terms of service and beneficiaries' profile. Third, it offers a comprehensive evaluation of the service in view of its compliance with minimum quality standards and proposes brief recommendations for the improvement of standards and service delivery overall to ensure a better quality of service provision that is person-centered, ensures personal autonomy and self-determination, and furthers independent living.

#### 2.1.1. Legal and institutional framework

Sheltered houses are a type of residential center<sup>78</sup> where persons with disabilities can be offered services as a protection measure.<sup>79</sup> The objective of sheltered housing as a type of social service is simultaneously seeking to: (i) provide accommodation to minimum 2 and maximum 10 persons, and (ii) offer, mainly through a day center,<sup>80</sup> activities corresponding to the specific individual needs of adults with disabilities for a determined period, in order to prepare them for independent living.<sup>81</sup> According to legislation, the service aims to facilitate the transition of persons with disabilities previously institutionalized in residential centers to a life in the community and to provide support for learning independent living skills they had lost or had no opportunity to develop as a consequence of institutionalization.

Two types of sheltered houses can be currently licensed as social services. According to minimum quality standards, sheltered housing services can be provided as *minimum* or *maximum* services. Overall, both types of sheltered houses are expected to offer similar types of activities and living conditions to their beneficiaries, with some notable differences in terms of service objectives and location of activities and services provided, as well as of beneficiaries' profile. Specifically, maximum sheltered houses (MSHs) provide services to beneficiaries 24 hours a day in order to support the

<sup>&</sup>lt;sup>78</sup> Besides CPVIs, CAbRs, CIAs and Respite Centers/Crisis Centers, Law no. 448/2006, Art. 51 para (3). Sheltered houses are also considered social services that provide accommodation for a fixed or indeterminate period of time, besides residential centers or night shelters (Law no. 292/2011 of social assistance, Art. 30 para. (3) let. a).

<sup>&</sup>lt;sup>79</sup> Besides personal assistance or personal professional assistance, home-care services, services in day centers. Law no. 448/2006. Art. 5. 23^1.

<sup>&</sup>lt;sup>80</sup> The analysis of Day Centers as community-based services for persons with disabilities is provided in the following chapter.

<sup>&</sup>lt;sup>81</sup> Order no. 82/2019, Annex 2. Mandatory minimum quality standards for residential social services - Sheltered housing for adults with disabilities.

development of their independent living skills. Services may be provided in a day center, on the premises of the sheltered house, or in the open air.<sup>82</sup> On the other hand, minimum sheltered houses (mSHs), provide beneficiaries with conditions for a life with minimum support, in order to consolidate the necessary skills for independent living. Beneficiaries of mSHs are employed, except for those for whom it was established lost working capacity, and the services they need are provided by day centers (DCs) or other services in the community.<sup>83</sup>

Sheltered houses are one of the most developed services with a residential component for persons with disabilities in Romania. According to NARPDCA data, on March 30, 2021 there were 144 public sheltered houses providing services to 1,017 persons with disabilities nationwide. 84 While the number of sheltered houses increased by almost half since 2015, the number of beneficiaries grew only slightly, leading to a decrease in the average number of beneficiaries from 8.5 in 2015 to 7 in 2020 (see Table 4). The increase in the number of sheltered houses was supported through EU as well as national funds over the past five years. For instance, the EU Regional Operational Program 2014-2020 is funding 18 projects totaling 57 sheltered housing and 18 day centers for 467 persons with disabilities previously institutionalized in residential centers. 85 In addition, the Program of National Interest (PNI) "Developing social services such as day centers, respite/crisis centers and sheltered houses for the purpose of deinstitutionalizing persons with disabilities from old type of institutions and for preventing institutionalization of persons with disabilities in the community,"86 initiated by NARPDCA in 2016, has been another source of funding for developing sheltered houses for persons with disabilities from large institutions. PNI is funding 40 projects that aim to build 83 sheltered houses and 28 day centers for 694 institutionalized persons with disabilities.<sup>87</sup>

Table 4. Evolution of sheltered houses and beneficiaries, 2013-2021

2013 2014 2015 2016 2017 2018 2019 2020 Mar 2021

<sup>82</sup> Order no. 82/2019, Annex 2. Module I, Standard 1, Minimum requirement 5.1.

<sup>83</sup> Order no. 82/2019, Annex 2. Module I, Standard 1, Minimum requirement 5.2.

<sup>&</sup>lt;sup>84</sup> NARPDCA (2021).

<sup>&</sup>lt;sup>85</sup> The Ministry of Funds (currently the Ministry of European Investments and Projects) has allocated through the Regional Operational Program the amount of 16 million euros related to POR/8/8.1/8.3/B/1 for the development of social services infrastructure. In the period 2018-2019, the Regional Development Agencies concluded financing contracts with the GDSACPs in the counties of Argeş, Bacău, Prahova, Timiş, Tulcea, Vaslui and Vrancea (World Bank, 2021: 213).

<sup>&</sup>lt;sup>86</sup> The PNI was approved through the Government Decision no. 798/2016 and allocated 74.507.000 RON from the national budget.

<sup>&</sup>lt;sup>87</sup> Financing contracts were concluded with the GDSACPs in Vrancea, Vaslui, Bacău, Neamţ, Cluj, Iaşi, Brăila, Constanţa, Arad, Buzău, Suceava, Maramureş, Bistriţa, Bucharest Sector 2, Botoşani, Braşov and Giurgiu (World Bank, 2021: 214).

Sheltered houses	85	93	100	113	116	133	137	145	144
Beneficiarie s	723	782	851	882	909	919	983	1,017	1,004

Source: NARPDCA statistical bulletins (2013-2021).

At European level there have been growing concerns that sheltered houses reproduce institutionalized care and are a form of re/institutionalization. 88 Various international reports have shown that sheltered houses as a form of congregated care<sup>89</sup> that clusters and sets apart a group of persons with disabilities who live together and offer them bundled services reduce autonomy and choice and perpetuates isolation from the community (see the box below). Sheltered houses (alternatively called "group" homes" or "half-way houses" operate in a closed-circuit system, 91 similar to large institutions where all services (employment, medical, recreational, etc.) are either provided on-site or in another location for all residents, who are moved around usually together, with little possibility for individualized activities (separate from other residents or service staff). In such homes, residents had little control over daily schedules, everyday life activities, what to eat and how to dress, social relationships, etc. In the context of a lack of other support options in the community, including housing, residence in sheltered houses tends to be prolonged indefinitely. The longer the time spent in sheltered houses, the lower the prospects "for exiting the system, exercising more choice, and increasing opportunities for true community inclusion."92

Box 10: Excerpt from "The right of persons with disabilities to live independently and be included in the community", drafted by the Council of Europe Commissioner for Human Rights

"Other forms of segregation practiced in placing persons with disabilities in congregate care which, though situated geographically in the community (for example in a residential neighborhood), actually mirror institutional life. "Group homes", often code for residential settings of between two and 15 persons with disabilities, are an example of such settings.

In some countries where deinstitutionalization processes are taking place or have concluded, group homes are sometimes introduced as the alternative. It is thus particularly timely to identify this as an issue and prevent group homes from becoming the default solution that presumes to embody the principles of the right to live in the community.

<sup>&</sup>lt;sup>88</sup> See "Common European guidelines on the transition from institutional to community-based care", document prepared in 2012 by the European Expert Group on the transition from institutional to community-based care in order to support authorities in understanding structural funds as essential opportunities for creating community services and not for creating alternatives that may continue practices that violate human rights and human dignity.

<sup>89</sup> Council of Europe Commissioner for Human Rights (2012: 40).

<sup>&</sup>lt;sup>90</sup> The European Expert Group on the Transition from Institutional to Community-based care warns against the possible long-term institutionalization in half-way houses built sometimes in the vicinity of residential centers to supposedly support former residents with developing independent living skills (2012: 129).

<sup>&</sup>lt;sup>91</sup> Idem, p. 40.

<sup>&</sup>lt;sup>92</sup> Idem, p. 41.

The fact of grouping people together already sets the people apart from society as a group of their own, drawing the community's gaze to disability (rather than to each individual person) and running counter to the obligation to promote "positive perceptions and greater social awareness towards persons with disabilities".

The larger the group, the higher the risk of resembling an institution, as a person's life is still dependent on and subject to the will and decisions of a narrow set of staff. Such settings, despite being physically placed in a city

neighborhood or a suburb, may operate as a closed-circuit system and be as isolated as an old-style mental institution. Particularly for those who require more intensive support, the chance foofonnecting with the community and making individual choices decreases. Because of size, strong forces are at play to bring services onsite, such as medical, employment-related, or recreational services, or to transport the group as a whole to access such services in the community, thereby reducing the chances for meaningful interaction with the community.

Group homes are often a model which links together the disability supports a person requires with a particular stock of housing, thereby restricting people's choices about where they will live. They can only access supports they require by submitting themselves to a service provider who owns or operates certain housing stock. Persons with disabilities do not require special housing stock; they require supports which they can take into the housing market to access rental or other housing tenures just like other people."

Source: Council of Europe Commissioner for Human Rights (2012: 40).

The proliferation of sheltered housing services as the preferred option for deinstitutionalization and community living for persons with disabilities reduces the authenticity of choice. No authentic choice can happen in the absence of a wide range of independent living options in the community for persons with disabilities. The development of sheltered houses to the detriment of other types of services, severely restricts the possibility of choice and forces persons with disabilities to accept available services. More housing options should be provided to persons with disabilities that do not link service provision to residential alternatives, enabling them to access rental or other housing tenure just like any other person. 93 Promoting and securing financing for accessible and disability-inclusive social housing is one of the main recommendations of the current EU Strategy for Persons with Disabilities to ensure that persons with disabilities can live independently in the community. 94

#### 2.1.2. Description of services

#### Service profile

In Romania, sheltered houses are social services that provide housing, and through day centers or other services in the community provide specific activities for independent living, for two up to 10 adults with disabilities per sheltered house. They work as a form

<sup>&</sup>lt;sup>93</sup> Council of Europe Commissioner for Human Rights (2012: 40).

<sup>94</sup> European Commission (2021: 9).

of residential centers, offering both housing and specific services for independent living, either through own staff, that of the day center or through other services in the community, or through outside providers that are contracted.

For the 100 SHs included in this evaluation, the average number of beneficiaries per room is 2, with a slightly lower average for the minimum SHs (see Table 5 and Table 6). Only 10 percent of SHs are located in buildings with other general-population residential apartments, while most (87 percent) are self-standing, located in buildings or houses with no additional destination. Over half of SHs (54%) share, however, the yard, the building, or the immediate vicinity with other social services, in particular other residential centers. Generally, SHs provide good living conditions, but around 5 percent present hygiene or comfort problems. According to the external evaluation, about one fifth of SHs have bedrooms that are cramped or crowded and do not offer the necessary comfort to their residents. Interviews with service coordinators indicated that the physical living conditions are an improvement compared to the those in the large residential centers where many of the current beneficiaries used to live.

Table 5. Average number of beneficiaries per bedroom in sheltered houses included in the evaluation, by type, in 2020

		Total N of beneficiaries	Total N of SHs
Maximum SH	2,0	641	89
Minimum SH	1,6	62	11
Total	2,0	703	100

Source: World Bank survey of sheltered housing (2021).

Table 6. Average number of beneficiaries per bedroom in sheltered houses included in the evaluation, by capacity, in 2020

		Total N of beneficiaries	Total N of SHs
2-4	1,6	33	10
5-9	2,0	472	71
10	2,2	150	15
11+	2,6	48	4

Source: World Bank survey of sheltered housing (2021).

The system of sheltered houses operated by the GDSACPs is geographically uneven and heterogenous. The system covers less than half of the counties in Romania and concentrates almost half of the services and beneficiaries in only four counties (Alba, Bihor, Constanta, and Dâmbovita) (see Figure 2). According to the NARPDCA data, in March 2021 there were 144 units serving a total of 1,004 residents. 95 Among the 100

<sup>&</sup>lt;sup>95</sup> NARPDCA (2021).

sheltered houses evaluated for this diagnosis, two-thirds were opened before 2015. There are significant disparities in terms of the mode of organization and functioning (part of a larger service complex or self-standing), size (ranging from 2 to 13 beneficiaries per SH), and location (rural or urban, integrated into the town or at the periphery/outside of the town).

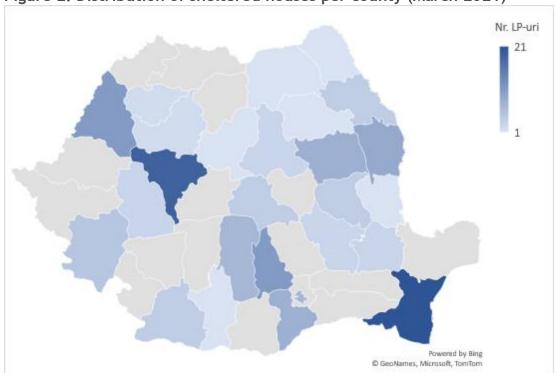


Figure 2. Distribution of sheltered houses per county (March 2021)

Source: NARPDCA (2021).

Physical adaptation and accessibility seem to be a problem for most sheltered houses. This is particularly concerning since many of them were built or repurposed especially to become living spaces for persons with disabilities. A third of SHs do not have accessible entrance (ground-levelled or with a ramp) and three-quarters do not have accessible bathrooms. There is also limited support for beneficiaries in learning about assistive devices and technologies.

Sheltered houses are small residential centers, sometimes physically isolated from the community. In Romania, SHs are group homes that host an average of 7.5 residents/home, going as high as 13. The average number of persons in a room is two, although the standard recommends only one. Even though the minimum quality standards require SHs to be located in the community, sometimes social isolation of persons with disabilities still occurs about one-third of SHs are located outside or on the outskirts of the town or village. Even if the pandemic certainly contributed to the isolation and forced many of the activities to take place inside the sheltered houses, few have partnerships with external service providers, activities being primarily provided by day centers (DCs). Life in the SH is largely strictly organized, being structured by the services and activities offered, as well as by the intervention of the staff. Most residents come from within the system of residential centers for adults and children with disabilities. In our sample of 100 SHs, half of the residents came from a residential center and a third from the children's protection system (temporary centers or group homes). Only 9 percent of the residents came from the community or living with their family. In some cases, the SHs were actually family-type homes/apartments from the child protection system, that were transformed once the beneficiaries became adults. About one third of the SHs share the same building, yard, or immediate space with another social service (mostly residential centers and SHs). Most of the DCs that are used are integrated with the SHs, so that the residents rarely leave the system for services or activities and have little opportunity for life in the community.

Most of the SHs work as long-term/permanent solutions, but there are services throughout the country that are invested in moving beneficiaries through the system and integrating them in the community. Although the mandatory minimum quality standards provide for a maximum of 5 years spent in an SH and many SHs are built in recent years, more than half of beneficiaries have lived in the same SH for more than 5 years. Moreover, many of the SHs are first and foremost solutions for rehousing beneficiaries coming from residential centers that are reorganized/restructured. Yet, interviews with service coordinators of mSHs have showed a commitment on the part of some of these services to offer their beneficiaries assistance and support to integrate in the community, both before and after moving out of the SH. They use the example and experiences of beneficiaries who were able to move and live on their own to motivate other beneficiaries. Furthermore, they understand and work to undo the resistance that some staff might have towards the "graduation" of beneficiaries by reassuring them that this does not mean they will become unneeded and lose their jobs.

There are situations when sheltered houses do not provide beneficiaries with conditions for autonomy, choice and control over daily and life decisions. In only half of the SHs, beneficiaries were able to visit the house before moving there, and in the case of 40 percent of the centers, beneficiaries are not there as a result of their own choice. Moreover, the beneficiary survey and interviews with service coordinators have revealed a life that offers little opportunity to make choices, explore options, and experience life in the community. Only one third of the interviewed beneficiaries declared that they can always make choices regarding their everyday life, and only one guarter said they are allowed to make these choices in the case of important, life decisions. In about one half of the SHs in the sample, the wake-up and sleep time are common for all beneficiaries and decided by the staff, and in less than a third of the beneficiaries can buy, prepare, and cook their food by themselves, with or without assistance from the staff, whenever they want. Less than half of the interviewed beneficiaries can shop and pick themselves their own clothing or personal items. There

are also limits or formal or informal restrictions on having a pet, a boyfriend/girlfriend, or leaving the SH. Privacy and having a personal space are also a problem in most centers. In only 9 percent of the SHs all beneficiaries can have their own room, in 33 percent privacy and confidentiality of the beneficiaries' private communication are respected, and in 25 percent of the SHs beneficiaries are not consulted when someone from outside the house is invited to spend time there.

Maximum and Minimum SHs differ in terms of number, type of beneficiaries, and services offered. There are almost ten times more Maximum SHs than minimum SHs. While differences between them are negligible in terms of standards and requirements (beneficiaries of minimum SHs are required to have a job), there are significant differences in terms of living conditions, as well as the profile of beneficiaries and activities offered. The living conditions are better in mSHs, with a lower average number of beneficiaries per room (1.6 compared to 2), larger bedroom surface areas per beneficiary, and generally cleaner and more spacious facilities. Maximum SHs reported having more problems with ensuring the necessary staff, spaces, or facilities than minimum SHs. Beneficiaries in both types of centers have different profiles, with those in MSHs having a higher proportion of persons with accentuated and severe degrees of disability, a slightly higher proportion of persons with mental disabilities, and beneficiaries with lower levels of formal education (see the Beneficiary Profile section below). Activities and services in the area of information (about rights, alternative services, opportunities in the community), support for and preparation for education, work, autonomous life tend to be offered more in minimum SHs.

There is a shortage of staff in the sheltered housing system. The current legal framework stipulates that MSHs beneficiaries be provided with services by DCs, at its premises, in open space or, as the case may be, in the MSHs, while mSHs beneficiaries are provided by DCs or other services in the community. <sup>96</sup> At the time of data collection, there were 734 vacancies in SHs and 172 vacancies in DCs. Of these, 684 are in MSHs and 151 in DCs serving MSHs beneficiaries, with an occupancy rate of approximately 90, respectively 93 percent. Most of the vacancies in the MSHs organization charts are for doctors and psychologists. Lack of staff is also invoked by most SHs when explaining difficulties in either delivering services or ensuring the success of their beneficiaries.

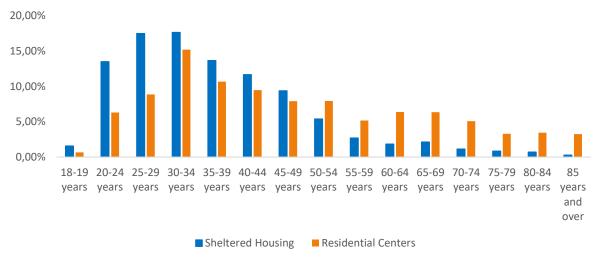
#### Beneficiary profile

While it is unclear what the selection process entails for admitting beneficiaries in the SHs, there is a stark difference between beneficiaries of Residential Centers and those of Sheltered Housing. Beneficiaries in SHs are on average younger and with lower degrees of disability than those in Residential Centers (see Figure 3 and Figure 4). Interviews with GDSACP directors indicate that when transferring beneficiaries from residential centers, there may be a preference for selecting those who are or may

<sup>&</sup>lt;sup>96</sup> Order no. 82/2019, Annex 2, Module I, Standard 1, Minimum requirements 5.1. and 5.2.

become autonomous. Interviews with SH service coordinators did not indicate any selection practices, but rather the admission of beneficiaries on a first-come, firstserved basis or the acceptance of beneficiaries sent by residential centers for relocation.

Figure 3. Comparison of age distribution between beneficiaries of residential centers and sheltered houses included in the evaluation



Source: World Bank survey of sheltered housing (2021) and World Bank Survey on residential centers for adults with disabilities (2020) (Output 3.1 under this Reimbursable Advisory Services Agreement).

Note: Data on beneficiaries of residential centers is collected for 2019, and data on beneficiaries of sheltered housing is collected for 2020.

Figure 4. Comparison of distribution by degree of disability between beneficiaries of residential centers and sheltered houses included in the evaluation



Reimbursable Advisory Services Agreement).

*Note*: Data on beneficiaries of residential centers is collected for 2019, and data on beneficiaries of sheltered housing is collected for 2020.

residential centers for adults with disabilities (2020) (Output 3.1 under this

Most beneficiaries in SHs have spent most of their lives in residential institutions. Overall, 75 percent of beneficiaries have spent most of their adult lives in an institutional setting. Before moving to the current SHs, more than half had lived in a residential center for adults with disabilities, more than a third came from the child protection system (residential center or family-type homes/apartments), and less than 10 percent had lived with their families. Beneficiaries coming from a family context or child protection services have in higher proportions degrees of severe and high disability than the rest. There is, however, a discrepancy in the analyzed data: while data reported by SHs indicated that there are no beneficiaries who previously lived in another SH, beneficiary questionnaires showed that at least 18 beneficiaries (9 percent of our sample) had lived in an SH before moving to the current one. Moreover, interviews with service coordinators suggested that there are beneficiaries who move from one sheltered house to another, sometimes even far away, as a result of the process of reorganization and restructuring of large residential centers (SHs are used as temporary accommodation solutions, until a center is opened/reorganized or new SHs are opened). Roughly half of beneficiaries have known family.

Beneficiaries in Minimum SHs are slightly older compared to those in Maximum SHs (see Figure 5). The difference in age needs further investigation as it cannot be explained by the process of transferring children from the protection system (family-type homes/apartments) to SHs once these children become adults (one service coordinator called the process "adultization"), as the proportion is similar for both types of centers (around 34%). At the same time, in some cases, there seems to be slight prejudice against older persons when it comes to them being admitted or kept in SHs. One service coordinator has indicated that they prefer to move older persons (over 50) into facilities dedicated to the elderly, because the service is no longer a fit for their needs.

Figure 5. Age distribution of beneficiaries in minimum and maximum sheltered houses included in the evaluation, in 2020 (proportions)



Source: World Bank survey of sheltered housing (2021).

While the difference in types of disability between the two types of SH is relatively small, the profiles in terms of the degree of disability are significantly different. The proportion of persons with mental disabilities is much higher in MSHs (15 percent) than in mSH (5 percent) (see Table 7). There is no objective explanation for this difference. On the other hand, beneficiaries in the mSHs have in general lesser degrees of disability (see Figure 6). One hypothesis is that employers may consider persons with less severe disabilities to be "fit for work," and thus they would have a job (which is a requirement for Minimum SHs). Another hypothesis is that they are more likely to be seen as fit for independent living by those who decide their transfers from larger residential centers.

Table 7. Distribution of beneficiaries by type of disability in sheltered houses included in the evaluation, by type of sheltered house, in 2020 (proportions)

	Physi cal	Audito ry		Intellec tual	Psychoso cial	Associat ed	HIV/ AID S	TOTAL
Maximum SH Minimum	2,8	0,2	0,3	68,5	15,3	12,3	0,6	100
SH	6,5	0,0	1,6	72,6	4,8	14,5	0,0	100
Total	3,1	0,1	0,4	68,8	14,4	12,5	0,6	100

Source: World Bank survey of sheltered housing (2021).

Figure 6. Distribution of beneficiaries by degree of disability in sheltered houses included in the evaluation, by type of sheltered house, in 2020 (proportions)



Source: World Bank survey of sheltered housing (2021).

Around 8 percent of beneficiaries in both types of SHs do not have legal capacity. Roughly three quarters of those without legal capacity have a family member as a legal representative. The number of persons losing or about to lose their legal capacity is growing. One third of those without legal capacity have lost it since 2018. Also, the external evaluation has shown that SH staff/coordinators are working towards taking away the legal capacity of some beneficiaries. Secondly, this status should be of concern as it is often used as an explanation/justification for not involving beneficiaries in making decisions about their lives or the services they receive.

A large number of beneficiaries do not develop their skills for independent living. The objective of sheltered housing services is to support beneficiaries to develop and consolidate their independent living skills while they live on service premises. Beneficiaries may be provided with support forms for developing a wide range of skills related to cognition, communication, social interaction, self-care, daily tasks, mobility as well as economic transactions. 97 During 2020, about half of beneficiaries either regressed or only managed to maintain their independent living skills, with a higher percent in mSHs than in MSHs of beneficiaries who rather regressed (11 percent compared to 7 percent) or who only registered slight improvements (24 percent compared to 30). While more beneficiaries in mSHs did make significant improvements regarding their skills (16 percent compared to only 6 in MSHs), as the standard stipulates for this type of SHs, it is still worrying that in most SHs none or the majority of beneficiaries registered any improvement (see Table 8). Service staff reported that lack of improvement may relate to the lack of staff adequately trained (in SHs or DCs) or lack of access to other relevant services. However, the main reason invoked in more than half of SHs is the constant need for support that a lot of beneficiaries need and the poor prognosis for improvement. This raises the question about the use of sheltered houses for these beneficiaries other than for long-term residence. Alternatively, access to more housing options should be ensured in the community with adequate support

<sup>&</sup>lt;sup>97</sup> Order no. 82/2019, Annex 2, Module IV, Standards 5-13.

services (including personal assistance) that persons can choose and control in line with their needs and preferences.

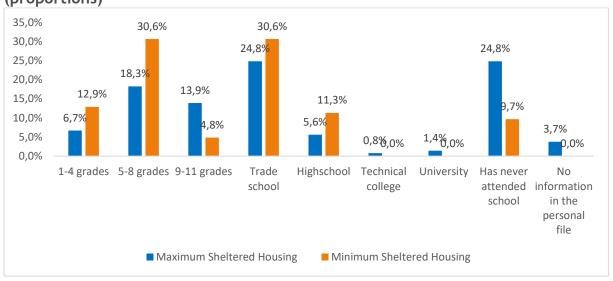
Table 8. Number and proportion of sheltered housing services where none or the majority of beneficiaries showed no progress in their independent life skills, in sheltered houses included in the evaluation, in 2020

Independent life skills:	None of beneficiaries in the SH showed progress		Most of beneficiaries showed no progress	
	Numbe r	%	Numbe r	%
Cognitive abilities	58	58%	80	80%
Daily life abilities	49	<b>49</b> %	76	<b>76</b> %
Communication abilities	50	<b>51</b> %	76	<b>77</b> %
Mobility	48	63%	54	<b>71</b> %
Self-care abilities	51	<b>52</b> %	74	<b>75</b> %
Self-health care abilities	61	61%	78	<b>78</b> %
Self-management abilities	51	<b>51</b> %	76	<b>76</b> %
Social interaction/interpersonal relationships abilities	53	54%	73	<b>74</b> %
Gaining economic independence	69	<b>69</b> %	84	84%
Interest in work activities	70	71%	79	80%

Source: World Bank survey of sheltered housing (2021).

Beneficiaries in SHs had limited access to formal (in particular to mainstream) education. Less than a fifth of beneficiaries were able to access mainstream education, and about a quarter never went to school. The rest were enrolled in special education. Educational profiles of beneficiaries in both types of SHs vary slightly: persons in Minimum SHs are more likely to have stayed in school longer and less likely to not have attended formal schooling at all (see Figure 7).

Figure 7. Distribution of beneficiaries by the level of formal education, by type of sheltered house, in sheltered houses included in the evaluation, in 2020 (proportions)



Source: World Bank survey of sheltered housing (2021).

Although sheltered housing services are designed to be a temporary housing solution that prepares beneficiaries for life in the community, they function as long term and even permanent solutions for a significant proportion of beneficiaries. Almost one third of beneficiaries in mSHs and about a fifth in MSHs have lived in the same house for more than ten years. Moreover, almost half of the mSH residents have been in the same center for over 5 years, the maximum allowed length of stay according to the standard. Contracts were, however, renewed and the reasons indicated by the services were: lack of independent living skills, lack of family involvement, health/disability related issues, lack of alternatives in the community, and lack of desire to move on the part of the beneficiary. Of beneficiaries that were surveyed, about one third said they would like to move out of the SHs and into the community.

Not all beneficiaries of minimum SHs have jobs. Although there is an obligation for beneficiaries of minimum SHs services to have a job as a condition of receiving the service, only 13 percent of them currently have a job. Moreover, the proportion of beneficiaries in each type of SHs who hold jobs are not significantly different (10 percent in MSHs). According to the self-assessment, among the Minimum SHs surveyed, there are only eight beneficiaries who have jobs. What is puzzling is that the proportion of persons who have legally been declared to have lost their work capacity is much higher in Minimum SHs than in Maximum SHs (20 percent compared to 7 percent), which raises questions about the compliance with the admission procedure to services, as well as about the future of beneficiaries who may consequently become long-term institutionalized. Of the 29 surveyed beneficiaries who declared they have a job, most perform unskilled, physical work (see Table 9 and Table 10).

Table 9. Type of work surveyed beneficiaries are performing

Type of work/position	N
Textile worker	6
Cleaning/green spaces	6
Carrying/moving merchandise	9
Unskilled worker	2
Kitchen help	2
Makes keyrings	1
Animal caretaker	1
Day laborer	1
Does not know	1
Total	29

Source: World Bank survey of sheltered housing (2021).

Table 10. Length of employment at the current job (surveyed beneficiaries)

Number of months	N
<= 6	10
7 - 12	7
13 - 36	6
37+	6
Total	29

Source: World Bank survey of sheltered housing (2021).

A quarter of beneficiaries pay for part of the services. Beneficiaries with any type of income are required to pay a share of their income towards the service, and in some cases, their families are also required to pay. Payments do not go directly to particular services, but rather to an umbrella service provider, GDSACP. A small share of the income is left for beneficiary's use but is insufficient to allow for any savings or more significant personal purchases.

Most beneficiaries of SHs live in social isolation and experience an impoverished social life. Over half of beneficiaries have no friends outside of the SH system and almost half have nobody else to turn to for help with a problem or making a decision outside of SH staff. Over half have never had a boyfriend or a girlfriend and 37 percent do not know any of their neighbors by name. For the one month before the survey more than half had no contact of any kind with a friend or a family member outside of the SH. In this context, access to social spaces outside the SH becomes critical as well as support from service staff with fostering diverse social relationships and opportunities for socialization.

<sup>&</sup>lt;sup>98</sup> Government Order no. 1887/2016 from 15 September 2016 establishes the conditions and the algorithms for these payments, which apply to all social services, depending on type and amount of income of beneficiaries or their families.

Most beneficiaries are autonomous in terms of basic everyday activities, but the majority need assistance in performing or completing instrumental activities. About 84 percent of surveyed beneficiaries declared that they have total autonomy when it comes to basic activities like eating, getting dressed, getting washed, using the toilet; about 13 percent reported that they need some assistance in performing these activities. A much smaller proportion (6 percent) stated that they need no assistance with more complex tasks like making food, going to the doctor, cleaning their home, or going shopping. More than half (55%) indicated that they need a moderate amount of assistance, and the rest (40 percent) are either entirely or to a great degree dependent on assistance. Reaching medical services and administering medication/treatments seems to be the need that raises most of the problems for beneficiaries that were surveyed.

#### 2.1.3. Standards compliance and implementation analysis

This section presents a detailed evaluation of the compliance with the minimum requirements in the standards, using both service's self-evaluation and information gained from the external evaluation, a questionnaire applied to a representative, a probabilistic sample of 195 beneficiaries, and an analysis of documents provided by the services.

#### Module 1. Social Service Management

The first module ensures compliance with relevant laws and regulations regarding the organization and management of the service, more precisely establishing the service, hiring and maintaining qualified staff, offering the service to particular kinds of beneficiaries, maintaining proper internal administrative paperwork, and establishing relevant partnerships in the community. This module also establishes minimum requirements related to assuring the comfort and safety of beneficiaries in terms of spaces, physical access, accessibility and adaptations, materials, and equipment. There are two additional standards, one referring to feeding, care, and assistance, and one referring to health assistance.

#### Standard 1: Organization and functioning

Standard description The standard details the general conditions for organizing the service and managing it, encouraging partnerships with other entities, offering training for the personnel in areas like equality, preventing negligence, violence, and abuse, facilitating an independent life for the beneficiary, etc. The standard also indicates the minimum necessary documentation. Moreover, the standard stipulates who can benefit from the service, and what the minimum and maximum capacity for the service should be (2) and 10 beneficiaries, respectively). It also mentioned the two types of services that can be organized: maximum sheltered housing and minimum sheltered housing services.

#### Self-assessment

Only 25 percent of all SHs in the sample comply with all the requirements of the standard. Most of the problems seem to be concentrated around a few requirements: staff training in the areas mentioned by the standard (only about 2/3 organized the required training and have it in their training plan) and the annual report (less than half have all the requirements—less than two thirds, for example, have included an analysis of the beneficiary satisfaction questionnaires and proposals to improve the activity of the unit).

4 of the services do not comply with the size requirement (between 2 and 10 residents).

Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis

According to data from the external evaluation, while not all SHs had annual plans for staff training that included mandatory thematic modules as required by the standard, an even smaller number of services have actually carried out trainings in 2020. The proportion varies depending on the theme of the training modules: in the case of Maximum SHs, trainings have been offered in only 36 percent of services on "Respect for diversity" going up to a maximum of 71 percent in case of modules on "Prevention, recognition and reporting of forms of exploitation, violence and abuse". In minimum SHs with only 18 percent of services offer trainings on "Respect for diversity" and "Respect and encouragement for individual autonomy and independence of persons with disabilities".

The interviews with service coordinators also confirmed that while training courses aimed at the personnel are really valued, they are not organized often enough. Some are organized internally, but it appears that in some cases the entity responsible for organizing such courses is the GDSACP, which is not really active in this area. Also, courses organized and training needs that were mentioned by service coordinators were not mentioned in the standards, but rather more practical approaches, closer to service provision (courses offered by the Red Cross, the Department of Public Health). One service coordinator mentioned that they would really appreciate the training that involved learning about best practices and exchanging information and experience with other similar services.

All centers have reported carrying out performance evaluations of staff regarding their fulfillment of tasks and responsibilities in the job description, in most cases, with a yearly frequency.

in one room. About one quarter of the SH services have at

- least one room in which more than 2 beneficiaries live. Most of these services are maximum sheltered houses.
- Requirement 11: in one fifth of services, the requirement that bathrooms should not be shared by more than 4 beneficiaries is not met.
- Requirement 12: in about 30 percent of SHs there are problems with the physical accessibility of living spaces and bathrooms.
- Requirement 25: in 30 percent of SHs where surveillance video cameras exist, the requirement about placement (only in common spaces and at the entrance) is not respected, possibly infringing on the right of beneficiaries to privacy.

Comprehensive evaluation: external evaluation, questionnaires, interviews. document analysis

Service's location in the community warrants further discussion. Although all services comply with the requirement (according to the self-assessment), the data collected further showed that 65 percent of all SH services (and 93 percent of those in the rural areas) are at an average distance larger than 4 km from relevant community services and spaces. Moreover, only 10 SHs are truly placed in the community—in an area (and in a building) that has only other residential or public establishments, but not residential centers or disability services. More than half of the SH services share a yard or a building with other social services.

For 90 percent of beneficiaries included in the survey, housing is one of the most important services offered by the SHs. A very large proportion (95 percent) declared that they are pleased with the living conditions.

According to data from the external evaluation, most centers are located either in the center of the locality, or between the center and the periphery, while a third are at the very margins and two SHs outside of the locality. Four SHs are in areas where no other public or residential buildings are visible and four are in an area with no easy access to public transportation. All SHs located in rural areas have access to transportation that either runs every hour (50 percent of them - 10 SHs), or at least every 2-3 hours. Vehicles adapted for persons with physical disabilities or low mobility or for the rest of beneficiaries with no immediate access to public transportation exist in 17 percent of SHs. Alternatively, more than two thirds of SHs may receive a vehicle from GDSACPs upon request in case of need. It is however unclear how these vehicles are used to ensure beneficiaries access to services in the community or facilitate their activities or how responsive GDSACPs are to requests.

The general state of the SH buildings was satisfactory in most centers that were externally evaluated. All but 3 SHs were surrounded by a land or courtyard that was well maintained. About 69 percent of SHs had none of the following problems broken windows, windows that do not close, seepage and mold, broken floors, or perforated roof. About 27 percent had only a few of these problems and 4 centers had most or all of them. Generally, SHs did provide beneficiaries with a comfortable temperature and natural lighting, permanent supply of cold and hot water, and with clean spaces (activity rooms, bathrooms, common areas, outdoor spaces) - only 2 SHs had no permanent hot water, one had no access to a hygienic source of drinking water and in 3 SHs the spaces were rather not clean. In 5 SHs toilets were not equipped with consumables (toilet paper and soap), while 71 percent of all SHs did not have at least one adapted bathroom and toilet. 30 percent of all SHs did not have a ramp of access in the building for wheelchair users.

Privacy is not always respected in SHs. Although housing more than one person (two, actually) in one room is allowed by the standard, this does not mean it is free of problems. About 40 percent of beneficiaries said that they do not have any place where they can be alone or have privacy if they wish to. Although the standard asked explicitly for beneficiaries' consent to share the room, more than half of beneficiaries have indicated that it was not their choice to live with their current roommates. Data from the external evaluation indicated that only 9 percent of SHs provided beneficiaries with individual rooms, while only in almost one third of SHs the privacy of residents' personal space respected, without the intrusion of other residents or staff. In addition, evaluators also indicated that in 21 percent of SHs, all or most beneficiaries' dormitories are not spacious.

Interviews with service coordinators indicated that they are preoccupied with improving living conditions, but that they are limited by budget issues—they hope more funds will be allocated to this purpose by their respective GDSACPs. Service staff also reported during the external evaluation that beneficiaries had a series of complaints in 2020 related to aspects relevant to this standard, such as complaints related to the quality of living conditions (in 5 SHs), insufficient cleaning materials (in 2 SHs), lack of sports utilities (tennis table, gym, etc.) and of internet access (in 3 SHs) Only complaints related to the absence of cleaning materials were reported to have been subsequently implemented.

Some of the problems with this standard's compliance come from the process of developing the service and working with the material base that was left after dismantling other social services/residential institutions. Other problems come directly from the lack of options for housing in the community, which makes crowding of the existing SH-type services be accepted by service providers.

#### Standard 3: Food and feeding

## Standard description

The standard details the minimum requirements in terms of offering meals, access to food, and conditions for meal preparation. including equipment, staff training, and responsibilities. The requirements are slightly different for the two types of SH. In the case of minimum SHs, food shopping and meal preparation are to be done by beneficiaries themselves. There are also provisions for ensuring healthy food.

#### Self-assessment

34 percent of the SH services comply with all the requirements in the standard. One of the main findings, for almost half of the services, is that the staff involved in any given activity is different from the one indicated in the standard which is supposed to be only the nurses and social pedagogues. The involvement of social workers (in 49% of all SHs) or education instructors (in 17%) makes up for the vacancies of nurses in the system, as well as the lack of any social pedagogue positions in the organizational charts of all SHs - the two occupations responsible for providing nutrition-specific activities according to standards.

There are other issues, but for a smaller number of services. For example, although the standard requires beneficiaries to shop for food and prepare their own meal, one mSH (out of 11) does not do this. Also, almost one fifth of all SH services do not have a separate room or space for storing food. Only 2 SHs serve catering meals (out of the 6 without their own kitchen), the remaining 4 being part of a service complex that includes a residential center with a kitchen used to prepare food.

Almost a quarter of the centers (23) have their own garden, where vegetables are grown with the involvement of beneficiaries and/or staff. In 22 of these places, beneficiaries are involved in working the garden also in accordance with their own individual service plans.

# Comprehensive evaluation: external

Although according to the self-assessment, only 11 beneficiaries participate in meal preparation, the beneficiary survey showed that the number is actually higher: about 44 percent participate

in such activity every day, and only 24 percent never. Furthermore, it is interesting to note the potential for autonomy (something that should be encouraged): about 26 percent of beneficiaries said that they do not need support for meal preparation and 39 percent indicated that they could prepare a meal by themselves. These numbers are also supported by interviews with service coordinators, who stated that they encourage their beneficiaries to get involved with meal preparation, and this gives them a sense of self-worth and autonomy. One service coordinator recounted how much beneficiaries have changed in this respect after they moved into SH (coming from a residential center where they were not able to do anything).

Food quality is not satisfactory in all SHs. In 2020, beneficiaries complained about food quality, lack of diversity in the food menu as well as lack of the certain type of food in 16 SHs (close to 19 percent of all services). In only 6 SHs measures were subsequently implemented as a result of beneficiaries' complaints.

#### Observations

Meal preparation has the potential for equipping beneficiaries for independent living—beneficiaries should be involved in this activity with proper supervision where necessary, and given as much autonomy and trust as possible. However, it is not clear how much those who have the task of inspecting and monitoring compliance with the standard understand this. An interview with a private service provider (also for SHs) indicated that it was difficult for them to convince the inspectors that it was fine to let the beneficiaries buy food - the inspectors were convinced that the beneficiaries were in danger of buying and eating poison.

In one minimum sheltered house where beneficiaries are not involved in shopping for and preparing their own meal, it is unclear how the preparation for independent life in this domain is taking place.

One of the standard's requirements is worded vaguely (that meals are to be offered in complementarity with the day center)—more precise wording is needed.

#### Standard 4: Health assistance

## Standard description

The standard specifies the minimum requirements in terms of ensuring the health of beneficiaries. The staff can offer medical assistance only in case of minor issues (colds, for example) and emergencies. Most of the standard refers to managing medication and special kinds of situations, assistance with administering treatments, and documenting all of these procedures. There are

involved preponderantly routine blood tests or flu immunization

A large number of beneficiaries are being administered psychotropic medication - 71 percent, with a much higher proportion in MSHs than in mSHs (73 percent and 47 percent, respectively). Service staff involved in the administration of psychotropic medications are preponderantly medical assistants (in 57 percent of SHs) and nurses (in 29 percent). However, medication is also administered by non-medical staff such as social workers (in 36 percent of SHs) or even education instructors (in 12 percent of MSHs). This situation raises other questions about the practices that require the provision of medical information about the nature of medications, diagnosis, possible side effects, and life-threatening health risks.

Medical treatment without the informed consent of beneficiaries is a practice in some services. In 17 SHs medication is being administered without the informed consent of beneficiaries. Service staff mentioned that administration of psychotropic medication is administered without the informed consent of beneficiaries either due to the lack of the latter's capacity to understand the purpose of the medication, or because the doctors' recommendations are prioritized, and in some cases, due to beneficiaries' inability to sign a consent form that they are not able to read. This practice is more prevalent in Minimum than in Maximum SHs (14 percent and 8 percent, respectively), even though beneficiaries with more severe disabilities and a presumably higher level of support for understanding are concentrated rather in Maximum SHs. In addition, other nonconsensual medical treatments are being applied to beneficiaries. For instance, in 2020, 18 beneficiaries were also being involuntarily committed to psychiatric hospitals, mostly as a consequence of aggressive behavior or crisis states, as reported by service staff. Contraceptives are being administered only with beneficiaries' informed consent only in 65 percent of SHs.

The practice of ensuring beneficiaries' informed consent for medical treatment requires adequate knowledge and procedural safeguards. However, service staff reported that only 85 percent of SHs employees are familiar with the necessary steps for ensuring consent, while beneficiaries have this knowledge only in 62 percent of SHs. In 15 percent of SHs, beneficiaries have no

possibility to contest non-consensual treatment. In addition, in only 3 SHs, beneficiaries are encouraged to develop an advanced directive whereby they can specify treatment and rehabilitation options for use in a future situation where they will not be able to communicate their choices. It is not clear however how and when service staff and beneficiaries are provided information on how to ensure informed consent and what to do in case this right is not respected.

Ensuring informed concern requires that beneficiaries are provided accessible information on the purpose and side effects of medication, as well as on alternatives to medication that they may also access easily. While access to psychiatric medical care seems not to be an issue for beneficiaries of SHs, the frequency of consultations varies from one to three or more times per year with a large proportion of beneficiaries meeting a psychiatrist only once a year (17 percent of those in MSHs up to 39 percent in mSHs). This low frequency coupled with insufficient access to other mental health services such as psychotherapy or psychological counseling (one third of psychologist positions are vacant) further deprives beneficiaries of necessary options and conditions for providing informed consent for being administered psychotropic medication.

According to service coordinators interviewed, the health state and needs of beneficiaries can greatly influence their access to the service. Especially in rural or more remote areas, beneficiaries with high or complex medical needs are moved to other units closer to hospitals or urban areas, and since the number of SHs is low, these beneficiaries end up institutionalized in residential centers. However, currently, a large number of beneficiaries in SHs (approximately half of all beneficiaries in both types of SHs) do have complex health needs and individualized prevention, intervention, and recovery plans.

#### Observations

Access to quality medical health care - primary and specialized must be ensured for all beneficiaries in SHs, since long-term residence, communal living as well as long-term administration of psychotropic medication increases the risk of both transmittable and chronic diseases. Ensuring informed consent for all medical treatments remains to be achieved by requiring that all service staff and beneficiaries are informed on the necessary steps of the process and by implementing clear procedures on how beneficiaries can contest forced treatment. In addition, training must be provided on how to de-escalate crisis situations to

# Module 2. Accessing the social service

Module 2 offers a framework for accessing the service, from informing potential beneficiaries about the service and admitting them, to managing their information and the final termination of service. The module standards and requirements place special emphasis on the administrative paperwork that is related to these processes, and in particular its transparency and compliance with the law.

# **Standard 1: Information**

Standard description	The standard is meant to assure a full and adapted access to information about the service to interested persons with disabilities that could benefit from it. The standard requires that materials are published (on paper and/or electronically), and that they comply with particular requirements. No provisions are made as to how the materials are to be distributed to those who are interested.
Self-assessment	A little over 40 percent of the services are complying with all requirements. About 15 percent of SHs are missing all the required elements in the informative materials. There are also issues with obtaining consent for using beneficiaries' images and personal data in the informational materials. Three services do not allow visits from prospective beneficiaries if they have any vacancies.
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	Visiting the service beforehand is an essential step in the process of ensuring the service is freely chosen by beneficiaries. However, visiting the premises is not actually a common practice, partly because beneficiaries have little choice in coming here. This was confirmed by 34 percent of the surveyed beneficiaries who said it was not their choice to come to this particular SH. In addition, only 14 SHs received 26 visits from prospective beneficiaries in the past two years, even if 173 new beneficiaries were admitted in this period, amounting to a quarter of the total number of current beneficiaries. Moreover, only 28 percent of surveyed beneficiaries visited the service before moving here. Service staff also confirmed during the external evaluation that in 37 out of 100 SHs beneficiaries had not visited the service before the admission.  A large proportion of SHs had not provided relevant information about the service to current beneficiaries before their admission. For instance, 20 percent of SHs did not inform current

beneficiaries about the organization and functioning of the service. Furthermore, current beneficiaries did not get to know the other beneficiaries already living at the time in the service nor the service staff in almost one third of SHs, while in 27 percent of SHs beneficiaries were not provided information on other services in the community, including residential alternatives.

Information materials about the service available to beneficiaries in accessible formats are not provided by all SHs, as data from the external evaluation indicate. Between 14 to 22 percent of all SHs do not provide materials with information on the description of the service, admission requirements, services and activities provided, beneficiaries' rights an, d obligations. An even higher percentage of SHs do not provide information materials on conditions for suspension/termination of contract and on beneficiaries' financial contribution to service costs in 46 percent of SHs and 53 percent, respectively.

#### Observations

It appears that the efforts for communicating about the service to the community and the prospective beneficiaries are minimum—most of the current residents (84 percent) come from within the system: a residential center for adults or children or another SH. One service coordinator indicated that when they have a vacancy, they advertise only to residential centers. Moreover, quite a large number of SHs had not provided beneficiaries with the opportunity to find information about the services, meet other beneficiaries and service staff, which raises additional questions about the extent to which services center first and foremost the interests of beneficiaries and respect their autonomy in choosing the service.

#### Standard 2: Admission

# Standard description

The standard details the requirements for admission, in particular involving beneficiaries and and their representative the contents of the admission file, the procedure, and provisions related to signing the contract. The procedure should have a number of required elements (application for admission, copy of identity papers and disability certificate, PIS and PIRIS, proof of income, social investigation report). There are separate admission conditions for the two types of services (for mSHs, there is an employment provision: beneficiaries have to be employed in order to benefit from the service, with a respite period of 3 months if they lose their job).

#### Self-assessment

According to the self-assessment, 25 percent of all SHs comply with all the requirements of the standards. There are issues with half of the requirements:

- One quarter of the centers do not have beneficiaries' files that include all the elements stated in the standards. Among the missing documents are copies of the legal representative's ID, admission requests, the beneficiary's individualized plan of service (PIS or PIRIS), proof of income. PIS and PIRIS are the mandatory documents that are most often absent from the files in 13 percent of SHs and 17 percent respectively. Proof of income is missing from files in 13 percent of MSHs.
- o Almost half of SHs offered service contracts for more than 5 years (the maximum length stipulated in the standard, which may be extended in certain situations).
- o 13 percent of SHs do not use accessible formats for the contract or the explanations about the contract. Data reported by SHs show that there is a need for an accessible format for the contract/explanations about the contract. In the past two years, there were 17 cases when such formats were needed for the contract and the explanation-it was provided in 13 of these cases.
- o In 3 out of the 11 mSHs, contracts do not include the provision that the beneficiary has a job for the length of the stay in the SH.
- o 10 percent of SHs do not have a payment agreement with the beneficiary or his/her family or legal representative.

Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis

coming Some contradictory information is from the comprehensive evaluation: services declared that only 8 people are employed while 29 percent of beneficiaries reported having a job. Not all mSH beneficiaries are employed, as required by the standard.

There are further contradictions regarding compliance with provisions related to beneficiaries' employment status. The standard requires that a person admitted in a minimum Sheltered Housing is working (has a job), but 5 persons living in mSHs do not have legal capacity and legally cannot sign a work contract. According to the Labor Code, Art. 13 para. (4), hiring someone who does not have legal capacity is forbidden.

Admissions to SHs are not always for the beneficiaries to decide. In fact, data from the external evaluation indicated that in more than 41 percent of all SHs (26 MSHs and 3 mSHs), at least some beneficiaries have been admitted to the service not as ra esult of their personal choice. The reasons reported by service staff are multiple - the choice either belonged to legal representatives (in more than half of MSHs and all mSHs), beneficiaries have a high support needs for decision-making and communication (in more than half MSHs and all mSHs), the alternative that beneficiaries prefer does not exist in the community (in around one third of SHs), the evaluation team considered that admission to the SH is the best option for the person (in more than two thirds of MSHs and all mSHs), or the person was evaluated as not having independent living skills appropriate for community living (in 79 percent of MSHs and all mSHs). In a few other situations, beneficiaries' choices had been sidestepped either.

Further ensuring that beneficiaries are freely choosing the service requires that they are constantly consulted regarding their option. However, beneficiaries from a quarter of MSHs (i.e. 22 SHs) are never consulted whether they prefer to reside in the SH or somewhere else. In the rest of the cases, beneficiaries are consulted with different frequencies (daily, weekly, monthly or yearly). While beneficiaries from most mSHs are consulted weekly, the frequency in MSHs varies to a greater extent between services, with 16 percent of MSHs where beneficiaries are consulted only once a year. Service staff in more than a third of all SHs also reported that beneficiaries are consulted whenever necessary or in case this is necessary, without further specifying what this may entail.

The prolongation of beneficiaries' stay in SHs beyond the legal period of 5 years may be influenced by a series of factors. Lack of adequate independent living skills was invoked by service staff in close to half of SHs (40) with beneficiaries who had resided there for more than 5 years. The health status or the degree of disability also contributed to the prolongation of the accommodation period, according to staff statements in a third of SHs. Other motives indicated are, in this order, the lack of family cooperation, lack of alternative housing and of financial resources, beneficiaries' unwillingness to leave the SHs, old age, lack of work capacity as well as of appropriate education level, and discriminatory attitudes in the community.

The prolongation of stay may also be influenced by the lack of support from service staff. Almost a third of all MSHs (27) do not offer support to beneficiaries who want to leave the SHs to identify and access alternatives in the community. In addition, in 23 percent of all SHs beneficiaries who wanted to leave the

service during the previous year were not able to do so. Among the reasons reported by service staff were, in order, lack of adequate independent living skills (in 19 out of 23 SHs), high level of support needs for understanding, communication and decisionmaking (10 out of 23), lack of residential alternatives in the community (11 out of 23), lack of services that beneficiaries may need in the area where they could have resided in (5 out of 23). In 7 SHs beneficiaries who had decided to leave the service eventually changed their minds, according to service staff. In other situations, beneficiaries could not leave because their families convinced them not to, or the legal guardian disapproved, families could not take care of them, insufficient income levels, difficulties in finding employment either due to lack of jobs or reasonable accommodations, difficulties in getting used to life outside the SHs, or lack of adequate living conditions in residential alternatives.

#### **Observations**

There is a need to ensure decision-making support for all prospective beneficiaries, as well as information materials in accessible formats, to ensure that they are admitted and can access the service with their full and informed consent. In addition, beneficiaries must be continuously consulted on their preferred residential options and adequate support must be provided to identify and access alternatives in the community to avoid prolonged stays.

# Standard 3: Beneficiary's personal file

Standard 5. Denem	cially a personal file
Standard description	All beneficiaries should have a personal file. The standard details the conditions under which it can be consulted by various people (beneficiaries or their legal guardians, employees from the protection systems or outsiders).
Self-assessment	According to the self-evaluation, 90 percent of all SHs comply with all the requirements in the standard. The lack of compliance comes from not respecting the requirements related to consulting beneficiaries' files (an agreement from the beneficiary/legal representative is needed if someone from outside the system is consulting it, the agreement has to be on file). Only one SH does not offer a copy of the file to beneficiaries upon request. While all SHs reported that beneficiaries or their legal guardians can ask to see their files at any time, in 2020, only 17 beneficiaries in 8 SH asked to see their files.
Comprehensive evaluation:	No additional information.

representatives of beneficiaries. In 2020, the service was

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Terminating the contract after the maximum length of 5 years is considered to compromise the prospects for beneficiaries' inclusion in the community in some situations. Some SSPs point the lack of social housing in the community and to the low wages of beneficiaries which prove to be insufficient for covering renting costs in the community. The need for a support service that can help beneficiaries in finding housing, as well as for support services for beneficiaries who may not be able to live on their own have been indicated as necessary measures to ensure independent living after beneficiaries leave SHs or as an alternative to SH. In their absence, however, the termination of the service contract for SH after the maximum 5-year period, may in fact increase the vulnerability of beneficiaries and could potentially lead to their re-institutionalization.

#### Module 3. Evaluation and planification

The third module seeks to ensure that the service is constantly provided in accordance with beneficiaries' needs, through proper evaluation and monitoring and a properly personalized plan. The requirements focus on procedures as well as on the resulting documentation.

#### Standard 1: Evaluation

Standard description	The standard details the requirements for the procedure of evaluation (what is to be evaluated, how, by whom, and what documentation to use). There is a separate requirement that beneficiaries should be involved in the process and that they or their legal representatives have to be informed of the result of the evaluation and have to sign the form.
Self-assessment	According to the self-evaluation, less than half (41 percent) of the centers comply with all the requirements in the standard. While there are issues with most of the requirements in the standard, at least for a few centers the most serious problem seems to be with the multidisciplinary team which must include 3 members with particular specializations - 16 percent of the centers do not comply with this requirement. There are also issues with the legal representative—although required by the standard, in almost one quarter of the centers where this is the case, the legal representative is not present for the evaluation nor has signed the required form to be informed of the result. In 4 centers (4 percent of all centers), the beneficiary/legal

During the evaluation, staff involved is expected to follow the recommendations from PIS and PIRIS, from other evaluation documents made by specialized structures, other specialists or other public institutions/services. 94 percent of all SHs reported compliance with this requirement.<sup>99</sup>

Involving beneficiaries and listening to their opinion during the evaluation is a mandatory requirement. However, 7 SHs reported non-complying with this requirement. In addition, a high proportion of services do not involve at least some of their beneficiaries (33 percent) or listen to their opinion (18 percent) This translates in 20 percent of beneficiaries that cannot be involved in the evaluation process and 14 percent whose opinion is ignored. The reasons invoked are, in order of the number of occurrences, from the highest: low comprehension capacity, low communication capacity, and lack of legal capacity. The lack of legal capacity, while it is a legal status, cannot be substituted for a direct evaluation of the ways in which a beneficiary can be involved.

Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis

Evaluation of samples of beneficiaries' files confirmed that most SHs (83 percent) had evaluated their beneficiaries within 5 days from the approval of admission - as stipulated by the standard. However, only 60 percent of SHs do in fact have evaluation fiches that contained all aspects stipulated by the standard (information about the evaluation, identified needs, short and medium-term objectives, the specialized staff involved in the evaluation, their signatures as well as those of beneficiaries' or of their legal representatives). The short and medium-term objectives, a mandatory aspect of evaluation fiches, lacked in approximately 50 percent of all SHs, with a higher proportion of Minimum SHs (36 percent).

The evaluation is generally service-oriented, meaning that beneficiaries are assessed according to the services and staff available. Cultural needs are usually overlooked, and educational needs are not being assessed, as the evaluation instruments measure only the education level. Furthermore, educational activities are proposed only in sheltered houses that employ a reintegration teacher ("pedagog de recuperare"). Less than 10

<sup>&</sup>lt;sup>99</sup> In fact, 22 percent of beneficiaries who receive services from around one third of SHs have neither a copy of their PIS nor a PIRIS included in their file.

percent of the Evaluation Fiches record beneficiaries' preferences by asking questions about enjoyed spare time activities, hobbies, desires for the future, and beneficiaries' accommodation preferences. Aspects related to sexuality are not measured, and only a few instruments record whether beneficiaries are intimately involved with another person in the sheltered housing.

It is not clear how multidisciplinary teams involve beneficiaries during the evaluation process and consider their opinion. Only close to one quarter of all SHs have evaluation fiches that describe what the beneficiary considers important and what kind of support he or she needs. While this is not a requirement of the standard, some services reported that this absence does indeed reflect the lack of beneficiaries' involvement in their evaluations which in most cases is due to beneficiaries' high support needs for understanding and communicating (in 34 percent of SHs) or the prioritization of the opinion of the evaluation teams or legal representatives. In other cases (approximately one quarter), services reported that beneficiaries sign an agreement to be evaluated or reevaluated and this stands as proof of their involvement, even if the evaluation fiches do not include a description of how this is being carried out, or that beneficiaries are indeed involved in the evaluation without necessarily being asked what they need or consider important for themselves.

The service rather than the person-centered aspect of evaluation is prioritized also due to service restructuring. Due to the fact that many of the SHs are actually closely connected with residential centers and are part of the process of restructuring, there are problematic intersections between the different processes of evaluation that are taking place (and whose objective is to place beneficiaries in different residential arrangements so that the process of restructuring of residential centers can take place). Thus, information from interviews showed that, in one case, even though beneficiary had been admitted after an evaluation that takes into account the needs of the whole pool of possible beneficiaries, he/she can be moved back into a residential center so that people with more potential to be integrated into the community can move in. The decision is explained as "the beneficiary needs a particular type of service" and this is why he/she is re-institutionalized. In other words, although the evaluation is presented as being person-centered, it is actually more concerned with the functioning of the disability services system, within the current set of constraints (limited

support from them.

o In 11 percent of services, the Personal Future Plan does not contain all the required elements. Elements that tend to not

- be included are the time length of the activities that are indicated, the materials and equipment needed, and the conclusions.
- o Although services have declared that they all comply with the requirement that the plan is analyzed and revised at least every 6 months, in 8 percent of them the plans were not revised in the past 6 months (for 10 percent of beneficiaries).

Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis

The external evaluation of beneficiaries' files from the large majority of services confirmed that Personal Future Plans in some SHs did not include some mandatory requirements, mainly: the duration and schedule of activities (12 percent and 18 percent respectively), the type of activity - individual or in groups (11 and 27 percent), as well as the conclusions (28 and 27 percent). The signatures of beneficiaries or of their legal guardians were also missing from the plans in 9 percent of SHs evaluated.

While all SHs reported that all Personal Future Plans set short- (6month) and medium-term (12-month) objectives for preparing each beneficiary to maximize independence, in some SHs that the objectives could not be identified in the plans (19 percent of Maximum SHs and 36 percent of Minimum SHs). In addition, the analysis of standardized plans submitted by all SHs showed that most Personal Future Plans do not have section recording objectives, and in many instances, objectives overlap with supports and activities. Objectives include disease prevention and providing three meals per day, which do not represent short- or medium-term objectives. Also, most Personal Future Plans do not have a section recording conclusions.

It is not clear how multidisciplinary teams involve and consider the opinion of beneficiaries during the process of elaborating and revising their Personal Future Plan. Only a small proportion of SHs (around 13 percent of Maximum SHs and no Minimum SHs) have Personal Future Plans included in all files evaluated that describe how beneficiaries' opinions were taken into account regarding each of the following aspects: what beneficiaries consider important short and long-term, what type of support he/she needs, what has been functioning or not, and what needs to be changed. Similarly, only 7 percent of SHs have Personal Future Plans that mention how the preferences of beneficiaries were taken into account, despite the fact that, according to document analysis. Document analysis indicated that, in fact, none of the standardized Personal Future Plans the 100 SHs use record beneficiaries' desires or preferences (only one sheltered house Moreover, beneficiaries report lack of involvement and preoccupation with informing and explaining the plan to them. Thus, only 15 percent of beneficiaries that were surveyed declared that they know what is in their Personal Future Plan. Also, 19 percent said they were involved in developing the plan all the time, and a further 9 percent said that sometimes.

In the case of mSHs, and in particular those that have beneficiaries with a higher degree of autonomy, the Personal Future Plan (which one service coordinator called "integration plan") is more clearly built with the involvement and control of beneficiaries. One service coordinator indicated that developing and revising the plans can be considered a form of preparing beneficiaries for independent life: "we just give them advice, but we cannot make the decisions for them."

#### **Observations**

The process of developing and revising the Personal Future Plan must be better understood. More effort should be put into involving beneficiaries in the development of the Personal Future Plan, and in particular in supporting them understand what they are agreeing to (what they activities entail in terms of time, effort, effects, etc.). If it turns out that there is a mismatch between the plan and what beneficiaries need and want, this mismatch should trigger a revision of the plan (instead of waiting for the multidisciplinary team to meet/be available). Providing access to a person that may offer support in decision-making to beneficiaries or may act as a facilitator for beneficiaries during the evaluation/Personal Future Plan revision, can further ensure the involvement of beneficiaries more effectively.

# **Standard 3: Monitoring**

# Standard description

The standard lays out what the minimum requirements are in terms of monitoring the actual implementation of the services indicated in the Personal Future Plan, as well as the required documentation. No provisions are made to include beneficiaries. Each beneficiary is assigned a case manager that coordinates, monitors and evaluates the fulfillment/implementation of the plan.

Only 80 percent of SHs comply with all requirements in this standard, while the only requirement that all services complied with is that beneficiaries should have a case manager assigned to them. For all other requirements, between 21 and 4 percent of the services reported lack of compliance. The requirement with the least degree of compliance concerns the monitoring fiche that lacks: the summary of the discussion between the case manager and the staff involved in working with the beneficiary (in 21 percent of SHs) as well as mentions of how the beneficiary is offered an environment free of exploitation, violence, abuse, torture and inhuman, degrading, and cruel treatments (in 20 percent). Regarding the frequency of meetings held by the case manager with the service team to discuss beneficiaries' situation, while 95 percent of all SHs reported holding monthly meetings, when probed further only 80 percent had had at least 6 such meetings in the previous 6 months.

In terms of how SSPs make sure case managers are fulfilling their obligations in terms of implementation, evaluation, and monitoring, the most frequently mentioned method was by consulting various documents (monitoring and evaluation fiches, activity reports, action plans), followed by periodic visits of inspectors from the case management and social services monitoring department. Talking to beneficiaries as a method for verifying the evaluation of the implementation of the Personal Future Plan (by the case manager) was only mentioned 7 times.

Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis

Data from beneficiaries' personal files that were externally evaluated indicated lower compliance with the requirements of the standard, regarding the mandatory monthly meetings between case managers and multidisciplinary team (in 23 percent of SHs), case managers' fulfillment of their monthly responsibility of writing down the progress made by beneficiaries in the monitoring fiches (29 percent), or the content of the monitoring fiche - summary of meeting results (34 percent) as well as aspects related to protection against violence and abuse (42 percent of SHs non-compliant).

This low compliance is also reflected in the structure of standardized monitoring fiches sent by SHs for evaluation. Most monitoring fiches have three sections: the synthesis of the discussions between the case manager and sheltered housing staff, objectives or services, and conclusions. Only nearly 20 percent of fiches measure beneficiaries' situation in terms of progress, stagnation or regress, with no indication as to what this

All beneficiaries from all but one SH are being allocated a case manager, the total number of case managers being 111 (101 in Maximum SHs and 10 in Minimum SHs). Most SHs (89 percent) have only one case manager assigned to all their beneficiaries, and only 9 SHs have 2 case managers each and 1 SH has 4 case managers.

#### Observations

While the number of case managers apparently do not constitute a difficulty in ensuring the monitoring of the implementation of service plans for beneficiaries, the effectiveness of case management remains to be probed further, considering both the incomplete content of monitoring fiches evaluated and the lack of beneficiaries' involvement in the meetings between case managers and service staff regarding their own progress, or in separate meetings with their case managers. In addition, SSPs rarely involve beneficiaries in the process of evaluating the activity of case managers, which raises questions as to how the person-centered aspect of service provision can be optimized in the absence of beneficiaries' feedback.

#### Module 4. Services and activities

Module 4 indicates the standards and minimum requirements for the specific activities that services have to provide (there are 15 standards in total). Some services are offered in SHs, and some in Day Centers or outdoors.

All the standards in the module have two types of items: (1) minimum requirements that are common to all standards and have to be complied with, and (2) listings of possible specific activities that can be offered to beneficiaries if their Personal Future Plans recommend it.

Below we present an assessment of the compliance with the common minimum requirements for all standards in Module 4. The specific activities will be described and analyzed in the following section.

# Common minimum requirements

Description	of	The requirements indicate that the activities be included in
requirements		the Future Personal Plan, that all activities in the plan should be offered, that the case manager should monitor and evaluate the implementation of these activities, and activities should be properly documented. There is a separate provision that the staff should treat beneficiaries in a respectful and supportive manner.
Self-assessment		According to the self-assessment, 89 percent of services in the review complied with these requirements. The levels of compliance are similar for both minimum and maximum Sheltered Houses.
		The lowest level of compliance as in the case of the most important of the items, that all the activities are done in compliance with the recommendations in the plan. In 11 percent of the centers there are differences between the activities implemented and the plan. It is unclear if the difference was due to the pandemic or to other causes.

#### Specific activities

Module 4 is structured around fifteen types of activities to be offered by the SHs. Each type of activity is described in a separate standard that lists the specific activities that can be offered, the staff that should be involved in providing these activities, as well as other relevant information about materials, equipment, staff training, other specific aspects, as needed. In the rest of the section, we will briefly present the standards and then globally analyze their implementation.

#### Box 11: Overview of the standards in Module 4

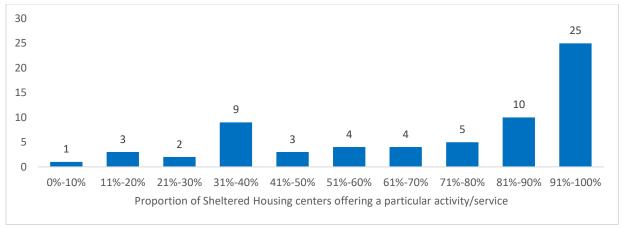
S1: Information	The service provider is required, through this standard, to offer a
and social	wide array of services and activities related to accessing

counseling/social assistance	mainstream and specialized services in the community: information and support in accessing other community services, support in maintaining social relationships (with family and friends), support with integration in social networks (including finding support groups), support for learning about and accessing social and disability rights, support in accessing transportation, support in finding jobs or in the relationship with employers, etc. The service can be offered in the SH, in a DC or in an outdoor location. The staff involved in offering this service is a social assistant.
S2: Psychological counseling	Psychological counseling is offered to all beneficiaries who are evaluated as having a need for such support. The standard is meant to assure the psychological and emotional security beneficiaries need in their everyday life as well as in supporting other specific services and activities offered by the provider. The staff who can offer these activities is: a psychologist or psychotherapist, but, if needed, other specialists can be involved if the beneficiary needs specific kinds of services.
S3: Habilitation and rehabilitation	The standard lists the activities that should take place in the center and that should assist beneficiaries to develop their autonomy and functional potential. Also, activities should include assisting beneficiaries to learn how to use assistive technologies and devices. The rest of the standard details the staff that can be involved, the corresponding documentation and administrative procedures.
S4: Care and assistance	The standard presents the minimum requirements for the activities of care and assistance directed at beneficiaries, including providing necessary materials, staff responsibilities, staff training (respecting beneficiaries' dignity and privacy, first aid). The activities included in the standard are diverse, and range from support for bodily care, movement and mobilization, hygiene, housework, feeding, to access to medical tests, administering medication, and communication.
S5: Independent living skills: Developing cognitive skills	The standard lists a range of activities that can be offered by any given SH that can help beneficiaries develop their independent living skills, in particular cognitive skills (activities related to sensory experiences and learning, basic learning activities, applied learning activities). The standard also includes minimum requirements related to respecting and supporting beneficiaries, staff responsibilities, staff training, documentation, and procedures.
S6: Independent living skills: Developing	The standard lists a wide range of activities that can be offered by service providers to help beneficiaries develop their everyday life skills: from organizing the daily schedule and managing time,

living skills: Developing social interaction skills	living skills, in particular social interaction skills in relation to friends, family members, acquaintances and strangers. The exercises aim at developing skills for sustaining a conversation, behaving in particular situations, or using a public service. The standard also has provisions for sex education and for making available means of communication (phone, email, mail). The standard also includes minimum requirements related to staff involvement.
S13: Independent living skills: Gaining economic independence	The standard lists a range of activities that can be offered by service providers to help beneficiaries develop their independent living skills, in particular skills that can help him/her gain economic independence: understanding and using money, taking part in commercial transactions, managing their personal budget. The standard also includes minimum requirements related to staff involvement.
S14: Education, preparation for work	The service provider can offer activities and assistance that help beneficiaries improve their education and preparedness for work and has partnerships with institutions and firms that can offer practical training or internships. The activities are meant both prepare beneficiaries for employment and support them in their jobs, and therefore include not only practical activities, but also employment and legal counseling and accessing support groups. Also, The SHs offer support so that beneficiaries can pursue formal and alternative education. There are also provisions about the staff involved, the documentation and the administrative procedures.
S15: Social and civic integration and participation	The standard indicates the activities and services aimed at ensuring beneficiaries' participation in the life of the community. Besides procedural requirements, it lists a series of possible forms of assistance and support related to participating in cultural, sports, leisure activities, in using public transportation, voting, and participating in family events. The standard includes provision for the type of staff involved, as well as different administrative procedures and documentation of activities.

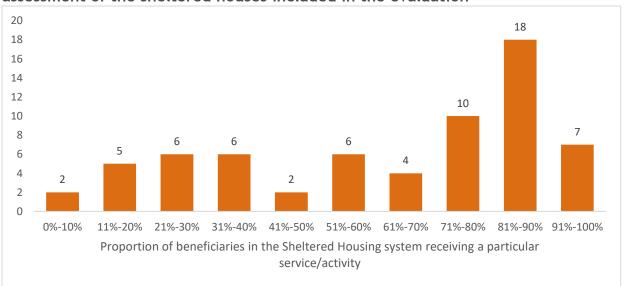
None of the activities recommended in the standards are offered to all beneficiaries or in all SHs. On the contrary, activities are offered unevenly throughout the SH system. This unevenness most likely reflects on the one hand, the diversity of needs of beneficiaries, but, on the other hand, it reflects the uneven availability of staff or thirdparty providers, as well as differences in service approaches. From interviews with service coordinators, the availability of services is a reasonable possibility, influenced by location, degree of development of services in the area, as well as restrictions dictated by the pandemic. As Figure 8 below shows, of the 66 activities/services listed explicitly in the standards and the requirements in the module, more than half are offered in more than 70 percent of SHs. At the same time, the proportion of beneficiaries who receive a particular activity/service at the level of the entire system is slightly moved to the left: not all beneficiaries in a center will receive a service (even if it is offered) and possibly some larger centers might offer fewer activities than the smaller ones (see Figure 9).

Figure 8. Number of activities and proportion of sheltered houses in which they are offered, according to the self-assessment of the sheltered houses included in the evaluation



Source: World Bank survey of sheltered housing (2021).

Figure 9. Number of activities and proportion of beneficiaries in the sheltered housing system who are receiving a service/activity, according to the selfassessment of the sheltered houses included in the evaluation

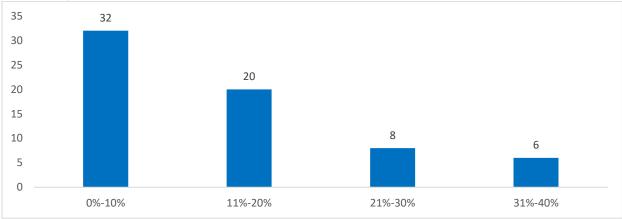


Source: World Bank survey of sheltered housing (2021).

The distribution of activities depends on the availability of resources, their characteristics, as well as on how they are perceived by service staff. Activities most often offered (both in terms of the number of SHs and the number of beneficiaries) fall into one or more categories: they are simply easier to offer, they are seen as closer to the core of the standard's objectives, or are more practical/applied in nature. For example, offering information on disability rights and existing social facilities (offered in 92 out of 100 SHs to 83 percent of the total beneficiaries), exercises for completing a task (in 98 SHs and 93 percent of beneficiaries), developing conversational skills (in 95 SHs and 87 percent of beneficiaries) and learning socially adequate behavior (in 97 SHs and 91 percent of beneficiaries). Conversely, the activities that are offered in smaller proportions are either objectively needed by a smaller proportion of beneficiaries, require more effort on the part of the service providers, or are seen as non-essential, even though they are essential and apply to all or most beneficiaries. The risk here is that drive service planning and delivery is not beneficiary's need or expressed option, but rather the vision and the willingness of the provider. For example, activities that seem like they could benefit all or most beneficiaries are only offered to a fraction: only 37 percent of the centers offer information about alternative or complementary services and activities offered in the community, 37 percent offer information on support groups for people in similar situations (but only 8 percent of beneficiaries that were surveyed said they received such information), 53 percent offer support for transfer/mobilization/movement, including going shopping, 69 percent offer support in using communication tools, 53 percent support for mobility, including using mass transportation means, 61 percent support for getting involved/attending sports, cultural, arts activities in the community, 36 percent offer instruction in using assistive devices or technologies, and 82 percent (not 100%!) information on sexually transmitted diseases.

The activity profiles of the two types of sheltered houses are different. Maximum and minimum SHs are meant to serve significantly different types of beneficiaries. On the one hand, almost half of the activities are provided in equal proportions in both types of SHs (the difference is less than 10 percentage points between mSHs and MSHs). However, significant differences are observed in the case of 6 activities (more than 30 percentage points). The largest difference (36 percent) corresponds to Support for goods acquisition, offered more to beneficiaries in minimum SH. Other activities with differences higher than 30 percent are Information and support for adapting the home, Information about alternative or complementary services and activities in the community, Speech therapy or psychotherapy, Pre- and post-employment counseling, Exercises for basic types of learning. With the exception of the last activity, all are offered more in minimum sheltered houses. For three activities, the difference is less than one percentage point: Using communication tools, Awareness exercises for understanding and respecting medical advice/personal security problems and dangers, Caring for assistive devices, Learning about economic transactions/managing money.

Figure 10. Difference in the proportion of beneficiaries of minimum and maximum sheltered housing beneficiaries receiving a particular activity/service, according to the self-assessment of the sheltered houses included in the evaluation (absolute numbers)



Source: World Bank survey of sheltered housing (2021).

proportion of beneficiaries from minimum SHs The participating activities/receiving services is consistently higher than that of beneficiaries from maximum SHs. For some activities, the differences are considerable: for example, offering information on alternative or complementary services (a difference of 35 percentage points), speech therapy or psychotherapy (32 percentage points), or purchasing goods (36 percentage points). The reasons for this difference are unclear, but could be related to: (1) standards being slightly skewed towards offering more activities aimed at beneficiaries that are more autonomous or closer to the point of community integration, (2) beneficiaries in mSHs being seen as more in need of or apt for particular kinds of activities, and (3) other reasons connected to staff, resources, organization of the system at the county level.

Psychological counseling is not offered in all SHs. According to their self-assessment, not all SHs offer psychological counseling (either on the service premises, in a day center, or in the community). The service is offered in 92 percent of SHs, and the proportion is higher in the case of minimum SHs. In total, 85 percent of beneficiaries receive psychological counseling. Although in most SHs psychological counseling is provided by a psychologist, a significant number of SHs provide this service through other categories of staff (physiotherapists, social workers, or nurses). It is unclear whether they work as secondary staff or are the main providers of this service. Contrary to the situation in other types of services (such as day centers or crisis centers), only 39 percent of beneficiaries who were surveyed declared that psychological counseling is a service that is important to them. Interviews with service coordinators showed that psychological counseling is sometimes used as support for other objectives, in particular helping beneficiaries to understand and reflect upon the process of community integration, as well as monitoring the success of other activities. Like in the case of

other services, "psychological counseling" is sometimes interpreted broadly as emotional and social support offered to beneficiaries, although according to quality standards this activity involves specific and complex objectives and interventions aimed at the psycho-socio-emotional development of a person. 100

There is a significant overlap between the requirements and activities for different standards leading to redundancies in service provision, staff work load, and documentation. It is unclear if in these cases activities are offered separately, in different contexts and by different providers, or if there is a synergic approach when one activity is used to check off several requirements in the standards. Either way, there seems to be a need for clarification and direction on the part of the standard, and a great degree of coordination and integration on the part of the service provider. For example, craft/handwork activities appear in several different places, as well as activities that deal with mobility, moving outside the home and using different modes of transportation, cleaning one's living space, activities connected to being able to communicate, exchange ideas, hold a conversation. In addition, where the activities appear to be identical, there are significant differences in the proportion of centers providing them and the proportions of beneficiaries served.

In 2020, most activities were offered in SHs, and not in day centers or other locations. This situation is undoubtedly connected to the restrictions imposed by the pandemic and in most cases it was unavoidable. At the same time, it might be a continuation of practices from before. In over 90 percent of SHs, most activities are offered on SHs premises. There are even situations in which some activities that should be normally offered in the community, are mostly offered in the SH (for example "Support for going to a medical office, the hospital, or pharmacy" is offered, in 66 percent of the cases, in the SHs). 80 percent of the activities held in day centers are each offered in less than 15 percent of the SHs. The numbers are similar for activities held outdoors/in the community.

Most activities are offered by staff other than that indicated in the standard. Causes for this situation include staff shortage, practicalities of tasks, or even a lose understanding of the requirements of the activity at hand. One service coordinator explained that often times, waiting for the appropriate staff to deliver the service might feel like a formality, when someone else (including him/herself) is available and can do the job. In practice, this approach leads to some unusual situations: kinesiotherapists or nurses providing psychological counseling or psychologists or educational instructors providing care and assistance services. In the case of Standard 4 (Care and Assistance) for example, the staff indicated in the requirements is less than one third of the staff actually delivering the service (106 out of 379). While in some cases the nature of the activity makes it possible to involve other staff, this is not the

<sup>&</sup>lt;sup>100</sup> Order no. 82/2019, Module IV, Standard 2, Minimum requirements 2 and 3.

case in all centers, which raises questions about the quality and safety of the services provided. Or, conversely, if a service/activity can be provided safely and successfully by staff other than that indicated by the standards, this raises questions about the content of the standards requirement.

The requirement that activities should be run only by staff from day centers is not respected by most sheltered housing services. In 13 out of the 15 standards (with the exception of standards 4 and 15) there is a common requirement about who should be offering the services: "The activities of ... are run by the day center, at the center, outdoors, or, depending on the case, at the maximum sheltered house." The control indicators (used for monitoring) also state clearly that activities should be delivered by day center staff. However, for the 13 standards there are far more SH staff members involved in offering the service than day center staff (for some standards nine times as many). The discrepancy raises the question of how realistic this requirement is and how in practice it is used in licensing public and private social services.

Not all beneficiaries are receiving the services and activities they indicated they **need.** For example, of beneficiaries that indicated they needed a particular type of service, the proportion of those who received it was 84 percent for speech therapy or psychotherapy; 76 percent for massage, kinesiotherapy, physical therapy; 62 percent for hydrotherapy, balneotherapy, thermotherapy; 78 percent for occupational and art therapy. Overall, 87 percent beneficiaries who were surveyed indicated that they receive the services and activities that are important to them.

There is a mismatch between the level of need for support, services and activities perceived by beneficiaries on one side, and identified and addressed through the evaluation process, on the other. Beneficiaries reported their support needs in numbers that are consistently lower than the ones reported by SHs themselves. In some cases, the difference was 50 percentage points or even higher: support for getting dressed, putting on shoes, choosing adequate clothing, support for daily hygiene, support for housekeeping, and support for communication. The three types of services where the differences are lower (around 10 percentage points or lower) are support for taking medication, for going to medical offices/hospitals, and for having the required medical tests. In almost all categories, the proportion of those who answered positively was lower when the interviewee was alone, and no SH staff was present.

Only a part of SHs provide the training required by the standards in the module. As part of the standard on Care and Assistance, these training sessions are critical, as they are meant to protect and ensure the respect for and safety of beneficiaries. About one fifth of SHs do not offer or facilitate training sessions related to respecting the dignity and privacy of beneficiaries, and more than half do not offer training on first aid.

Although beneficiaries of mSHs are required to have and keep a job in order to benefit from the service, support for finding or maintaining a job is insufficient.

There are five different requirements in the module directly concerning support for finding or maintaining a job or mediating the relationship to the employer, but about 63 percent of centers offer them to less than 60 percent of beneficiaries. The beneficiary survey confirms the limited support they receive in obtaining and maintaining a job. Thus, about one third of beneficiaries said they needed such support and only 82 percent of them received it. Also, when asked if during the past year they have learned something that can help them find a job, only 20 percent said they did.

# Module 5. Protection and rights

The final module combines standards that refer to beneficiaries' rights, their protection, questions of ethics, risk management, mechanisms for complaints and for measuring beneficiaries' satisfaction.

Standard 1: Respecting beneficiaries' rights

Standard	The standard ensures that beneficiaries' rights are respected by
description	making the rights known to service staff through training sessions. Among the rights listed, there are provisions for respecting beneficiaries' dignity and privacy and protecting them from neglect and abuse. Rights also include involving beneficiaries in making decisions about service provision and ensuring that they can freely express their opinion on the services. The list of rights and the training sessions are listed as mandatory, but the standard has no provisions to ensure that the listed rights are respected.
Self-assessment	According to the self-evaluation filled out by the SHs, not all centers are complying with the standard, in particular with the requirement that they organize training sessions on the issues mentioned in the standard. Six centers do not organize such sessions (and have not during 2020). In 2020, no complaints were registered in 99 percent of all SHs regarding.
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	According to the beneficiary survey, only 40 percent responded they know their rights, and 52 percent said they were informed of their rights. About two thirds of beneficiaries declared that the staff involve them in the decisions about services and activities they receive, and a similar proportion said they believe their rights are respected. Examples of rights that were denied to them include: going to the doctor by himself/herself; right to personal belongings; leaving the town or the SHs (person without legal capacity); right to work; right to live with his/her partner in the same room.
	Services must ensure that beneficiaries have access to information about their rights at all times, in addition to relevant

	information being offered at the moment of admission. 19 percent of SHs do not currently provide their beneficiaries information about their rights.
Observations	While the standard includes mandatory training sessions with service staff on the topic of beneficiaries' rights, it does not stipulate a similar obligation of providing training and information to beneficiaries in accessible formats, nor about ongoing effective feedback and complaint mechanisms that can ensure access to prompt solutions and remedies. Currently, the standard does not include any requirement about ensuring that staff knows and respects beneficiaries' rights, such as recurrent assessments of staff performance to evidence their adequate understanding and application of the training content at all times in relation with beneficiaries. There are also no specifications regarding the type of material used and the persons providing the mandatory trainings.
Standard 2: Risk m	anagement
Standard description	The standard covers aspects related to management of risk situations, such as existence and content of a specific procedure that is known and accordingly applied by the service. The procedure must include examples of risk behaviors and types of interventions, including in the aftermath of the situations. There is a separate requirement that service providers should be notified within 4 hours from a crisis intervention, and that such intervention should be included in the beneficiary's file.
Self-assessment	Only 80 percent of services comply with this standard, and the main issues are the content of the procedure (not all required elements are included), notifying the service provider, and documenting the intervention in the beneficiary's file. In 2020, there were emergency interventions in 18 SHs, and in 8 of them there were more than one intervention.
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	Out of 85 risk managements procedures submitted by the services, 5 documents were in fact general guidelines applied by GDSACPs for risk management at the level of all subordinated institutions (being unrelated to this standard, these documents were excluded from the analysis). Most of the remaining 80 documents addressed in various degrees the mandatory aspects stipulated by the standards. There are substantial discrepancies regarding the content of the procedures and how mandatory aspects are detailed:  • Although almost all procedures include at least a short definition for behavioral crises or destructive behaviors, only

- half of them provide concrete examples, as the standard requires and only 13 procedures include specific criteria for identifying such behaviors. 101
- Only a few procedures specify the types of risks that could jeopardize beneficiaries' health and safety while on center grounds (such as improper infrastructure, storage of hazardous substances, alcohol or drug abuse, staff behavior). Furthermore, many documents fail to specify the types of psycho-social risk factors and events that may arise. In only one instance contagious infections are mentioned as a potential risk.
- Only a few procedures include deescalating strategies, such as providing clear instructions on how to interact with beneficiaries, the type of personnel who should interact with beneficiaries (for example, the staff who knows beneficiaries best), and so on. Across all analyzed documents, sometimes these deescalating strategies present contradictions (for instance, the advice not to divert the conversation to another topic vs. the recommendation to redirect the conversation).
- Only a few procedures contain actions to be followed in the aftermath of an emergency to support beneficiaries other than calling the emergency service 112 - such as psychological counseling or medical care (on site or at the hospital). In one document it is mentioned that psychological counseling is provided if necessary or if requested by the beneficiary.
- Some procedures call for "administrative sanctions" or "coercive measures" for beneficiaries after emergency situations but do not provide other details about such actions. Terminating the service contract indicated in two circumstances as the most severe measure that can be taken.
- A limited number of procedures include indications on how the service staff manages the situations in which a beneficiary is hospitalized as a result of an emergency.102

<sup>&</sup>lt;sup>101</sup> In most cases, the examples refer to the physical aggression of other beneficiaries, staff or one's own person, runaway episodes, causing damage to the service's infrastructure, and committing criminal offenses. In many cases, the failure to comply to outward visits rules is labeled as a runaway episode (non-compliance with the time period for which the beneficiary was granted permission to go out, for example). In one case, the unjustified absence from the service was labeled as "vagrancy". With the exception of theft, no other examples are provided for behaviors that may be the subject of criminal offenses. In some cases, it is stipulated that beneficiaries having mental capacity are financially accountable for any damage of service infrastructure produced during a crisis.

<sup>&</sup>lt;sup>102</sup> These indications include accompanying the beneficiary and providing information on the medical condition (including medical treatment). In 17 cases it is mentioned that the staff accompanying the beneficiary to the medical emergency unit will not give their written consent for treatments or surgeries even if requested. This aspect is

- Only a few procedures contain indications on how the service staff will report to the police a missing person.103
- Only a few protocols specify how and when beneficiaries should be informed about risk management, and only a few specify that beneficiaries should be informed verbally at the time of admission. Similar, only a few protocols specify staff training and information sessions related to risk management.
- procedures Some recommend physically beneficiaries, not as a punitive measure, but to prevent selfharming or harming other persons or destroying the center infrastructure and material resources. Few documents stipulate that this action can be taken based on a medical recommendation and only 4 documents provided detailed information about physical restraint-reasons to communication with the beneficiary prior to the immobilization, how to use the physical restraint (with a duration not exceeding 2 hours, technical aspects to prevent harm, monitoring of health parameters during the physical ensuring restraint, that nutrition and physiological requirements are met).

# **Observations**

Given the variety of procedures analyzed, standards can be helpful in providing further instructions on how to manage a crisis situation, by requiring that services implement specific measures to prevent and manage risk situations that respects beneficiaries' right, including autonomy and bodily integrity.

Risk management requires adequate know-how about deescalating emergency situations rather than appealing to solutions that could aggravate beneficiaries' state. The standard does not include any clear provision about trainings or other ways to provide such information to service staff and beneficiaries. In addition, the minimum requirements regarding the content of the procedure do not include any provisions on ensuring the informed consent of beneficiaries in any risk situations that may lead to forced treatment or non-consensual interventions such as physical restraints (for instance, through planning in advance the

detailed in a single document, which says that only the legal representative or the coordinator of the center can offer the consent.

<sup>&</sup>lt;sup>103</sup> These indications include the provision of a description for the missing person, a photograph, details of the medical condition (including medical treatment) and other details of the beneficiary's habits. A number of 4 documents stipulate that any member of staff who notices the presence of a beneficiary outside the unit without the right to do so, is obliged to notify the service, to detain the person in question and to take all steps to bring him/her back to the unit (no further details are provided for this requirement).

	interventions beneficiaries might want or not want to experience in the event they might not be able to give consent).
Standard 3: Code of	of ethics
Standard description	The standard indicates that: (i) the provider should have a Code of Ethics; (ii) this should have provisions for the equal treatment of beneficiaries; and (iii) the service should be provided in their best interest, and that professional ethics should be observed. The provider should also organize staff training sessions on the Code of Ethics.
Self-assessment	While all SHs declared they have a Code of Ethics, there are issues with the rest of the requirements. Seven SHs do not organize training sessions for their staff, and the two provisions about the content of the code (equal treatment and ensuring the best interest of beneficiaries) is each not respected by one center.
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	A number of 85 services submitted their Code of Ethics for evaluation. The minimum requirements stated by the standards, such as equal treatment and provision of services in the interests of beneficiaries, were included in the majority of documents. Most Codes, however, only state these features as principles, with no further explanation of how these principles are to be implemented in practice or what a breach of these principles would entail. In addition, over two thirds of the Codes presented do not regulate the activities of specific SHs, but rather the activities of all employees at the GDSACPS level. The remaining documents are collections of excerpts from these processes that apply at the level of all GDSACPS-subordinated institutions. Only a third of the Codes state that failing to follow these principles will result in disciplinary action, but no elaboration on what those implications might be (it is only mentioned that existing legislation will be used). A number of 11 documents list the rebuke, warning, and dismissal as possible disciplinary outcomes for non-compliance with these principles. Staff may be required to attend various training courses depending on the situation, according to the same sources.  Only 5 documents out of 85 make brief mentions of staff working with beneficiaries who are unable to participate in decision-making ("Staff must guarantee that these beneficiaries' interests and rights are respected").
Observations	Some procedures (8 out 85) provide a section regarding service staff responsibilities in relation with beneficiaries that stipulates that staff is allowed to limit beneficiaries' self-determination whenever the latter's choices contradict professional ethics or whenever their present or future actions may endanger

	themselves or other persons. The procedures do not give any clear example about such situations, and in the absence of any provisions in the standards regarding clear steps for ensuring the informed consent of beneficiaries, including through provision of decision-making support, there is a risk that beneficiaries' rights could be limited arbitrarily.
Standard 4: Protec	tion against negligence, exploitation, violence, and abuse
Standard description	The standard stipulates minimum requirements for assuring the protection against negligence, exploitation, violence, and abuse: what the procedure should contain, how it should be applied, the resulting documentation, and that the staff should receive the necessary training.
Self-assessment	84 percent of the SHs are complying with the standard, according to their own evaluation. While all centers have a procedure on negligence, exploitation, violence, and abuse, 13 do not have procedures that contain all the elements in the standard. Also, although 98 percent of SHs s declared that they organize yearly training sessions with their staff, only 90 percent actually did so in 2020. No cases of negligence, exploitation, violence, or abuse were registered in any of the centers in 2020.
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	81 percent of SHs summited the specific procedure. Document analysis showed that the documents include clear responsibilities of staff and SSPs for identifying and reporting cases of violence, exploitation and abuse, as well as concrete actions. However, there is substantial variance in the procedures employed by the services to ensure that beneficiaries are protected from exploitation, violence, and abuse.  Different methods for identifying and reporting such situations can be identified in the reviewed documents. However, the degree to which these methods are detailed varies. Three broad methods are mentioned: (i) submitting a notification when one comes across such a case; (ii) administering questionnaires to beneficiaries; and (iii) carrying out activities that involve beneficiaries (psychological counseling sessions, group activities held regularly, daily discussions with beneficiaries).  Almost all documents stipulate that reported cases may be related to situations of abuse by another beneficiary, a staff member, a family member or the legal representative.  A small proportion of documents contains information on indicators that may signal the presence of an abuse situation. Similarly, there are very few general mentions

- regarding beneficiaries' protection against repercussions after they notify situations of abuse.
- Not all procedures require that beneficiaries are informed about their rights to be protected against negligence, violence, and abuse. When such requirements exist, it is not always clear when and how beneficiaries should be informed (some centers specify yearly or quarterly training sessions, while others are supposed to provide information to beneficiaries on demand or through information materials available in the center or information sessions at the time of admission).
- Providing information is the main prevention measure in the analyzed documents. Other measures include banning alcohol, drugs or medications other than those prescribed, unannounced monitoring visits by the specialist coordinator (but no details provided).
- Very few procedures provide a clear timeline for acting in case of violence and abuse.
- Only a few procedures address the possibility of providing postabuse counseling by service staff or other groups, and most procedures lack guidelines on how service employees should interact with the victim and perpetrator to minimize subsequent trauma.
- Very few procedures make reference to the administration of medication, as required by the standard, as well as to the management of beneficiaries' money. However, some procedures exclude the administration of medication according to doctors' instructions in the absence of beneficiaries' consent from the list of situations of violence and abuse. The same procedures also exclude physically restraining beneficiaries from the list of violent and abusive practices.

While all SHs that were externally evaluated reported they support and encourage beneficiaries to identify and notify cases of violence, exploitation and abuse, most do so by providing beneficiaries with information (formally or informally) about the procedure, their rights or other relevant themes either when beneficiaries are admitted or at various times during their stay in the SHs. Only 32 percent of SHs reported providing beneficiaries with regular information sessions on how to identify and notify situations of violence and abuse. In 24 percent of SHs beneficiaries are being administered questionnaires that may further facilitate the identification of such cases. Only a few SHs provide support to beneficiaries to report abuse to competent

	institutions or make available contact details of persons outside the SHs.
Observations	To ensure adequate protection from violence and abuse, standards must include clear provisions on:
	<ul> <li>How services are expected to encourage and support beneficiaries to identify and notified situations of violence, exploitation, and abuse, as well as prevent the occurrence of such situations.</li> <li>Informing beneficiaries on how to identify and report situations of abuse, as well as ensuring their protection from possible retaliation from perpetrators in case these are service staff or beneficiaries.</li> <li>Ensuring that at all times beneficiaries are treated only with their full and informed consent, and that non-consensual practices are avoided (such as involuntary administration of medication or physical restraints).</li> <li>Ensuring the access of beneficiaries to relevant services in the event of such situations, for instance, psychological counseling, shelters, etc.</li> <li>Ensuring access to an independent, external mechanism for reporting and reviewing such cases should be made available to the beneficiary, as well as access to legal and counseling services and advocates.</li> </ul>
Standard 5: Protect	tion against torture and cruel, inhuman, or degrading treatment
Standard description	The standard indicates minimum requirements for assuring the protection against torture and cruel, inhuman, or degrading treatment: what the procedure should contain, how it should be applied, the resulting documentation, and that the staff should receive training in this matter.
Self-assessment	A large proportion of the SH centers comply with all requirements (96 percent). The highest compliance (97 percent) corresponds to the requirement that the centers organize training sessions on the topic of protection against torture and cruel, inhuman, or degrading treatment. When asked if they organized a training session in 2020, the proportion was lower: only 89 percent organized at least one session. No cases of torture or cruel, inhuman, or degrading treatment were recorded in 2020.
Comprehensive evaluation: external evaluation, questionnaires,	A total of 83 services summited the specific procedure. Of these, 20 documents do not define the terms 'torture' and 'cruel, inhuman, or degrading treatment', another 4 documents define only one term, respectively 'torture' and 59 documents define all terms. Generally, the services use a similar format and structure

interviews, document analysis	for specific procedures required by Standard 5 and similar results from document analysis apply.	
Observations	See Standard 4	
Standard 6: Assista	ance in the event of death	
Standard description	The standard indicates minimum requirements in the case of terminal stage or death. This includes pain management, assisting the separation from other beneficiaries, informing the family, funeral arrangements. The service provider should have a special procedure for this.	
Self-assessment	According to the self-evaluation, all SHs comply with all the requirements except one: 7 percent of SHs have incomplete procedures (procedures that do not contain all elements listed in the requirement).	
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	Out of 100 SHs, 13 had not sent the procedures regarding assistance in the event of death. Out of the 92 procedures sent, 5 have no specifications regarding assistance during terminal stages, focusing more on situations pertaining to the aftermath of beneficiaries' death; and 9 procedures make no mention of separating terminally ill beneficiaries to respect their dignity. On this issue, many procedures only mention installing a partition or screen as a separation measure. The minimum conditions of the standard with regard to the content of the procedure are met in 90 percent of procedures. However, only 46 percent specify ways in which the personnel are to be instructed on these procedures. Some procedures are more comprehensive than the minimum standards (in counties such as Alba, Cluj, Bacău, etc.), containing things like first aid steps for the terminally ill, the importance of establishing the needs of the terminally ill, psychological counseling for family members, steps to be taken if death occurs outside of the SH.	
Observations	Palliative care as well as communicating with family and friends in the event of the death of a beneficiary requires specific skills that staff - both medical and non-medical - should be trained in. Currently, the standard does not include such requirements.	
Standard 7: Notifications and complaints		
Standard description	The standard indicates that there should be a procedure for registering and solving beneficiary complaints, minimum contents of the procedure, as well as some other requirements regarding documentation and filing as well as the possibility of using	

	external mediation at the request of the service (not the beneficiary). The procedure also includes aspects about informing beneficiaries on how to submit notifications and complaints.
Self-assessment	According to the self-evaluation submitted by the centers, 96% of the SHs comply with all requirements. The only requirement that raises problems is the one that stipulates the possibility to use mediators in critical situations (4% of the centers indicated they do not allow for this possibility). No formal complaints were filed in 2020.
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	Although all services have a notifications and complaints procedure, the procedure is not necessarily set up to facilitate beneficiaries' access to exercising this right. Beneficiaries have direct and ready access to information about how to file a complaint only in less than 40% of the services. The majority of the procedures do not offer multiple ways of filing a complaint, and in some cases, the only way to file one is in writing, through regular mail. Only two services out of 100 allow for anonymous complaints or notifications to be filed, and only one offers a solid framework for ensuring the confidentiality of the person filing the complaints.
	The proportion of services that do not allow for the possibility of using an external mediator is much higher than indicated in the self-evaluation. Over half of SHs do not allow for one. Moreover, no procedures include a list of mediators that could be used in case the need arises.
	SHs do not offer a framework for protecting beneficiaries against other kinds of problems and abuses. Less than one quarter offer their beneficiaries information on how to file a complaint against their legal representative in case of conflicts of interest and less than a fifth of the reviewed procedures have provisions that describe how beneficiaries are protected from reprisals in case they file a complaint.
Observations	Notifications and complaints procedures should provide a framework that ensures beneficiaries' access to filing complaints and receiving proper redress without the fear of retaliation or other kinds of negative consequences. Many beneficiaries in the SHs are physically and socially isolated and filing a complaint against their own residential service through the mail can prove impossible. Also, access to third parties that can be used as mediators or advocates should be facilitated in all SHs.

Standard description	This standard is meant to assure a mechanism for evaluating beneficiary satisfaction with the service provided. Centers are required to apply questionnaires and include their analysis in their annual reports. Beneficiaries can ask for support from staff members, family, or the legal representative in filling out the questionnaires.
Self-assessment	Standard 8 has the lowest compliance rate in the module: only 69 percent of SHs comply with all requirements. 92 percent apply questionnaires to find out their beneficiaries' opinion of the service. Out of these, 82 percent provide a box where questionnaires can be returned, and 81 percent have the questionnaires analyzed and the results included in the annual report.
Comprehensive evaluation: external evaluation, questionnaires, interviews, document analysis	Beneficiaries' survey also tried to gauge the level of satisfaction with the service among beneficiaries. 78 percent of beneficiaries included in the survey said they are satisfied with the services received, and 95 percent are satisfied with their living conditions. Similar proportions (about three quarters) declared that they are regularly asked by the staff if they are satisfied with the service (the proportion is much higher if a staff member was present) and they feel they could tell a staff member is they are not satisfied.
	Service staff reported during the external evaluation that in 49 percent of SHs beneficiaries had no complaints or suggestions for improvement. In the rest of SHs, the most common issues raised by beneficiaries were related to food quality, diversity and type of food (16 SHs), insufficient opportunities for social and cultural activities (20 SHs), conflicts with other beneficiaries (10 SHs), the wish to move out of the SH (7 SHs), and living conditions (5 SHs). Only half of SHs that received complaints or suggestions from beneficiaries took some measures, mostly related to improving food quality, trips for beneficiaries, relocating beneficiaries to different rooms to as a conflict resolution.
	Document analysis showed an even lower proportion of annual activity reports that included an analysis of the results of satisfaction questionnaires applied to beneficiaries. Out of the 90 activity reports submitted by the SHs, only 44 mention the questionnaire, while only 21 (from the same county) offer a detailed analysis of questionnaires, with a detailed breakdown of each question. Hence, over half of the services that sent the activity report do not reference questionnaires or their analysis.

While the standard stipulates that beneficiaries should receive support for filling in the questionnaires (either from the service staff, legal representatives or family members), it does not specify the reasons why beneficiaries might need such support. This is particularly problematic since support offered by service staff might lead to a breach of confidentiality, conflict of interest and undue influence, given that staff themselves are an aspect of service provision that beneficiaries are expected to evaluate. In 2020, in 78 percent of all SHs service staff offered support with filling in the questionnaires to more than 60 percent of their respective beneficiaries. At the same time, analysis of questionnaires used by the centers indicated that 94 percent of questionnaires sent in by SHs include questions related to the interaction of staff with beneficiaries. Confidentiality is ensured in only 12 out of 95 questionnaires, while 9 out of 95 offer partial confidentiality since beneficiaries are required to sign the guestionnaire. In some counties, a model of satisfaction sent by GDSACP, with a disclaimer questionnaire confidentiality included, has been changed to actually include the name of the beneficiary. It is possible that support is also offered due to the lack of guestionnaires in accessible formats - only 38 MSHs and 1 mSH reported having questionnaires in easy-to-read formats, Braille, audio-video formats with subtitles.

#### Observations

While feedback is essential for ensuring that beneficiaries have control over services provided, the effectiveness of this process is dependent on conditions of anonymity, safety and trust. Standards need further improvement to ensure these conditions, either through providing additional requirements or by detailing how current ones are to be further implemented.

In effect, the evaluation of service provision by beneficiaries must be anonymous by: (i) providing questionnaires in accessible formats - easy-to-read, Braille, audio-video with subtitles, and (ii) by involving independent evaluators that can both offer support to beneficiaries for filling in the questionnaires and ensuring that, overall, data collection and analysis is carried out in a way that does not compromise the accuracy, completeness and reliability of the information provided by beneficiaries, and that keeps them safe from any negative consequences and retaliation.

# 2.1.4. Conclusions and recommendations Standards compliance and implementation

The excessive number of standards and the corresponding activities in the modules can lead to lives that are overscheduled and dominated by procedures, checklists, and requirements. In the end, they can limit the autonomy and the control beneficiaries have over their daily lives. Pressure to deliver services and activities according to standards as well as setting collective schedules characteristic to institutionalized living result in a succession of organized activities, mostly outside of beneficiaries' control. The beneficiaries' survey revealed that they have, indeed, little control over their daily lives and limited opportunities for learning how to manage and budget their day by themselves.

The standards are based on requirements/processes, rather than results, and offer no way of knowing the state or the evolution of beneficiaries in terms of preparedness for living independently. The standards and the requirements are built as a kind of "recipe", with the expectation that if all elements are put in, then the desired result (preparing beneficiaries for living independently) will be guaranteed. There are 331 requirements in total, but the analysis of the data collected showed that they are not measuring the effects that the services and activities provided in the standards have on beneficiaries or whether there are improvements/advancements in preparing them for independent living. The beneficiary evaluation-monitoring system is set up for ensuring the delivery of services and not for ensuring that beneficiaries are more or better prepared for living independently. Many beneficiaries are not involved in the evaluation of their own needs and preferences regarding service provision. Standards do not expressly require that beneficiaries are directly involved in discussions with case managers and service staff teams about their progress, while monitoring the activities of case managers by SSPs almost never involve discussions with beneficiaries.

Standards and requirements, in particular those relating to services and activities, contribute to the social isolation of beneficiaries. The fact that standards focus excessively on services and activities directs beneficiaries to the service rather than to the community, physically keeping them in their homes or at the nearest day care center, and limiting their opportunities to experience community life. The pandemic has made the situation even worse, but the infrastructure for service provision is the main reason for this situation. Few SHs work with smaller private service providers in the community - instead, there are sustained efforts to open day centers that primarily, and sometimes exclusively, serve people in the SH system.

The requirement that all activities pertaining to 13 standards in Module 4 (Services and activities) run by day centers (day center staff) is confusing, unrealistic, and not met by most sheltered housing services. The requirement is not respected as most SHs have their own staff delivering these services and activities. The separation between the private home of beneficiaries and public space of work for staff is also not respected: in over one quarter of sheltered housing services staff does not use a separate space (not even a separate bathroom) but shares it with the private residential

space of beneficiaries. Moreover, many day centers used by the SH beneficiaries are part of a service complex that also includes the sheltered house and sometimes other residential centers for persons with disabilities.

The excessive number of standards and requirements can lead to an overload of paperwork and bureaucracy to the detriment of beneficiaries. Service coordinators have complained that they are required to spend an excessive amount of time filling out paperwork and documenting services and activities, which, paired with the shortage of staff, means less time spent with and for beneficiaries. They have also complained that their task is made more difficult by the fact that they received no forms/models for building some of these documents, and they had to improvise and build their own, often not knowing if what they were doing was appropriate and in line with the standards.

The relationship between the service provider (GDSACP) and sheltered housing services has a significant influence on the quality of service delivered to beneficiaries. Interviews with GDSACP directors have shown that SHs are dependent on decisions that are made at the GDSACP level, even if they are about resources, services, service integration, staff hiring, staff training, or admitting/transferring beneficiaries at the SH level. While being part of a larger network of social services can have advantages, it also induces uncertainty and vulnerability for SH services. Moreover, there is no mechanism in place for beneficiaries to influence this relationship, which increases the lack of control they have over their own lives.

Some of the standards and requirements are not correlated with standards and requirements set by other state institutions. Sheltered Housing services are required to obtain different kinds of authorizations and certificates (e.g., sanitary) in order to be allowed to host beneficiaries and provide public services, oftentimes just like a restaurant or a hospitality business (from the Department of Public Health, the Inspectorate for Emergency Situations, etc.). For example, the Department of Public Health requires them to have, in one house, several different refrigerators, each with a separate destination to avoid food contamination. A service coordinator has pointed out that the limited space of a house thus has to be filled out with appliances, which would not be the case if the house would be treated as a residence.

Furthermore, the requirement that beneficiaries should pay for (part of) the service in case they have an income does not encourage leaving the SH and living in the community. The only jobs beneficiaries can usually get in on the labor market that in their view is scarce and discriminatory are minimum wage, unskilled, and uncertain jobs. Interviews with service coordinators have indicated that having to allocate part of the income towards paying for the service, although intended to make beneficiaries "more responsible," it actually discourages them to get a job. In addition, preparing to leave the SH means saving up for life outside the institution, which is very difficult due

to the obligatory contribution. Service coordinators have suggested lifting the requirement at least temporarily so that beneficiaries can save up and plan their lives. Therefore, we are making several recommendations regarding the standards and the connected legislation:

- The standards should be transformed so that they are based on output (result) based and offer a direct way of gauging the state and evolution of beneficiaries, as well as how well services respond to their individual needs and plans and fully respect their rights. Result-based standards could also ensure the fact that staff is trained (not just that it attended a training session, for example), rights are actually respected, and all activities and treatment are provided only with the full and informed consent of beneficiaries.
- The standards should ensure that services are person-centered and work through beneficiaries' direct involvement in all decisions regarding both specialized services and everyday life in the house. Thus, it is not enough to state that the staff is "concerned with beneficiary involvement" but should make sure that beneficiary involvement actually takes place. This can be further ensured through providing decision-making support whenever is necessary as well as information in accessible formats during all phases of evaluation, planning, and delivery of services. At the same time, standards should explicitly provide requirements to ensure the rights of beneficiaries, in such a way that they are not restricted, as is the case with procedures that allow beneficiaries to be restrained.
- Beneficiaries should also be used as a source of information in checking standards compliance through regular and ongoing anonymous feedback, not just documents and materials.
- The requirement that all services in module 4 (with the exception of the two standards) be offered by a day center should be either changed or clarified.
- Provisions should be made to allow beneficiaries to choose their own service provider from services available in the community and are not forced to use the SH staff or the connected day center.
- o Standards should be simplified and shortened. They should not create excessive bureaucratic burdens on service coordinators and staff.
- Standards and other kinds of legislation should be harmonized so there are no conflicting demands placed on the service.
- Beneficiaries who earn independent income (from jobs, for example) should be supported in preparing financially for leaving the sheltered house by being offered a respite from paying a contribution.

#### Value and success of the service

While SHs houses are expected, according to the standard, to provide services in a residential setting to their beneficiaries for a limited period of time to prepare them for living independently, in reality, this rarely is the case. Many beneficiaries have resided in SHs for more than 5 years - the maximum length of the service contract according to legislation, and some for even more than 10 years. Given a series of shortages indicated also by SSPs such as lack of social housing in the community, lack of adequate income for renting a place to live, and lack of support services (including personal assistance) that may enable beneficiaries to live independently in the community. SHs turn into long-term residential services for beneficiaries with no future prospects for living independently and included in the community. SHs seem to offer services to their beneficiaries for a virtual future that may never come, which raises the question about their utility, as well as pointing to their resemblance to long-term residential centers.

Acquiring and/or developing independent living skills may prove unfeasible for many persons currently living in sheltered house. Although the expressed objective of service provision in sheltered houses is to support beneficiaries to acquire and develop independent living skills, in 2020, all or most beneficiaries in the majority of services made no improvement. While some of the reasons may require further attention (such as lack of qualified staff, personalized activities, or access to needed services in the community), the most often invoked reason is the continuous and high need for support of many beneficiaries. For these beneficiaries, the service cannot achieve its objectives and is simply an inadequate type of support. To prevent their long-term institutionalization in sheltered houses, access to other forms of support in the community must be provided, once persons with disabilities are provided with their own housing, such as home-based care, personal assistance, peer support, day services, etc.

#### Moving forward

Sheltered houses are presented as the primary alternative to institutionalization. However:

- For many, it is not their choice to live in an SH, and if they agreed to the decision, they were not presented with other reasonable options. 8 percent of beneficiaries also do not have legal capacity.
- Sheltered houses create barriers to the integration of beneficiaries in the community. They group people based on their condition (disability) and keep them separate for most of their daily life: eating, leisure, services, and activities. They have limited contact with people in the community.
- About one third of all beneficiaries live in what are in practice small residential centers. Most share their room with at least another person.

- Beneficiaries are subject to block treatment in setting their daily schedules, use of the residential space, use of specialized services (in-house or through the day centers).
- Beneficiaries have limited privacy and control over intimate issues like relationships and personal movement.
- Sheltered houses are not similar to the homes for the general population, but are spaces with mixed residential and service provision purposes.

In the short to medium term, sheltered houses are very likely to remain the main strategy for de-institutionalization. A series of recommendations is proposed.

#### In the short-medium term

- There should be a clearer separation between service provision and housing provision functions of sheltered houses, both physically and institutionally. Sheltered houses should remain first and foremost homes, and services offered by providers should act as mediators and support in accessing specialized services in the community. This means not conditioning living in the house by attending services in the SH, untying SH and day centers, and giving residents the possibility to choose their own service provider.
- Sheltered houses should be first and foremost homes. This means ensuring privacy and the right to intimacy for all beneficiaries. While staff might come here to work, they remain visitors and should not use the space to the detriment of beneficiaries.
- The number of residents in a house should be reduced and all beneficiaries who want a private room should be provided one. While financial and material limitations are a reality and the social service system is trying to move as many people out of the larger residential centers as possible, this does not mean crowding people in a smaller residential center.
- Beneficiaries should have control over their daily schedules and the use of their residential space. In addition, support should be given so that houses are, as much as possible, autonomous by adopting rules developed by or with the involvement of beneficiaries, as it is the case, for the transition to independent living. Housework, making meals, communal activities should be designed with beneficiaries as the central point and not fit the staff's needs and preferences.
- Community contact and fostering social interactions should be a concrete priority. Beneficiaries should be involved in as many activities and situations outside the house as possible and use general services, just like any other person, whenever that is physically possible. Integration in the community has to be done as part of everyday life and not at yearly town festivals or holidays. This also means eliminating restrictions on having friends and relationships and handling safety issues in ways other than blanked prohibitions.

- o Once admitted into sheltered housing, steps must be taken to ensure that all beneficiaries have legal capacity, including in order to be able to sign employment contracts, in order to reduce the risk of long-term institutionalization.
- o The training of staff in sheltered housing should be improved by: (i) amending the standard to specify the people responsible for training staff, the type of materials to be used, and the fact that persons with disabilities should be involved as trainers in modules related to respecting their rights; (ii) creating mechanisms to verify that staff master the content of the training and apply it appropriately in relation to the beneficiaries; and (iii) monitoring how GDSACPs in each county take an active role in organizing and providing the necessary training and education.
- The requirements of the standards should be more precise in terms of activities for independent living, including participation in shopping and preparing their own meals.
- Efforts should be made to ensure that both the evaluation and the process of developing and reviewing the personal plan are person-centered. The standards need to describe more specifically how multidisciplinary teams can best ensure that beneficiaries are involved in the evaluation process and that their opinions are given priority. More efforts should be made to involve beneficiaries in the development of the Personal Future Plan and, in particular, to help them understand what they are agreeing with (what their activities entail in terms of time, effort, effects, etc.). If there is a discrepancy between the plan and the needs or wishes of the beneficiaries, this should lead to a revision of the plan (instead of waiting for the multidisciplinary team to meet/be available). Ensuring access to a person who can provide support to the beneficiaries in the decision-making process or who can act as a facilitator during the evaluation/revision of the personal future plan can ensure more effective involvement of the beneficiaries.
- Risk management requires adequate knowledge about de-escalation of emergencies, rather than the use of solutions that could worsen the condition of beneficiaries. The standard should include clear instructions on training or other ways to provide such information to service staff and beneficiaries. In addition, the minimum requirements for the content of the procedure should include provisions for ensuring the informed consent of the beneficiaries in any risk situations that may lead to forced treatment or non-consensual interventions, such as physical restraint (for example, through planning in advance the interventions that the beneficiaries may or may not want to experience if they are in a situation where they cannot express their consent).
- In order to ensure adequate protection against violence and abuse, standards should include clear provisions on: (i) the way services should encourage and support beneficiaries to identify and report situations of violence, exploitation and abuse, and prevent the occurrence of such situations; (ii) informing beneficiaries of

how to identify and report situations of abuse, and ensure that they are protected from possible repercussions by perpetrators if they are service staff or beneficiaries; (iii) ensuring that beneficiaries are treated only with their full and informed consent and that non-consensual practices (involuntary administration of medication or physical restraint) are avoided; (iv) ensuring that beneficiaries have access to relevant services in the event of such situations, for example, psychological counseling or shelters; and (v) beneficiary access to an independent external case reporting and analysis mechanism, as well as legal and advisory services and lawyers.

# In the long-term

The philosophy of independent living should be further embedded in the provision of services to mean not "living on one's own" but living inter-dependently with personalized and self-directed support. The focus should move from what the person is able do to live independently, to the type of support a person needs to live fully included and participate in the community on an equal basis with others. Such support must be unbundled and offered separately from housing that must not be clustered and fully chosen and controlled by the person, and not by service providers.

# Box 12: Assisted living as an alternative to independent living for persons with disabilities

Supported living has been proven to be a best practice alternative for persons with disabilities to live independently and included in the community, and requires the following:

- Dispersed housing of the same type and sizes as that of the majority of the population, located buildings and neighborhoods among the rest of the community residents;
- o Access to mainstream health and social services provided outside the home;
- o Flexible and individualized support that will allow persons to live in their own homes and continue to be included in the community;
- Individual choice regarding the places of residence, sharing the residence with other persons, as well as activities in the community the person may want to participate in;
- Untied housing and support that allow the persons to flexibly change and chose either accommodation or support.

Source: European Expert Group on the Transition from Institutional to Community-based Care (2012: 94-95).

# 2.2. Crisis and Respite Centers

This chapter offers an evaluation of two crisis centers with regard to compliance with the minimum quality standards provided by the Romanian national legislation. First, it introduces the legal and strategic framework that regulates the provision of this service. Second, it provides an overview of the services in terms of service and beneficiaries' profile. Third, it offers a comprehensive evaluation of the service in view of its compliance with minimum quality standards and proposes brief recommendations for the improvement of standards to ensure a better quality of service provision that is person-centered, ensures personal autonomy and self-determination, prevents institutionalization and enables further an independent life in the community.

#### 2.2.1. Legal and strategic framework

Crisis and respite centers are social services that offer a set of activities for a limited time tailored to the needs of persons with disabilities who access the service with maintaining their personal potential and institutionalization. 104 Both types of services are regulated by the same minimum standards, however, the conditions for admission to each service differ. While respite centers are aimed at persons with disabilities whose personal assistants, legal representatives or family members are temporarily unable to care for them, crisis centers admit persons with disabilities who are in critical life situations, such as sudden illness, accident or death of their personal assistant, eviction, natural calamity, etc. 105 In both cases, residence for persons with disabilities is to be provided for a limited period of time until further solutions are found to enable them to resume living independently in the community.

Crisis and respite centers are community-based services that are essential for preventing institutionalization. The European Expert Group of the Transition from Institutionalized to Community-Based Care enumerate crisis intervention and emergency services, as well as short breaks provided to persons with disabilities and their carers in residential settings as an example of services in the community meant to prevent institutionalization, as well as to support the re-integration and transition back to the community. The CRPD Committee also emphasizes the importance of respite centers as support services for family carers that in turn enable them to better support their relative with disabilities to live independently in the community. Setting up respite centers is also an essential part of the policy framework to guide the deinstitutionalization processes. Respite services have had a long history as community services and service delivery may be set up in a variety of ways (see Box 13).

<sup>&</sup>lt;sup>104</sup> Order no. 82/2019, Annex 3, Minimum mandatory specific quality standards for residential social services such as Respite centers for adults with disabilities, Crisis centers for adults with disabilities.

<sup>&</sup>lt;sup>105</sup> Idem, Standard 1, Minimum requirement 4.

<sup>&</sup>lt;sup>106</sup> European Expert Group on the Transition from Institutional to Community-based Care (2012: 90-91).

<sup>&</sup>lt;sup>107</sup> CRPD Committee (2017).

<sup>&</sup>lt;sup>108</sup> Special Rapporteur on the rights of persons with disabilities (2017).

# Box 13: Forms of respite services for persons with disabilities

Respite care was originally developed in the United States mental health field in the early 1970s as a response to the then-popular deinstitutionalization trend (which was created primarily to assist families). In the 1980s, there was a push to provide respite care to families of persons with disabilities and elderly people. Furthermore, for terminally ill patients and their carers, respite care became an essential part of hospice care. Similarly, since the 1970s, respite care has grown in popularity across Europe. In England and Wales, for example, respite care for children with disabilities was primarily given under the National Health Service Act of 1977, which allowed local authorities to provide services free of charge without having to take children into care.

Respite services can be provided in a variety of ways and settings to respond to personal circumstances:

- o Planned respite vs Emergency respite. Planned Respite Care is intended to become a regular activity for both the caregivers and the person for whom they are caring and may include the following: In-Home Respite (a trained worker visits the individual who requires care in their home to provide support), Day or Center-Based Respite (the person with a disability, or the caregiver can participate in programs outside the house that are meant to improve the well-being of both the person being cared for and the caregiver), Residential Respite (a planned break from the caregiver's home and normal routine for both the caregiver and the person being cared for), Caregiver Retreats (scheduled time away for the caregiver, complete with planned activities and recuperation). Emergency respite is usually provided in situations that occur unplanned and may be offered in-home or in a residential setting.
- o Formal vs. Informal respite care. Informal Respite Care is provided by friends, family and others who are not affiliated with any organization and are often not paid for services. It is usually short-term and out-of-home. It can be planned or emergency in nature. This type of respite care is the most adaptable and frequently available. There are no other service providers involved, and it is organized by the caregiver to meet their own and the beneficiary's needs. The flexibility of this informal source of relief is its greatest strength. Friends, relatives, and neighbors are unlikely to have professional training in caring for persons with disabilities, which is a significant drawback of informal respite care. Specialized personnel may be required if the service user has certain medical needs. Formal Respite Care is usually a paid service provided by qualified providers who have undergone training, and it is available on an emergency and planned basis.
- o Short-term vs. Long-term. The period of respite care is used to calculate this dimension. Short-term respite care ranges from a few hours to a few days (overnight or weekend respite care for instance). Long-term respite care can be offered for a few weeks (up to a month).

o In-home vs. Out-of-home. Formal In-home Respite Care may be planned, formal, and short-term. It entails a professional caring for the service user for a few hours at a time. Caregivers can take advantage of short pauses like these to attend to their own social needs as well as chores like shopping. Institutional facilities, such as specialized respite care units (but also hospitals and nursing homes), can provide Out-of-home Respite Care. Other alternatives include group homes in the community or living with another family. Out-of-home Respite Care is planned, formal, and usually long-term.

Sources: Mlitt & Canavan (2007), Smyer & Chang (1999), Robinson & Stalker (1993), Sydney Local Health District (n.d.).

Crisis centers as they are licensed by Romanian legislation are not an established service elsewhere. Usually, crisis or emergency respite services in other countries are actually forms of respite for persons with disabilities and may refer to the deployment of an in-home respite care specialized professional in the case of an unanticipated or scheduled event, or the temporary placement of the care recipient outside the home to relieve the caregiver. An emergency is defined as an unanticipated situation that forces the primary caregiver or backup caregiver to leave the home. In addition, emergency respite care should be employed in the case of unanticipated events that endanger the health and safety of the beneficiary or of the caregiver, putting the care recipient in risk. This definition is applicable to a variety of situations, including, but not limited to, caregiver illness (physical, mental, or emotional), caregiver hospitalization or doctor visit, illness of a loved one, funeral/wake, stress reduction, counseling/support, transitions abuse care recipient arrangements), loss of employment/work-related conditions. 109 Respite care can also be used as an alternative to hospitalization for persons with psychiatric diagnoses. Thus, crisis respite care centers can be a viable alternative to emergency rooms and hospitalization in situations of psychiatric crisis. A crisis respite care center provides shelter and supervision for a set period of time, with an emphasis on patients rather than caregivers. 110 Based on the findings of the literature review, a change in the caregiver situation (as indicated above) is linked to Emergency Respite Care, whereas a change in the care recipient situation is linked to Crisis Respite Care (psychiatric crises for instance).

Even though they are an important part of the landscape of community-based services for persons with disabilities, there are very few crisis and respite centers in Romania. As of March 31, 2021, there were only three respite centers<sup>111</sup> and two crisis centers nationwide.<sup>112</sup> Their number registered insignificant variation over the past five years: while the number of respite centers increased by one since 2013, that

<sup>109</sup> Illinois Respite Coalition (n.d.)

<sup>&</sup>lt;sup>110</sup> Hoge M.A., Davidson L., Sledge W.H. (1997: 191–204).

<sup>&</sup>lt;sup>111</sup> According to NARPDCA data, on September 30, 2020, only one of the respite centers were offering services to seven persons with disabilities.

<sup>&</sup>lt;sup>112</sup> According to NARPDCA data.

of crisis centers decreased from four. Even though NARPDCA launched in 2016 the Program of National Interest to fund services in the community, including crisis centers and respite centers, <sup>113</sup> their number remained low. In 2020, in the last session of public selection of projects, six projects were proposed for funding through which respite centers will be set up. The National Disability Strategy for 2022-2027 is committed to further increasing the number of crisis and respite centers as one of the outcome indicators for measuring the improvement of access for persons with disabilities to community-based social services necessary for independent living. <sup>114</sup>

The development of respite and crisis centers has been influenced by a series of difficulties. The main reasons invoked by GDSACP directors for the lack of initiatives to set up respite and crisis centers are: (i) budgetary limitations; (ii) the lack of demand for such services at the local level; (iii) the belief that it is rather the local public authorities or NGOs that should provide these services; (iv) the difficulty to justify expenses related to administrative and human resources costs, considering that these centers are meant to provide service for a limited period of time only and a constant flux of beneficiaries cannot be anticipated; and (v) lack of adequately qualified staff and/or of adequate space. 115 Funding cuts, staff shortages, bed closures, and the conversion of respite beds to transitional care or long-term care beds have all contributed to a reduction in respite availability in other countries as well. According to a study published in 2019 by Family Carers Ireland, the College of Psychiatrists of Ireland, and the University College Dublin School of Nursing, Midwifery, and Health Systems, 83 percent of carers' loved ones do not have access to appropriate respite. 116 Various advocacy actions highlight the ongoing needs in the field of respite care services. 117 The same concerns are expressed in media reports. 118

# 2.2.2. Description of services

#### Service profile

Currently there are only two crisis centers in Romania, which offer services to 17 beneficiaries. Both service providers are public under the subordination of local GDSACPs and located in small cities—one in the southern region, the other in the southwestern. Both services were established around the same time, Service 1 in 2006 and

<sup>&</sup>lt;sup>113</sup> "Developing social services such as daycare centers, respite/crisis centers and sheltered houses for the purpose of deinstitutionalizing persons with disabilities from old type of institutions and for preventing institutionalization of persons with disabilities in the community." The PNI was approved through the Government Decision no. 798/2016. <sup>114</sup> Operational Plan for the implementation of the National Strategy on the rights of persons with disabilities 2022-2027. Specific objective 5.3. Improving the access to social services in the community necessary for independent living. Measures 5.3.2. Providing social services such as respite and crisis centers, by setting up, including with funding from European funds, and/or contracting them and conducting awareness campaigns among persons with disabilities and their relatives about their existence. Currently in the consultation process.

<sup>&</sup>lt;sup>115</sup> World Bank (2020: 219).

<sup>&</sup>lt;sup>116</sup> Eurocarers (n.d.)

<sup>&</sup>lt;sup>117</sup> National Federation of Voluntary Service Providers (2019); Care Alliance Ireland (n.d.).

<sup>&</sup>lt;sup>118</sup> Wall, Martin (2021), BreakingNews (2021).

Service 2 in 2007, as a result of the decisions of the respective county councils where they are located. Even though only Service 1 is currently licensed as a crisis/respite service, the profile of current beneficiaries does not match that of a respite center as stipulated by standards. These services have a capacity of 12 and 15 places respectively, and, at the moment of data collection, Service 1 had 8 beneficiaries, and Service 2 - 9.

The objective of the centers is to offer services to persons with disabilities in difficult life situations. The objective of Service 1 is to offer support services to beneficiaries for overcoming difficult situations, preventing and combating the risk of social exclusion and promoting social inclusion and increasing their quality of life. 119 The objective of Service 2 is to ensure accommodation; medical assistance and personal care; neuropsychiatric recovery and rehabilitation; emotional support and counseling; developing independent living skills; and socialization, integration, and reintegration into the family of adults with disabilities who do not have caretakers or whose caretakers are unable to provide them with a supportive and protective environment. 120

The motives for beneficiaries' admission to both services do not match those specified in the standards for crisis or respite centers. While the standards for crisis centers mention explicitly that persons with disabilities are to be admitted to the service if they find themselves in critical life situations - such as sudden illness, accident, or death of their personal assistant; eviction, natural calamity - none of the current beneficiaries in the two centers have been admitted due to these reasons, as reported by service staff. However, the internal regulations of the services have broader provisions regarding the profile of persons who can access the service. Service 1 admits persons with disabilities in difficult situations (not further detailed), and under exceptional circumstances - homeless persons; persons without identification documents; persons who lack proper housing; victims of abuse; and physically and psychologically neglected, deskilled persons with no chances for social and professional reinsertion. 121 Service 2 admits persons who require permanent medical care that cannot be provided at home, cannot live independently, do not have legal caretakers or caretakers who are unable to provide care, have no income or an income that is insufficient for a decent living in the community, and are homeless.

The length of stay in the two centers for a longer period than the legal provisions indicates that they are not community-based services that must prevent institutionalization. The maximum length of stay in both centers over the past two years was 365 days, while the minimum length was 36 days in Service 1 in 2019 and 5 days in Service 2 in 2020 (see Table 11). Data from external evaluations showed that in Service 1, all current beneficiaries had been residing there for more than a year and 6 of them for more than 2 years, while the length of stay for all current beneficiaries of Service 2 was less than 1 year. Although the standard stipulates that activities in crisis or respite centers should be provided to persons with disabilities for a limited period of

<sup>&</sup>lt;sup>119</sup> ROF, Service 1, Art. 3.

<sup>&</sup>lt;sup>120</sup> ROF, Service 2, Art. 3.

<sup>&</sup>lt;sup>121</sup> ROF, Service 1, Art. 6(1).

time, it does not specify what the length of time should be in terms of a minimum and maximum number of days. However, both services evaluated do have their own provisions regarding the length of stay for their beneficiaries, between 15 and 35 days, 122 which they do not observe according to data collected.

Table 11. Length of stay of beneficiaries in the services included in the evaluation (davs)

(4.4.)		Service 1		Service 2	
Length stay/days	of _	2019	2020	2019	2020
Minimum		36	333	27	5
Medium		200	349	180	365
Maximum		365	365	180	365

Source: World Bank survey of crisis and respite centers (2021).

Despite their objective of supporting beneficiaries to overcome difficult life situations and ensure their integration in the community, the centers provide either long-term accommodation or a stopover on the route toward long-term institutionalization. There is a significant difference between the two services regarding the flow of beneficiaries. In the case of Service 1, only two beneficiaries had their service contracts ended in 2019 and only one in 2020, while most seem to reside in the center long-term. In the case of Service 2, 14 and 15 beneficiaries ended their stay in the center in 2019 and 2020 respectively. According to data reported from service staff as well as from the external evaluation of thrvice 2, most beneficiaries are admitted for a shorter time (weeks to months) and are subsequently transferred to long-term residential centers.

# Beneficiary profile

The majority of beneficiaries is represented by persons with a disability certificate for psychic and mental disabilities. Seven out of 9 persons who benefited from Service 1 in 2020 had intellectual disabilities ("handicap mintal"), while the distribution of the 18 beneficiaries from Service 2 in 2020 is more evenly distributed between mental, psychic and associated disabilities. The majority of beneficiaries from both services, however, have accentuated disabilities. Their age profile is non-homogenous, while most have known families (see Annex-Table 3).

The motives for beneficiaries' admission to the crisis center vary. The majority of current beneficiaries come from the special protection system for children (11 out of 17 beneficiaries in total) and were admitted because no other services could be

<sup>122</sup> As specified in the Regulations for the organization and functioning (ROF) of Service 2 provided by the service as part of data collection. In the case of Service 1, this information is included in a public information material about the center issued by the GDSACP (GDSACP Vâlcea, 2016). Available at: http://www.dgaspcvl.ro/documente/2016/material%20informativ%20CCRC%20Babeni.doc

#### 2.2.3. Standards compliance and implementation analysis

This section presents a detailed evaluation of the compliance with the minimum requirements in the standards, using both the service's self-evaluation and information gained from the external evaluation, interviews with service coordinators and beneficiaries, as well as analysis of the documents that were offered by the services.

#### Module 1. Social Service Management

The first module ensures compliance with relevant laws and regulations regarding the organization and management of the service, more precisely founding the service, hiring and maintaining qualified staff, providing the service to particular kinds of beneficiaries, maintaining the proper internal administrative paperwork, and establishing relevant partnerships in the community.

Standard 1: Organization and functioning

Standard description	The standard details the general conditions for organizing the service and managing it, such as the procedures for setting up the service; legal status, minimum service capacity (four places for respite and two for crisis centers); profile of beneficiaries that may be admitted to such services; type of necessary authorization; the responsibilities of coordinators; offering training for the personnel in areas like equality, preventing negligence, violence, and abuse, facilitating an independent life for the beneficiary, etc.; encouraging partnerships with other entities, including volunteers, non-governmental organizations, and other specialists.
Self-assessment	According to the self-assessment, the services were compliant with minimum requirements, with a few exceptions.
	<ul> <li>Service 2 reported not having been set up as a decision of a SSP, nor did it have an establishment notice from NARPDCA or a sanitary license.</li> </ul>

<sup>&</sup>lt;sup>123</sup> Children may benefit of special protection until they acquire full legal capacity at 18. This can be extended for up to 2 more years in case the persons cannot return to the family and is confronted with the risk of social exclusion and up to the age of 26, in cases when the person continues his/her studies. Law no. 272/2004 regarding the protection and promotion of the rights of the child. Art. 55.

Comprehensive evaluation: external evaluation, interviews, document analysis	<ul> <li>Both services had a yearly report about the service, however Service 2 did not include in the report aspects related to funded projects, monitoring visits, or an analysis of satisfaction questionnaires administered to beneficiaries in the previous year.</li> <li>Both services had yearly training plans for staff with mandatory training modules; however, Service 2 did not plan to provide training on respecting and encouraging the autonomy and independence of beneficiaries, neither did it provide training on this topic to staff in 2020. It also did not include any proof of trainings in the staff files.</li> <li>Service 2 reported that they do not encourage volunteering, nor collaborations with other organizations, specialists, or resource persons from the field. While promoting such collaborations, Service 1 reported having none in 2020.</li> <li>Both services reported that the service respects the requirements of the standard regarding the structure, qualifications and responsibilities of staff.</li> <li>The external evaluation and the documents submitted have revealed that, in fact, some of the standards are not met as the self-assessment had reported.</li> <li>The activity reports for 2020 for both centers did not include an assessment of the degree of standards compliance and of possible difficulties, nor the measures that may have resulted from the analysis of questionnaires administered to beneficiaries/legal representatives about the quality of life in the center, even though Service 1 did report having included these aspects in the report.</li> <li>Unlike the self-assessment regarding the compliance with mandatory yearly training provided to staff, the external evaluation showed that staff of both services was not provided training on respect for diversity, respecting and encouraging the individual autonomy and independence of persons with disabilities, and respecting the dignity and intimacy of beneficiaries.</li> </ul>
Observations	training for staff, the materials used, and how is staff to be assessed regarding skills learned.
Standard 2: Housing	
Standard description	The standard covers minimum conditions needed to ensure that beneficiaries have access to clean,

	comfortable, and safe living conditions—location of the service in the community, dormitories, socialization and leisure rooms and spaces, clothing, sanitation facilities, and access to means of communication.
Self-assessment	According to the self-assessment form, there are a few minimum requirements with which the services did not comply, while the compliance regarding other requirements was achieved differently in each case.
	<ul> <li>Both services have been reported to be located in the community, with Service 1 situated farther away from community services and facilities such as the local store, post office, bank, train station, park, and church, as well as public transportation. Service 2 however is located much further away from a public hospital, at 20 km.</li> <li>Both centers had rooms that lodged more than two</li> </ul>
	beneficiaries as required by the standards (two rooms in the case of Service 1 and all three rooms in Service 2), while only Service 1 included the consent of beneficiaries for sharing the room with other beneficiaries.  Overall, Service 2 was reported as being to a lesser extent compliant with minimum requirements, such as the fence surrounding the service that impaired the visibility in and out of the location, the lack of a socializing room for beneficiaries, the use of the toilet and bathing facilities by more than four beneficiaries,
Comprehensive evaluation: external evaluation, interviews, document analysis	and no access to the internet.  Data from external evaluations confirmed that Service 1 is rather isolated from the community and no residential or public buildings could be seen in the proximity, while Service 2 provided beneficiaries with less of a familial atmosphere, and much more of a segregated living environment with window bars, no socializing rooms, impersonal sleeping areas, missing bathroom tiles, no toilet paper or soap in the toilets, and generally a degraded state of the building—overall a reminder of an old type of residential centers.
	Both services are not entirely accessible for persons with physical disabilities or low mobility, failing to ensure one or most of the following aspects: wide-opening doors, no stairs and interior sills or access ramps or inclined planes, handrail, tactile paving. The evaluators assessed the

buildings as providing overall good living conditions (no broken windows, non-closing windows, seepage and mold, broken floors, perforated roof), and in general with an infrastructure that poses no danger to the safety of beneficiaries.

Beneficiaries interviewed as part of the external evaluation were generally satisfied with living conditions, but some complained of insufficient seasonal heating, ventilation, or the state of bathrooms. Some beneficiaries did not have access to a mobile phone or phone credit for communication with friends and family, while also expressing the wish to have access to laptops and the internet.

# Standard 3: Food and feeding

Standard description	The standard includes requirements about ensuring beneficiaries with diverse, nutritious, and adequate food, prepared and served in hygienic conditions and in a familial environment.
Self-assessment	According to the self-assessment form, most requirements are complied with, but there are some exceptions. In the case of Service 1, beneficiaries were not provided with the possibility of serving their meals either in a dining room, socializing space, or their own sleeping rooms. Service 2 did not have a kitchen and a food storage facility, since the food is prepared and served by the residential center in the proximity. Service 2 also reported that they avoid serving precooked and processed food by providing fresh fruits and homemade desserts to beneficiaries at least three times a week, as the standard requires.
Camanahanaha	External evaluations indicated that Coming 2 coming the

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Comprehensive evaluation: external evaluation. interviews. document analysis

External evaluations indicated that Service 2 served the food in a large dining room with 16 places that had only tables and chairs and did not resemble a familial environment. Beneficiaries are neither involved in food shopping or cooking, nor in deciding the menu. One beneficiary did in fact complain that sometimes the food was not enough, while, in general, beneficiaries pay out of their pockets for sweets and extra food thy may want to consume. Although the feedback questionnaires on the service quality administered yearly to beneficiaries of both services do include questions about the food, and at least Service 2 reported during the external evaluations

	that beneficiaries did make suggestions via the questionnaires, none of the yearly reports included any measures related to improving the food quality. It is unclear how and whether beneficiaries can make their food preferences known otherwise and whether these are taken into account.
Standard 4: Health assista	nce
Standard description	The standard includes minimum requirements the service must be observe to care for and maintain the health of beneficiaries, such as knowing and applying the specific procedure of preserving their health, monitoring their health, helping beneficiaries to access primary and specialized health care, and support with administering medication, as well as consent-related aspects.
Self-assessment	According to the self-assessment form, most requirements are met, except for the requirement about ensuring the beneficiaries' or their legal representatives' consent for treatment or care in exceptional circumstances and including their consent in the personal file, which Service 1 reported not meeting. Moreover, Service 2 also reported not having included in the specific health procedure the mandatory section regarding ways of intervening in case of alcohol and drugs consumption, as well as smoking.
Comprehensive evaluation: external evaluation, interviews, document analysis	Although the center staff reported that all beneficiaries have a family doctor, data from external evaluations indicated that none of them actually know the doctor's name nor may they contact the doctor directly should the need arise, as accessing primary care is mediated exclusively by the staff.
	Beneficiaries who have been residing in the center for longer than a year had in 2020 a minimal medical checkup: all eight had their blood pressure measured and four had routine blood tests. All but one beneficiary are being administered psychotropic medication. In both centers, psychotropic treatment is administered by the nurse. Although all beneficiaries have been reported to have access to psychiatric services three or more times in 2020, beneficiaries of Service 2 did not have access to mental health services in the form of psychotherapy, counseling, etc.

Although according to the standard the specific mandatory procedure for health maintenance must include provisions regarding the right of beneficiaries to choose a certain treatment, Service 2 did report during the external evaluations that at least some beneficiaries are being administered psychotropic medication without their informed consent. The staff indicated that although the beneficiaries are not de facto forced to take medication, the practice of ensuring consent is difficult in the case of beneficiaries with high support needs for communication and understanding. Even though during monitoring visits from state authorities pointing out this problematic practice and the further obligation to ensure informed consent for all treatments, staff reported that they have no knowledge about the steps of ensuring informed consent and neither do beneficiaries. In contrast, Service 1 reported during the external evaluations that all medication is administered only with the beneficiaries' informed consent, since staff make sure to explain the benefits of medication to beneficiaries who sometimes refuse to take the medication. Interviews with beneficiaries suggested limited knowledge about the type of medications administered and their indications, even though some could specify their diagnoses and the name of medications. Generally, beneficiaries referred to the administration of psychotropic medication as to a long-term practice that was allegedly carried out for "their own good" and not as the result of decisions that must continuously involve them.

Documents presented by the services do not include any provisions about the obligation to ensure the full and informed consent of beneficiaries for the administration of any medication, nor about knowledge that staff must have about ensuring informed consent, even though the staff did reference some documents that include these aspects (such as procedure regarding the maintenance of beneficiaries' health, regulations regarding the organization and functioning of the service, code of ethics).

#### Observations

The standard should specify what the mandatory yearly medical checkup should include, to ensure that beneficiaries have access to preventive as well as curative health care, considering that most beneficiaries of the

centers evaluated have complex health issues (half of the beneficiaries of Service 1 and all of Service 2 have complex health problems and an individualized plan for prevention, intervention, and rehabilitation that is overseen by the centers). In addition, the standard should include provisions on how to ensure the informed consent of beneficiaries by providing both staff and beneficiaries with materials and training on steps that should be taken to ensure consent. This is particularly important in the case of beneficiaries who are being administered psychotropic medication, given that informed consent depends on providing adequate and accurate medical information in accessible formats on medical diagnoses, side effects of medication and medical, and as well as access to non-medical alternatives, including mental health services. peer support, etc. Currently, psychotropic medication and psychiatric services are the only health services provided to beneficiaries with psychiatric disabilities in the two crisis centers evaluated, which also restricts the possibility of providing informed consent.

# Module 2. Accessing the social service

The second module covers a series of requirements related to the provision of information about the service (admission, activity and, services provided by the centers; rights and obligations; service contract), including information in accessible formats for potential beneficiaries, the admission procedure, aspects related to the content of beneficiaries' personal files and confidentiality, as well as aspects related to the suspension/cessation of the service provision contract.

#### **Standard 1: Information**

Standard description	The standard covers aspects the service must ensure regarding information provided about the service to anyone that might benefit from the service, information that must also be provided in accessible formats, as well as the opportunity to visit the service before admission.
Self-assessment	According to the self-assessment form, some requirements were not respected.
	<ul> <li>Service 2 did not include in the mandatory information materials regarding the service contract, nor about the beneficiaries' rights and obligations.</li> <li>Neither service provided information materials in accessible formats such as Braille, audio-video</li> </ul>

Comprehensive evaluation: external evaluation, interviews, document analysis	presentations, or sign language interpretation, although they did provide information in easy-to-read formats. Service 1 reported that the provision of information in other formats was not needed, presumably because there were no current beneficiaries who needed access to such formats.  Although both services allow visits of persons interested in the service, there was only one visit to Service 1 over the past years, presumably due to lack of free places, as reported by the service staff.  Data from external evaluations, as reported by service staff, shows that only the beneficiaries of Service 1 could visit the center before admission, had received information about the organization of the service, could meet the other residents and service staff, and received information about other community-services, including alternatives to crisis centers. However, beneficiaries interviewed from both services rather indicated they had received minimal information about the service and activities provided in the center and about the service contract and only once they were already admitted to the centers. In addition, only Service 1 provides information	
	for beneficiaries on spaces accessible to them anytime during their stay in the center, but this information only covers activities and services provided in the center and the beneficiaries' rights and obligations.	
Observations	Both SSPs and service staff should make sure that beneficiaries are provided all relevant information about the services in accessible formats, can visit the service and meet the staff and beneficiaries before being admitted to the service and for the entire time of their stay afterward.	
Standard 2: Admission		
Standard description	The standard includes aspects related to the necessary steps a potential beneficiary must make to be admitted to the center and the timeline of admission, as well as the obligation to explain beneficiaries the provisions of the service contract using accessible formats of communication.	
Self-assessment	Both services reported compliance with the minimum requirements of the standard. No beneficiary admitted in the past two years required communication and	

	information about the service contract in accessible formats.
Comprehensive evaluation: external evaluation, interviews, document analysis	Only one of the beneficiaries interviewed had a copy of the service contract, which was kept in the office of the service coordinator, while the others could offer no information about the contract, neither if they signed one nor about its content. Since all beneficiaries have full legal capacity and no legal representatives that might have signed the contract in their place, the lack of their familiarity with the contract (regardless of the time of their admission) raises questions about the accessibility and effectiveness of communication between staff and beneficiaries regarding the content of the contract.
Observations	Service staff should make sure that all beneficiaries are provided support in communication and understanding the service contract provisions.
Standard 3: Beneficiary's	personal file
Standard description	The standard covers requirements related to mandatory documents that must be included in any personal file of al beneficiaries, as well as confidentiality issues about personal files data.
Self-assessment	Both services reported full compliance with the standard. All personal files included the admission: a) the application for admission, signed by the beneficiary/legal representative; b) the admission order from the SSP, in original; c) copy of the identity and civil status documents, as the case may be, of the beneficiary; d) copy of the valid document certifying the degree of disability; e) the service provision contract signed by the parties, in original. No beneficiaries had requested to see their files in 2020.
Standard 4: Suspension/ce	essation of service
Standard description	The standard refers to aspects related to the situations that can lead to the suspension/cessation of the service contract and the phases of the procedures and the necessary documents, as well as the SSPs responsibilities.
Self-assessment	Both services were standard compliant, but there were significant differences between the two services regarding the causes for the suspension and the cessation of the service. Service 1 had more cases in 2019 and 2020

	for the temporary suspension of service due to admission to hospitals for more than 30 days or at beneficiaries' request and very few for the termination of service, illustrating the long-term residency of beneficiaries. In contrast, Service 2 had a very large numbers of cases of termination due to transfer to other residential institutions, 12 in 2019 and 15 in 2020, proving the failure of the service to prevent institutionalization while providing instead a temporary residential solution for youth coming from the child protection system before they become further institutionalized.
Comprehensive evaluation: external evaluation, interviews, document analysis	NA
Observations	Standards should include a maximum length of stay in the centers for adults with disabilities and prohibit consecutive readmissions as well as the transfer of beneficiaries to residential centers.

# Module 3. Evaluation and planification

The third module ensures the fact that the service is constantly provided in accordance with beneficiary's needs, through proper evaluation and monitoring and a proper personalized plan. The requirements focus on procedures and on the resulting documentation.

Standard 1: Evaluation pre-admission to respite centers/post-admission to crisis centers

Standard description	The standard covers minimum requirements related to the evaluation of beneficiaries: how it is carried out and by whom and the use of the evaluation results.
Self-assessment	Most of the minimum requirements are met according to the self-assessment form, with several exceptions. The standard requires that the beneficiary be involved in the evaluation process by the evaluation team and his/her opinion must be taken into account, but Service 1 reported that none of the eight beneficiaries could be involved in the evaluation due to their "reduced ability to understand/mental retardation," while Service 2 could not involve one beneficiary whose speech had been affected in the aftermath of a stroke.

Comprehensive evaluation: external evaluation, interviews, document analysis

All beneficiaries' files evaluated during the external visits were compliant with the standard in that they included the majority of aspects that evaluations are expected to cover health status, level of autonomy and community, specific needs of care and assistance, rehabilitation, relationships, educational and cultural aspects, and (partly) risks related to alcohol and drug consumption. All evaluations fiches included the results of the evaluations, identified needs, services, and activities provided and staff responsible with providing them, as well as the beneficiaries' signatures. However, the evaluations did not include a description of how beneficiaries were actively involved in the evaluation process and whether they could communicate the things that are important to them, and the type of support they would have liked to receive. In fact, some of the interviewed beneficiaries could recall only vaguely some form of evaluation when they had been admitted to the center or details about other subsequent evaluations. Beneficiaries of Service 2 specifically indicated that the evaluations were not aimed at identifying what kind of services and activities they may need or what they themselves would want or like, but more at their general satisfaction with their lives in the center.

The process of interviewing the beneficiaries of crisis centers showed that there were indeed differences between the level of their support needs for understanding and communication. However, although in the case of Service 1 the staff reported that no beneficiaries could be involved in the evaluation process and further in the planning of the activities they were provided, external evaluators had no difficulties in carrying out the interviews with at least some of the beneficiaries as their support needs for understanding and communication were minimal.

#### **Observations**

The standards must include further requirements to effectively ensure the participation of beneficiaries in the evaluation process, including provisions for accessible communication and decision-making support.

Standard 2: Personalized plan

Self-assessment	Beneficiaries of both services had assigned case managers that monitored and evaluated the carrying out of activities according to the Personalized Plan. However, in the case of Service 1, case managers only met six times with the evaluation team over the previous six months to discuss the situation of beneficiaries, while the standard requires a mandatory weekly frequency for such meetings. In addition, the monitoring fiche that case managers must fill in with the conclusions of these weekly discussions did not include either the comments on how to provide the beneficiary with a safe environment in terms of protection against exploitation, violence and abuse of protection; against torture and cruel, inhuman, or degrading treatment (Service 1), nor the summary of the weekly discussions between case managers and the team (Service 2). Only the case manager from Service 2 prepares a monthly report for the SSP about the monitoring and evaluation activities.
Comprehensive evaluation: external evaluation, interviews, document analysis	The evaluation of the sample of monitoring fiches from the beneficiaries' personal files indicated that in the case of Service 1 these did not include the aspects required by the standard, neither the summary of the discussions between the case manager and evaluation team, nor the comments on how to provide beneficiaries with a safe environment.
	None of the interviewed beneficiaries from either service knew what a case manager was and who their case manager was.
Observations	The standard does not require that case managers meet with beneficiaries as part of their monitoring and evaluation responsibilities, nor that beneficiaries must participate in the meetings with case managers and the evaluation teams to discuss jointly their situation with respect to activities offered, complaints, or other forms of support needed.

# Module 4. Services and activities

Module 4 includes the standards and the minimum requirements for the specific activities the crisis center has to provide, information and social counseling/social assistance, psychological counseling, care and assistance, and regular life schedule. These services and activities constitute the core of the service provision.

Standard 1:	Information	and social	counseling/	/social assistance

	The service is required to provide hereficiaries with
Standard description	The service is required to provide beneficiaries with information about their rights and social benefits. This information may include aspects related to medical facilities and rehabilitation services, transportation services, alternative and complementary services provided by private SSPs, assisted employment, etc.
Self-assessment	All eight beneficiaries of Service 1 were offered: (i) information about the social rights and benefits; (ii) support for maintaining relationships with family and friends; (iii) information on medical services, including those for habilitation and rehabilitation; and (iv) information and support for obtaining transportation services with the involvement of the social worker, medical nurse, and psychologist. In contrast, beneficiaries of Service 2 were only offered the first two types of information and support by the social worker. In all cases, the services covered by the standard were offered on the center's premises.
Comprehensive evaluation: external evaluation, interviews, document analysis	Only one of the beneficiaries interviewed had received some of the activities covered by the standard, such as information on services for habilitation and rehabilitation, transportation benefits, and help in maintaining contact with the family. While both services reported during the evaluation that no beneficiary needed support in finding and maintaining employment, at least two of the interviewed beneficiaries have expressed the wish to continue their education and find employment and have also indicated the availability of service staff to offer them support in the near future.
Standard 2: Psychological	counseling
Standard description	Psychological counseling is the activity provided to beneficiaries to ensure their psycho-affective balance.
Self-assessment	Only Service 1 provided psychological counseling to nine beneficiaries in 2020.
Comprehensive evaluation: external evaluation, interviews, document analysis	Most beneficiaries interviewed could not indicate if they received psychological counseling or if they would need such an activity. Only one beneficiary interviewed from Service 1 was receiving psychological counseling with a monthly frequency, which the beneficiary assessed as being a useful activity. With respect to Service 2, one

Self-assessment	Both services reported that activities in the centers are not provided to help the beneficiaries to continue their usual life schedule since this is a standard that applies to respite centers. Only Service 2 is also licensed as a crisis/respite center; however, as reported by center staff, the service has the profile of a crisis center exclusively.
Comprehensive evaluation: external evaluation, interviews, document analysis	According to interview data, the daily lives of beneficiaries in both centers is mostly filled with unstimulating activities, such as drawing, watching TV, cleaning the center premises, and less with specific activities that may enable them to acquire new knowledge and skills, or provide them with the support they may need for rehabilitation.

# Module 5. Protection and rights

The final module combines standards that refer to the beneficiaries' rights, their protection, questions of ethics, risk management, mechanisms for complaints, and measuring beneficiaries' satisfaction.

Standard 1: Respecting beneficiaries' rights

Standard 1. Respecting be	
Standard description	The standard must ensure that the beneficiaries' rights are respected by making them known to the service staff through training sessions. Among the rights listed, there are provisions for respecting the beneficiary's dignity and privacy, as well as including the beneficiaries in making decisions about the service provision.
Self-assessment	According to the self-assessment, each service organized one training session in 2020 with the personnel about respecting the beneficiaries' rights. The services also reported no situation in which the beneficiaries' rights were not respected.
Comprehensive evaluation: external evaluation, interviews,	External evaluations and interviews with beneficiaries indicated that at least some of beneficiaries' rights were not respected.
document analysis	<ul> <li>With regard to beneficiaries' right to take part in the decision-making process regarding the service provision, staff from both services considered beneficiaries to be incapable of understanding what this may entail, and consequently they decide to not actively involve beneficiaries in this process.</li> </ul>

Observations	<ul> <li>Both centers are spaces where beneficiaries' intimacy is rather disregarded, where dormitories do not fulfill the function of a personal space where beneficiaries can safely keep their personal items without intrusion from staff and beneficiaries. Some beneficiaries complained about other beneficiaries' going through their personal items and stealing or taking them without asking. In general, both centers gave the impression of impersonal hospital-like places where staff and beneficiaries had unrestricted access to the other beneficiaries' dormitories and spaces.</li> <li>None of the interviewed beneficiaries had the notion of beneficiaries' rights or the rights of persons with disabilities, some pointing out that they had never been told about this issue.</li> <li>While the standard includes mandatory training sessions with service staff on the topic of beneficiaries' rights, it does not stipulate a similar obligation of providing training and information to beneficiaries in accessible formats, nor about ongoing effective feedback and complaint mechanisms that can ensure access to prompt solutions and remedies.</li> </ul>
Standard 2: Risk managem	ent
Standard description	The standard covers aspects related to the management of risk situations, such as the existence and content of a specific procedure that is known and accordingly applied by the service.
Self-assessment	Both services indicated compliance with most minimum requirements of the standard. The mandatory procedure regarding risk management was reported by both services to include all aspects required by the standard—examples of beneficiaries' behavior that requires emergency intervention, including police intervention, as well as specific indications on how to act in case of runaway, aggression against beneficiaries, and post-risk management. Emergency situations must be reported to the SSP in a maximum of hours; however, Service 1 reported non-compliance with this requirement, while also reporting having had seven such emergency situations.
Comprehensive evaluation: external	Document analysis of risk management procedures submitted by both services indicated that procedures have general provisions regarding the management of risk

situations, with most situations being solved by calling the emergency number 112, while in the case of Service 1, staff may also resort to restraining beneficiaries, with no further specifications about concrete situations in which this measure may be applied. While both procedures include the obligation to provide staff training on relevant themes related to risk management, neither the yearly activity reports nor the service training registers contained any proof of such training having been provided in 2020. The procedures also include measures for preventing risk situations, but in the case of Service 1, these are not further exemplified, while Service 2 includes: (i) mandatory sessions for staff for providing information on how to communicate with beneficiaries to prevent hostile attitudes, and (ii) mandatory medical evaluation of beneficiaries to assess their health status and provide adequate treatment to prevent any subsequent behavioral risks.

#### Observations

Risk management requires adequate know-how about deescalating emergency situations rather than appealing to solutions that could aggravate the beneficiaries' state. The standard does not include any clear provision about training or other ways to provide such information to service staff and beneficiaries. In addition, the minimum requirements regarding the content of the procedure do not include any provisions on ensuring the informed consent of beneficiaries in any risk situations that may lead to forced treatment or non-consensual interventions (for instance, through planning in advance the interventions the beneficiaries might want or not want to experience in the event they might not be able to give consent). This is particularly important given that most beneficiaries are being administered psychotropic medication and the frequency of admission to psychiatric hospitals is relatively high in the case of both services, and consequently, they are at a higher risk for forced treatment.

#### Standard 3: Code of ethics

Standard description

The standard indicates that the provider should have a code of ethics, that this should have provisions for the equal treatment of beneficiaries, that the service should be provided in their best interest, and that professional

	ethics should be observed. The provider should also organize staff training sessions on the code of ethics.
Self-assessment	Both services reported full compliance with the standard regarding the content and use of the procedures, as well as staff training.
Comprehensive evaluation: external evaluation, interviews,	The comprehensive evaluation showed that both services have a code of ethics and have carried out staff training in 2020.
document analysis	Both codes of ethics are detailed and comprehensive. In the case of Service 2, the procedure is meant to be used in the larger organization that provides the service (GDSACP) and to contain the elements that are required by the standard. There is no direct evidence that the employees actually know the provisions in the code of ethics, as the requirement indicates.
Observations	Both procedures provide a section regarding the service staff responsibilities in relation to the beneficiaries that stipulates that staff is allowed to limit the beneficiaries' self-determination when the latter's choices contradict the professional ethics or when their present or future actions may endanger themselves or other persons. The procedures do not give any clear examples about such situations, and in the absence of any provisions in the standards regarding clear steps for ensuring the informed consent of beneficiaries, including through provision of decision-making support, there is a risk that beneficiaries' rights could be limited arbitrarily.
Standard 4: Protection aga Standard description	The standard covers minimum requirements that are needed to ensure the beneficiaries' protection against situations of exploitation, violence, and abuse, such as the existence of a specific procedure that is known and applied by service staff; the yearly training of staff on the topic; the obligation of staff to encourage and help beneficiaries identify and report such situations;, and the obligation of the SSPs' to identify, register, and take prompt action should such situations occur.
Self-assessment	Both services reported compliance with most requirements. In the case of Service 1, the specific procedure did not include any provisions regarding the

Comprehensive
evaluation: external
evaluation, interviews,
document analysis

2020.

Document analysis showed that the specific procedures include clear responsibilities of staff and SSPs for identifying and reporting cases of violence, exploitation, and abuse, as well as concrete actions. There are however significant differences between the specific procedures used by the two services to ensure the protection of beneficiaries against exploitation, violence and abuse.

- Only the procedures of Service 1 mention thematic training for beneficiaries, in addition to those for staff, as well as preventive measures such as identifying risk factors regarding situations of violence, exploitation, and abuse in the center, including by administering questionnaires to beneficiaries.
- o Only the procedures of Service 2 state explicitly that beneficiaries can report such situations when these occur, directly to staff or by using the box for complaints on the center premises, as well as aspects related to the administration of medications and management of beneficiaries' assets and money, as required by the standard. The procedure also mentions preventive measures regarding the exploitation of beneficiaries that may occur by involving them in activities related to cleaning, cooking, or other lucrative activities outside the center. However, the measures are limited to obtaining approval for such activities merely from service staff and not also to ensuring that beneficiaries themselves consent to being involved in such activities. According to interview data, beneficiaries in both centers are cleaning in the routinely involved (sometimes 1-2 hours a day), even though services are expected to have cleaning staff responsible for this task.

According to external evaluations, beneficiaries are provided information on how to identify and notify situations of violence, exploitation, and abuse from service staff in an informal manner. Currently, the services are not providing guidelines or other information materials on the topic to staff nor to beneficiaries in

	accessible formats. There is no direct evidence that the employees actually know the provisions of the procedure and apply them accordingly, as the requirement indicates. In fact, at least one of the beneficiaries interviewed reported situations of both physical and sexual abuse he had been exposed to from other beneficiaries, as well as a lack of interest and subsequent measures taken by staff he had notified about the situations.
Observations	The standard does not include a requirement for ensuring the access of beneficiaries to relevant services in the event of such situations, for instance, psychological counseling, shelters, etc. An independent, external mechanism for reporting and reviewing such cases should be made available to the beneficiaries, as well as access to legal and counseling services and advocates.
Standard 5: Protection treatments	against torture, and cruel, inhuman and degrading
Standard description	The standard covers similar requirements as Standard 6, but with regard to situations of torture, and cruel, inhuman, and degrading treatment.
Self-assessment	Both services reported full compliance with the standard regarding the content of the procedure as well as yearly mandatory training for staff regarding the protection against torture, and cruel, inhuman, and degrading treatments. No cases of torture, and cruel, inhuman, and degrading treatments were registered in 2020.
Comprehensive evaluation: external evaluation, interviews, document analysis	Both centers use a similar format and structure for specific procedures required by Standard 4 and Standard 6. Similar results from comprehensive evaluation apply.
Observations	See Standard 4
Standard 6: Assistance in t	the event of death
Standard description	The standard covers minimum requirements the service must comply with regarding the situation of beneficiaries who are terminally ill or have died. The requirements concern the specific procedure related to palliative care and managing situations in the aftermath of a beneficiary's death - informing the family, facilitating

	access to relevant services, and facilitating or organizing the funeral.
Self-assessment	Both services reported full compliance with the standard.
Comprehensive evaluation: external evaluation, interviews, document analysis	Document analysis shows that both procedures comply with the standard requirements regarding the mandatory content. However, the procedure submitted by Service 2 provides a greater level of detail regarding the management of such situations, making specific reference to details about palliative care and signs of near death, as well as other specifics to be taken into account in the aftermath of a beneficiary's death.
Observations	Palliative care as well as communicating with family and friends in the event of the death of a beneficiary requires specific skills in which staff—both medical and non-medical—should be trained. Currently the standard does not include such requirements.
Standard 7: Notifications a	and complaints
Standard description	The standard covers requirements regarding the assurance of service quality by facilitating the beneficiaries' possibility to submit notifications and complaints according to a special procedure that is known and accordingly applied by the service. The procedure also includes aspects about informing the beneficiaries on how to submit notifications and complaints.
Self-assessment	Both services reported full compliance with the standard. No complaints were registered in 2020.
Comprehensive evaluation: external evaluation, interviews, document analysis	The specific procedures that both SSPs submitted for document analysis are rather brief and general and are focused merely on the phases of: (i) informing the beneficiaries on how to submit complaints, and (ii) the process of submitting, registering, and solving the complaints, but do not detail the aspects of service provision on which beneficiaries could submit complaints. In the case of Service 1, the procedure mentions that beneficiaries are provided with the procedure in an accessible format, but the service did not submit this document for evaluation. Beneficiaries can lodge complaints by placing them in writing in a specially designated box on the center premises. Neither procedures provide a timeline for solving the beneficiaries' complaints, nor any specifications

regarding the protection of beneficiaries from retaliation in case the complaint is aimed at a staff member. External evaluations showed that neither service had a list of external mediators to be contacted in critical situations (as required by the standard) a list to which beneficiaries may also have access. Some of the beneficiaries interviewed did have complaints about service provision, either about insufficient food, poor hygiene of bathrooms, or activities from which they would want to benefit but are lacking (psychological counseling, support in accessing education and employment, etc.). This data contradicts the lack of any formal complaints as reported by service staff and raises questions about beneficiaries' knowledge regarding the procedure and the efficiency of making verbal complaints, as well as about the observance of beneficiaries' rights generally by staff. **Observations** Beneficiaries should be provided with the specific procedure on lodging complaints in accessible formats. In addition, the procedure on notifications and complaints should also include more provisions on how to avoid any consequences that may occur in the event of complaints submitted by beneficiaries, verbally or in writing. Standard 8: Beneficiary satisfaction Standard description This standard is meant to assure a mechanism for evaluating beneficiary satisfaction with the service provided. The service is required to apply questionnaires and include their analysis in their annual reports. The beneficiaries can ask for support from staff members, family, or the legal representative in filling out the questionnaires. Self-assessment Services reported full compliance with minimum requirements, with the exception of Service 1, which did not have a box where beneficiaries can place the filledin questionnaires, as required by the standard. In 2020, questionnaires were filled in by 9 beneficiaries of Service 1 and 15 of Service 2. All but two beneficiaries of both services needed support to fill in the questionnaires. Comprehensive The evaluation of procedures submitted by services evaluation: external indicated that the analysis of the satisfaction

evaluation, interviews, document analysis	questionnaires was in fact not included in any of the two annual activity reports.
	External evaluations indicated that the questionnaires are generally not anonymous and staff from Service 1 did not consider anonymity to be necessary. The only complaint the service staff could mention during external evaluations regarded the insufficient quantity of sweets, which again, rather contradicts data from the interviews with beneficiaries that pointed out more points of discontent with service provision.
	Unlike data reported by staff about the administration of satisfaction questionnaires, none of the beneficiaries interviewed did report having filled in satisfaction questionnaires in 2020, which, in addition to the lack of questionnaires in accessible formats and the involvement of staff in the process of filling in the questionnaires, raises the question about the practice of effectively ensuring the beneficiaries' feedback on the quality of service provision.
Observations	It is unclear how questionnaires are administered to beneficiaries in both centers, given that the standard does not include a provision to ensure accessible formats for questionnaires, and that there is no analysis of the results included in the annual activity reports.

#### 2.2.4. Conclusions and recommendations

# Standards compliance and implementation

Minimum requirements covered by the quality standards have been reported by both services evaluated as being followed, with some exceptions; for instance, exceeding the mandatory number of beneficiaries per room, not carrying out some of the mandatory staff training, missing parts of certain procedures, lack of information materials or procedures in accessible formats for beneficiaries, lack of specific activities provided to beneficiaries (psychological counseling in the case of Service 2), absence of analysis of feedback questionnaires administered to beneficiaries from the annual activity reports. However, data from external evaluations of crisis center services, interviews with beneficiaries and analysis of service documents submitted by the two centers indicated some further irregularities in the implementation of standards and suggested several directions for improving the service quality in a way that ensures the choice and autonomy of beneficiaries, furthers their inclusion in the community, and overall ensures the protection of their rights, as follows:

 Standards should ensure that the services are offered for a limited amount of time to maintain their beneficiaries' personal potential and to prevent institutionalization. Beneficiaries from the two services evaluated had either been residing in the center for more than one or two years (Service 1) with few prospects for their reintegration in the community anytime soon, or ended up in the center transitioning from the child special protection system (Service 2) and will most probably be transferred to residential centers, as was the case with other beneficiaries before. Service 1 has rather the profile of a long-term residential center, while Service 2 seems to have the function of a transition space for its beneficiaries toward other residential centers. In both cases, the crisis centers fail to fulfill their function as temporary service for persons in difficult life situations, aimed at preventing their institutionalization. Standards should include a specific period of time for the beneficiaries' stay and forbid recurrent consecutive readmissions as a practice of sidestepping provisions about maximum length of stay.

- o In general, the centers evaluated provide beneficiaries merely with a residence option and less with opportunities for being full participants in community life. The implementation of standards for helping beneficiaries to find alternative services to live in the community is inefficient. While some activities included in the standards are aimed at ensuring beneficiaries with skills and resources for their reintegration in the community (such as support for finding and maintaining employment, psychological counseling, information about alternative and complementary services, etc.), data collected indicated that beneficiaries benefit from little support from the service in this direction. Some beneficiaries want to go to school, find employment, find their own housing in the community, but they seem to not know how to achieve that. In addition, most activities in the centers are not diverse enough and seem to be unstimulating for most beneficiaries-drawing, listening to music, watching TV, spending time in the courtyard, cleaning the center premises—and do not contribute to the realization of the beneficiaries' potential, neither do they enable them to acquire independent living skills for a future life in the community. Most beneficiaries do not have friends or cannot communicate with them because they have no access to phones or phone credit, while opportunities for socialization outside the center are very few.
- o The choice and control of beneficiaries over the service requires ensuring that the beneficiaries are properly informed, involved and have the opportunity to choose between different options. Most beneficiaries had not received information about the service before their admission and very little after their admission. For all beneficiaries, admission to the center seems to have been the only available solution considering the lack of family support or previous residential-type care. Generally, it was their families or local authorities who decided about their admission into the center. This practice is doubled by the attitude that staff has regarding beneficiaries they consider unable to understand and decide for themselves, and consequently unable to be involved in any decision regarding the organization of the service. External evaluations and interviews with beneficiaries showed that staff tends to

treat beneficiaries with paternalism and a dismissive attitude regarding their needs and complaints.

- o The person-centered dimension of service provision must be a priority and should be properly regulated. Beneficiaries seem to have little knowledge about the aspects included in the standards that are meant to ensure that they receive personalized services such as evaluation of their needs, personalized plan, case manager, multidisciplinary team, and they are not being involved in any of the decisions regarding service provision. In fact, in Service 1, all beneficiaries are considered by staff as having no capacity for understanding. Consequently, they are never involved in the evaluation and planning of activities nor are they encouraged to provide any feedback regarding the activities they do receive. This raises the question about the person-centered dimension of service provision, given that beneficiaries have minimal or no contribution to how the service is provided. Standards should include provisions about offering decision-making support to beneficiaries, providing training and materials to staff on decision-making support as well as on how to ensure that beneficiaries are constantly and effectively involved as active partners in all decisions that are taken about the services they receive. Standards should also include mandatory requirements regarding the provision of all existent service materials in accessible formats to beneficiaries.
- Staff training and service provision in a manner that respects beneficiaries' rights and ensure their protection from violence and abuse requires further provisions. While both standards and internal regulations of services requires mandatory staff training on themes regarding the dignity, autonomy, independence and protection of beneficiaries from any forms of mistreatment, it is unclear how these training sessions are being carried out, by whom and with what materials. All procedures that staff must know and adequately apply regarding the beneficiaries' protection against violence, abuse, torture and inhuman treatment, and risk management and complaints, present only in general terms how such situations must be dealt with, and do not include any guidelines on how staff is expected to treat beneficiaries either in the event of such situations or for their prevention. Standards should include additional provisions to ensure that staff receive proper training from specialists in the field, as well as provisions about recurrent assessments of staff performance to show their adequate understanding and application of the training content at all times in relation to beneficiaries.

#### Value and success of the service

The centers evaluated for this report have rather not fulfilled their purpose of preventing institutionalization of their beneficiaries and providing them with tailored services to maintain and develop their personal potential. Even though Service 2 has also been established as a respite center, none of the beneficiaries fit the admission criteria to a respite: they do not have caretakers who are unable to provide care only temporarily. In effect, the profile of the services seems to be rather that of a residential center or of a gateway to residential centers. Standards must be revised

to include clear requirements that will prevent long-term stays and help beneficiaries to find resources for independent living, be it disability-specific services, such as personal assistance, day services, or mobile services, or mainstream services, such as employment, housing, education, and health care.

Respite services must be provided in a variety of ways and contexts to respond to personal contexts of persons with disabilities. The provision of respite services only as a short stay in a residential center may limit the access to respite services for persons who may not able or willing to leave their homes or who may need services in other types of settings. In addition, services must also be designed to enable planned stays as well as emergency interventions. A planned service delivery as well as the setup of regional services may also secure the sustainability of services in terms of staffing, as well as material and financial resources. Standards must be amended to allow a broad-spectrum of respite services to operate - in-home, residential or day services, planned or emergency, formal and informal - in order to prevent institutionalization and facilitate independent living.

# Box 14: Example of various respite services in other countries

Australia: In-home respite, center-based day respite, overnight or weekend respite, community access respite (individual or group activities and events geared to give the client a social experience) are available through community access respite. This could be given throughout the day or at night. Residential Respite Care can be planned or can happen in an emergency. Emergency Respite Care offers a Carer Gateway phone line accessible 24 hours a day, 7 days a week for caregivers who find themselves unable to continue caring for a short period of time. Transition Care focuses on specific therapies for persons who have been in the hospital and are about to be discharged but require additional assistance.

United Kingdom: Day centers are designed to help those who find it difficult to socialize, establish friends, or participate in activities. Day care centers, for example, may include tea dances, singing, games, and arts and crafts. Hairdressing, foot care, and assisted bathing are among the services provided by some. A short stay in a care home, Shared Lives is a national scheme in which a disabled person can spend time at the home of another caregiver while their own caregiver takes a break. Holidays or short breaks offered by some organizations offer specific package vacations for disabled individuals and their caregivers. They include assistance with care responsibilities as well as easily accessible facilities. This allows the caregiver to take a break from their caring duties and spend quality time with the person for whom they are caring for. Carers' emergency replacement care schemes offer replacement care in an emergency.

**Ireland:** Schemes of respite ("Breakaway" or "Friendship" schemes) based in the community (an alternative family for instance) or in an institution. Different locations are providing various degree of respite care around the country. The forms of respite care that are currently available, besides the help from friends and family, are formal in-home respite care, out-of-home respite facilities, and recreation and holiday breaks (as described above).

**Germany:** Independent respite care facilities, nursing homes with respite care beds that are interspersed with other types of beds, and respite care beds on a separate ward.

Sources: Healthdirect Australia (2020), Alzheimer's Society (n.d.), National Health Service UK (n.d.), Citizens Information (n.d.), Kuske et al. (2016: 27-35).

#### 2.3. Home Care Services

This chapter offers a comprehensive evaluation of home care services with regard to compliance with the minimum quality standards provided by the Romanian national legislation. It first introduces the legal and institutional framework that regulates the provision of this service. Secondly, it provides an overview of the services in terms of service and beneficiaries' profile. Thirdly, it offers a comprehensive evaluation of the service in view of its compliance with minimum quality standards and proposes brief recommendations for the improvement of standards to ensure a better quality of service provision that is person-centered and ensures personal autonomy and self-determination.

At international level, home-based care is usually given in the home of the care-dependent person by licensed providers (staff or self-employed). Housekeeping, shopping, getting dressed, bathing, preparing and eating meals, as well as psychological support and assisting with social activities are all examples of home-based care. According to the personnel engaged, different forms of home care services can be classified. 125

- Nurses make up the majority of professional home-care workers. Nurses assess persons receiving home care, create care plans, provide professional nursing, and determine whether additional services are needed. Because of the extensive range of services they provide, home-care assistants (or aides) form the core of the home-care workforce. Their services might include everything from therapy and daily life tasks to food preparation. Home-care assistants are the ones that visit the persons who need help the most and spends the most time with them.
- o Social workers and therapists are two other types of home-care workers. People receiving care and their families can benefit from social workers' assistance in locating and obtaining community resources, overcoming excessive bureaucratic and financial concerns, and understanding social factors that may influence the treatment plan at home. Physical, occupational, and speech therapists analyze therapy needs, establish care and rehabilitation programs, and supervise any assistants performing therapy.

Access to services is critical to the well-being and dignity of those who are in need. Because these services allow persons to remain independent for extended periods of time institutionalization is avoided or postponed. In contrast to residential institutions, which are regulated environments, home care allows individuals to have the most independence possible. Home care is individualized, meaning it is tailored to each person's exact needs. <sup>126</sup> Also, home-based care is considered to be a more cost-effective

<sup>&</sup>lt;sup>124</sup> European Commission (2020).

<sup>&</sup>lt;sup>125</sup> Tarricone, R., Tsouros, A. D. (Eds.) (2008).

<sup>126</sup> Idem.

solution than institutionalized care, giving better care outcomes for beneficiaries and, most significantly, reflecting people's preference for home-based care. 127

The availability of formal home-based care is determined by the number and types of services provided, the cost and quality of those services, and their intensity. If formal home-based long-term care is insufficient in any of these areas, individuals and families must seek alternative care, such as institutionalized care (such as hospitals, mental health care facilities, or orphanages) or informal care provided by family, friends, neighbors, or other individuals. In addition to formal home-based care services, independent living may necessitate access to the built environment, accessible transportation, technical assistance, information and communication, as well as life and employment coaching and access to other community-based services. 128

Organizing a network of services may also be more difficult than administering a facility like a nursing home. Last but not least, there are rising concerns that there may be a major global shortage of home workers (especially for home-care assistants). The present transnational migration phenomena are contributing to a drain of the young active workforce in eastern European countries that export labor, as well as a potential care shortfall for these countries' older generations. 129

The emerging need for home care in Europe is emphasized by several factors like the demographic shifts of ageing population and changing dependency ratios; social change to small family units, female labor market participation, and mobility across countries; and changes in epidemiology. For instance, some conditions, such as Alzheimer's and dementia, are growing more common as the population ages; and diabetes, heart disease, respiratory disease, stroke, and cancer affect an increasing number of people. Science and technical innovation, such as medical science advances, medical and nonmedical technology advances, changes in attitudes and expectations, and policy priorities and choices toward deinstitutionalization and community-based solutions, and constraints on public expenditure all affect the need for home-based care. 130

#### 2.3.1. Legal and institutional framework

The Home-care Service in Romania is defined by the Service Standards<sup>131</sup> as a type of social service that offers assistance and care at eligible beneficiaries' home, for a limited amount of time, with the purpose of helping beneficiaries overcome a difficult situation and prevent institutionalization. The service is aimed at adults with disabilities of all types and degrees and can offer a maximum of 40 hours a week (8

<sup>&</sup>lt;sup>127</sup> European Commission (2020).

<sup>&</sup>lt;sup>128</sup> European Commission (2020).

<sup>&</sup>lt;sup>129</sup> Tarricone, R., Tsouros, A. D. (Eds.) (2008).

<sup>130</sup> Idem

<sup>&</sup>lt;sup>131</sup> Order no. 82/2019, Annex 4.

hours for 5 days a week) of service. The service can be offered by both private and public providers.

There is need for home care-services at community level, but they are seriously undeveloped nationally. The number of two home-care services remained constant from 2013, while the number of beneficiaries increased from 34 in 2013 to 88 in 2020. The insufficient supply of home-care services is partly due to both the expectation that local authorities should develop them and the inertia of a system that was built around residential centers as the main type of service for adults with disabilities. Only a handful of services are functioning in the country, although similar service aimed at older adults seems to be much better developed. 133

Home-care services can be very valuable in preventing institutionalization and improving the quality of life for persons with disabilities. The new National strategy regarding persons with disabilities 2022-2027 has included in one of its specific objectives extending home-care services, as a core part of the strategy of preventing institutionalization. The service is meant to be one of a larger array of community services made possible by the legislation and the institutional framework, which involves local authorities as well as national institutions (NARPDCA in particular).

## 2.3.2. Description of services

#### Service profile

Despite the need, there are 11 providers of home care services (both public and private) supporting less than 400 beneficiaries. As of May 2021, there are only two public providers offering home-care services in Romania, serving 78 beneficiaries. These providers offer services exclusively in urban areas (Craiova and Bucharest), although both service representatives have indicated that the need exceeds their capacity, both locally and regionally. Both services are organized under the subordination of the county GDSACP, which means that they are dependent both financially and institutionally on the larger institution.

The two public home-care services in existence have dramatically different profiles. One of the services (Service 1) is larger, is a licensed service provider, and functions as a self-standing center within the larger GDSACP. It offers home-care services to 70 beneficiaries and employs 45 care workers. The second service (Service 2) is smaller, not licensed as home care service, 136 and functions as a branch of a residential center

<sup>&</sup>lt;sup>132</sup> According to NARPDCA data.

<sup>133</sup> World Bank (2021: 222).

<sup>134</sup> Idem

<sup>&</sup>lt;sup>135</sup> Decision no. 865/2015, which adopts the official classification list for all social services in Romania. Home care services are listed as "Homecare Units" under the code 8810ID-I.

<sup>&</sup>lt;sup>136</sup> At the time of data collection, the service was in the process of obtaining a license to operate as a home-care service for adults with disabilities.

for the elderly, serving only 8 beneficiaries at the moment, with only 3 care workers <sup>137</sup> (see Table 12). There are also 9 private providers of home-care services supporting about 300 persons with disabilities.

Table 12. Public home-care services at a glance, in 2020

Table 12. Public nome-care service	Service 1	Service 2
Location	Craiova (Dolj	Bucharest
	country)	200.10.000
Area served	Urban only	Urban only
Number of beneficiaries	70	8
(current)		
Total people served in 2020	86	14
Total people served in 2019	81	15
Frequency of service per	Five times a	Three times a week
beneficiary	week	
Average duration of treatment	120 days	153 days
per beneficiary in 2020		
Number of specialized staff	Service	Service coordinator, plus 8
	coordinator,	specialized staff members:
	plus 74	- 3 care workers
	specialized	- 4 social assistant
	staff members:	- 1 psychologist
	- 45 care	
	workers	
	- 1 physician	
	- 1 psychologist	
Number of vacancies	1 psychologist	7 care workers
	15 care workers	
Services offered	Home-care	Home-care services: personal
	services:	care and hygiene, social
	personal care	assistance and information,
	and hygiene,	light housework and
	social	shopping, assistance with
	assistance and	meal preparation, assistance
	information,	with accessing other services
	light housework	(in particular medical
	and shopping,	services), assistance keeping
	assistance with	in touch with friends and
	meal	relatives.
	preparation,	
	assistance with	
	accessing other	

<sup>&</sup>lt;sup>137</sup> The service coordinator indicated that they have difficulties in hiring workers, as the salaries are too low.

	services (in	
	particular	
	medical	
	services).	
Equipment owned	None	None

Source: World Bank survey of home care services (2021).

One of the two services is not aimed only at persons with disabilities, but also at elderly people requiring home-care services. This profile has implications for some of the processes and practices within the service: admission is not conditioned by having a disability certificate, the initial evaluation is specific to elderly people (using a so-called "geriatric form" and not the form required by the standard), and some of the needs that should be attended to are seen by the service staff and coordinator as not appropriate for their beneficiaries (education, entertainment, employment-related services).

Both services have at the core of their mission preventing institutionalization. They both see their work as essential for maintaining their beneficiaries in their homes and, as much as possible, in the family environment—without this assistance they would all be in danger of being moved to a residential center. Their relationship to residential centers is therefore complicated: one of the services is actually a service within a residential center for the elderly and is meant to delay as long as possible admission to a center, and the other service sees itself as having nothing in common with residential centers (which are part of the same GDSACP).

Although home care was designed to be a comprehensive suite of services, both beneficiaries and providers regard it more as a housework and personal care service. The expectations for community integration, information, and social assistance are rather limited both for providers and beneficiaries. According to interviews with service coordinators and beneficiaries, one explanation might be that staff primarily interacting with beneficiaries is made up of care workers, who might go out of their way to help the people with whom they work but within the limits of helping beneficiaries live independently in their homes. Another explanation might be that most of the beneficiaries are over 65 and they see themselves as having limited needs in social, educational, and cultural areas, and even if they express having these types of needs, they do not expect any assistance from the home-care service in addressing them. However, staff has supported beneficiaries in order to get to medical appointments and access benefits to which they were entitled but had difficulties obtaining (because of mobility issues and extensive paperwork).

#### Institutional context

The shortage of public home-care services providers seems to emerge through a combination of lack of funding, passing the responsibility of developing community

services from one public institution to another, <sup>138</sup> and expecting local civic society to make up for the inadequacies of the local public services. From interviews with directors of GDSACPs, it became clear that they are required to assume an unreasonably high share of the financial and organizational burden of providing community services. They also stated that many times local administrations turn to them to address community needs that could be addressed through local budgets and services. Residential centers were privileged in the allocation of funds, probably because of the institutional history (such centers already existed and needed funds to continue) and because they were seen as addressing more acute needs (people needing close and constant assistance). Without adopting a clear deinstitutionalization strategy of preventing institutionalization developing new community services like home-care services—no matter how much needed—cannot even be imagined, let alone pursued.

Even where private providers are interested in offering home-care services, confusion about standards, requirements, and their application makes them give up and reorganize the service under different types of services and standards. For example, a large service provider NGO working with several types of beneficiaries (persons with disabilities included) and who has an extensive network of services in several counties, indicated that it was not able to license its services as official home-care for persons with disabilities because it could not assure the presence of a psychologist or speech therapist in their team (which covers large rural areas). In fact, the standard does not require this. In the end, the NGO licensed their service as a medical service.

Adequate public home-care services for persons with disabilities depend on a strong public institution (GDSACP) committed to developing and improving its community services. The large public home-care service (Service 1) is one among a larger portfolio of community services offered by the GDSACP. This GDSACP is juggling its wider strategy of deinstitutionalization with funding opportunities that sometimes push investments and projects in random directions. Its wider strategy is to explicitly prevent institutionalization as much as possible through an extensive offer of community services (it offers, for example, one of the two mobile teams in the country) and restructure the large residential institutions it administers as an intermediary step towards community living.

#### Beneficiary profile

Beneficiaries of public home-care services tend to be older. In 2020, more than 90 percent of beneficiaries of the two home-care services were over 60 years old. This age profile has significant consequences not only regarding the needs of beneficiaries, but also for their vulnerabilities, perception of their status, experiences, and sense of self. According to the UN Special Rapporteur on the Rights of Persons with Disabilities, older

<sup>&</sup>lt;sup>138</sup> GDSACP, local administration and their respective Public Services for Social Assistance.

persons with disabilities tend to go unnoticed in services and in policies aimed at persons with disabilities, and older people, as their specific needs and vulnerabilities are less documented, present in public discourse, or included in the social protection policy. They are more likely to face discrimination, lose legal capacity, and be institutionalized. They also are at higher risk of facing chronic diseases and having unmet medical needs. Older women with disabilities (about 75 percent of beneficiaries of these services are women) tend to be more at risk for poverty and abuse. <sup>139</sup> Public service providers recognize to some degree the specific needs of their beneficiaries and try to be proactive in addressing them. For example, as beneficiaries are also relatively poor, staff have made efforts to help them access assistive technologies that they could not afford. Staff also recognize the fact that for many the situation is very unlikely to improve, so they are actively trying to prevent reaching the point of institutionalization. Some beneficiaries, especially the older ones, have lost their entire social worlds, as many of their friends have died, so their care workers are helping them keep in touch with the friends and relatives that are still alive.

All beneficiaries have been evaluated as being between two levels of needs and assistance: they need assistance for everyday living activities such as personal care, housework, going out, or shopping but they are neither entirely dependent on somebody else, nor require constant attention and assistance. None of the beneficiaries have severe medical needs (if they do, the service is either terminated or suspended) and they can manage several days a week without assistance (even if they receive home care five days a week, they have to make do at least two days a week). Beneficiaries tend to be extremely attached to their homes and their living situations, and some of them have expressed concern about reaching the point where they would have to be institutionalized because they cannot receive the amount of assistance and care they need in their homes. Although the service is meant to be offered for a determined amount of time, beneficiaries would like to prolong the term indefinitely—many have used the service for more than five years.

The beneficiary profiles for the two services are quite different in terms of living arrangements and disability status and degree. For Service 1, more than half of the beneficiaries have physical disabilities, all but one live with their families, and the majority have certified high or severe degrees of disability. Beneficiaries of Service 2 are, on the other hand, all living independently and most do not have a certified disability, although their needs in term of the home-care service are fairly similar to those of persons with disabilities. The Service 2 beneficiaries are at high risk of institutionalization in the event their situation degrades to the point at which the respective service provider assesses them as not eligible for the home care. This risk is

<sup>&</sup>lt;sup>139</sup> UN General Assembly (2019).

compounded by the fact that the service provider lacks staff and they can offer the service at most three times a week.

Most beneficiaries experience isolation, which has been accentuated by the pandemic restrictions. Isolation is more severe if the disability was acquired later in life (generating shame and self-consciousness on the part of the beneficiaries) or if the person is old and has lost most friends and family (which makes them less interested in meeting new people and socializing). Furthermore, beneficiaries' age and disability make it difficult for them to access information, services, and such opportunities as support groups if these require digital or online access or communication. More effort should be put into making these technologies more accessible to them or mediating access to these services and support groups.

Although none of the beneficiaries have lost their legal capacity, some are not consulted or included in making decisions about the service they are entitled to receive. Instead, the person they have designated to represent them in legal and administrative matters is the one consulted. The situation is normalized in the case of Service 1 and not questioned by staff or beneficiaries.

#### 2.3.3. Standards compliance and implementation analysis

This section presents a detailed evaluation of the compliance with the minimum requirements as defined in the standards, using both service's self-evaluation and information gained from the external evaluation, interviews with a service coordinator and four beneficiaries, and analysis of the documents offered by the services.

## Module 1. Social Service Management

The first module ensures compliance with relevant laws and regulations regarding the organization and management of services, more precisely founding the service, hiring and maintaining qualified staff, offering the service to particular kinds of beneficiaries, maintaining the proper internal administrative paperwork, and establishing relevant partnerships in the community.

#### Standard 1: Organization and functioning

Standard
description

The standard details the general conditions for organizing the service and managing it, encouraging partnerships with other entities, offering training for the personnel in areas like equality, preventing negligence, violence, and abuse, facilitating an independent life for the beneficiary, etc. The standards also indicate the minimum necessary documentation. Moreover, the standard stipulates who can benefit from the service and what the minimum capacity for the service should be (40 hours a week for a minimum of 4 beneficiaries). It indicates that, under well-founded circumstances, a beneficiary can receive the maximum of service, that is, eight hours a day for five working days a week.

Self-assessment	According to the self-assessment, most of the minimum standards are met. For one of the services, however, there is no valid license and no annual report—the explanation was that "it does not apply." The situation is unclear, as the service is not a self-standing one, but a part of a larger, residential center for the elderly.
Comprehensive evaluation: external evaluation, interviews, document analysis	The external evaluation and the documents submitted have revealed that, in fact, some of the standards are not met, in particular those referring to the special training that the personnel should receive (on equal rights, diversity, supporting an independent life for the beneficiary, etc.). For one of the services, the training is done "internally" and there was no documentation to attest to the training done. For the other service, it seems that the larger institution (GDSACP—the social service at the county level) is fairly organized and offers frequent training sessions for the personnel, taught by internal and external staff. The annual report does not contain all the required information (it is limited to activities and the number of the beneficiaries, but nothing in relation the standards, improving quality, feedback from the beneficiaries, and so on. One of the services has had a collaboration with other NGOs in offering other kinds of services to their beneficiaries (psychological counseling, medical services).
Observations	Although not present in the minimum requirements, both services indicated that having an accessible vehicle that could be used for transporting beneficiaries (in particular to medical appointments) would be really valuable. None of the services have such a vehicle, but in some cases they can gain access to one from other services from the larger institution.
	Also, it is interesting to note that in the case of the providers, the service is offered at the maximum intensity (8 hours a day, 5 days a week), for a number of the beneficiaries (10 at the moment).

## Module 2. Accessing the social service

Module 2 offers a framework for accessing the service, from informing potential beneficiaries about the service and enrolling them, to managing their information and final termination of service. The module standards and requirements place special emphasis on the administrative paperwork that is related to these processes, and in particular its transparency and compliance with the law.

**Standard 1: Information** 

Standard description	The standard is meant to assure a full and adapted access to information about the service to interested persons with disabilities who could benefit from the service. It requires that materials are published and that they comply with particular requirements. No provisions are made as to how the materials are to be distributed to those who are interested.
Self-assessment	According to the self-assessment, most minimum requirements are met, with the exception of offering the information in an adapted form. In the case of one of the services, the information is not expressed in a simple and clear form.
Comprehensive evaluation: external evaluation, interviews, document analysis	The two services did not provide samples of their informational materials, therefore they cannot be assessed. According with the external evaluation and the interviews, all requirements are met, except those related to adapting the materials in an accessible form.
Standard 2: Admis	sion
Standard description	The standard details the requirements for admission, in particular informing and involving the beneficiary and the legal representative in the process, the contents of the admission file, the procedure, and using a contract. The procedure should have a number of required elements.
Self-assessment	According to the self-assessment, most requirements are met. One of the services did not include in the contract form the special provisions for beneficiaries who have a personal assistant or a processional personal assistant.
Comprehensive evaluation: external evaluation, interviews, document analysis	According to the comprehensive evaluation, the minimum requirements are also met.
Observations	Some of the beneficiaries have complained that gathering all the materials necessary for admission can be tedious and can take a long time, especially for those who have mobility issues and no support. Once they were accepted, the procedure was smooth and without any problems. One of the services even makes special efforts for matching the beneficiary with the most appropriate

	staff—the two meet when the contract is signed, so the match can be accepted by the beneficiary.
	For one of the services, it was indicated that if a potential beneficiary is evaluated as having needs that cannot be addressed through the service (for example, continuous supervision or special medical needs), the beneficiary is not admitted.
Standard 3: Benefi	ciary's personal file
Standard description	All beneficiaries should have a personal file. The standard details the conditions under which it can be consulted by various people.
Self-assessment	The two services respect the minimum requirements for the standard.
Comprehensive evaluation: external evaluation, interviews, document analysis	According to the comprehensive evaluation, the requirements are met.
Observations	None of the beneficiaries have ever asked to see their files.
Standard 4: Service	e termination
Standard description	The standard stipulates that terminating the contract must be done in conditions of transparency and in three forms: unilaterally (by the service provider), through mutual agreement, and at the beneficiary's request.
Self-assessment	All minimum requirements are met.
Comprehensive evaluation: external evaluation, interviews, document analysis	All minimum requirements are met.
Observations	The service was terminated in 2020 as follows: for Service 1, nine contracts at the request of the beneficiary, nine contracts at the recommendation of the service coordinator.
	The service is suspended during the beneficiary's hospitalization, when the beneficiary travels, or when the beneficiary has COVID (in order to protect the staff). Interviews have revealed that, in

1	6	1
1	u	1

Ī	some cases, the care worker continues to assist the beneficiary
	who is in the hospital even if the service is officially suspended
	(bringing food and clean clothes, running errands, etc.).

# Module 3. Evaluation and planning

The third module ensures the fact that the service is constantly provided in accordance with beneficiaries' needs, through proper evaluation and monitoring and a personalized plan. The requirements focus on procedures as well as on the resulting documentation.

## **Standard 1: Evaluation**

Standard description	The standard details the requirements for the procedure of evaluation (what is to be evaluated, how, by whom, and by what documentation). There is a separate requirement that the beneficiary is involved in the process.
Self-assessment	Most of the minimum requirements are respected according to the self-assessment form, with some exceptions:  O Not all beneficiaries are involved in the evaluation process, due to "severe functional deficiencies." Instead, the service has indicated that the legal representative is involved.  For one of the services, the evaluation fiche does not include the date of the next evaluation.
Comprehensive evaluation: external evaluation, interviews, document analysis	The analysis of the information revealed that there was a confusion as to what "legal representative" means: although the standards clearly refer to the situation when the beneficiary has lost legal capacity, the service uses the term to refer to the person delegated to represent the beneficiary in legal and administrative matters, and involves the representative in all matters regarding the service instead of the beneficiary.
Observations	For Service 2, the evaluation process involves a document called a "geriatric form", which is specifically designed to assess the elderly and not persons with disabilities.

# Standard 2: Personalized plan

Standard description	All beneficiaries should have a Personalized Plan that is the result of the comprehensive evaluation. The standard indicates the content of the plan and that the beneficiary should be involved in elaborating or updating it.
Self-assessment	According to the self-assessment form, all minimum requirements are met, with one exception: for one of the services, there is no mention of how the family will be involved.
Comprehensive evaluation:	Most of the information in the self-assessment is confirmed, with some exceptions:

external evaluation, interviews, document analysis	<ul> <li>There are problems with involving the beneficiaries in devising the Personalized Plan, by including their wishes, opinions, and expressed needs. One service provider indicated that, if the beneficiary signs the Personalized Plan, this means that he/she has agreed to it and his/her opinion is obviously included in the plan.</li> <li>One of the services uses a different form and approach than the Personalized Plan. Instead, it uses an Individual Plan for Care and Assistance, focusing primarily on the care and assistance needs of the beneficiary, following the model of a care and assistance service.</li> </ul>
Standard 3: Monito	pring
Standard	The standard lays out what the minimum requirements are in
description	terms of monitoring the actual implementation of the services indicated in the Personalized Plan, as well as the required documentation. No provisions are made to include the beneficiaries.
Self-assessment	All minimum requirements are met according to the self-assessment forms.
Comprehensive evaluation: external evaluation,	The external evaluation has revealed that for one of the services, there is no case manager and some of the minimum requirements (which include the involvement of responsibilities of a case manager) cannot be met.
interviews, document analysis	For the other service, the situation is more favorable than the standard—the monitoring visits happen more often and include open discussions with the beneficiaries, which has contributed to building trust in the service team.

#### Module 4. Services and activities

Module 4 indicates the standards and the minimum requirements for the specific activities that the services have to provide regarding home-care service, information and social counseling/social assistance, personal care, feeding and hydration, and social and civic integration and participation. These services and activities constitute the core of the service provision.

Standard 1: Information and social counseling/social assistance

Standard description	The service provider is required, through this standard, to offer a wide array of services and activities related to accessing mainstream and specialized services in the community: information and support in accessing the service, mediation in the relationship to other entities (administration, employers, etc.), support with integration in social networks, and support for social and cultural activities. The service has to be offered by a social assistant, part of the provider's staff.	
Self-assessment	According to the self-assessment, the minimum requirements are met. It is important to note that the list of the services that can be offered is optional ("if it is the case"), and therefore, some of the services in the list are not offered or are indicated as "not applying" to the situation by one or both of the providers. Among these:	
	<ul> <li>Information and support for adapting the home environment;</li> <li>Information and support for employment and the workplace;</li> <li>Information about support networks; and</li> <li>Information and support about participating in cultural, sports, leisure events.</li> <li>Some of the requirements cannot be directly verified (for example, the respect that the staff shows to the beneficiaries).</li> </ul>	
Comprehensive evaluation: external evaluation, interviews, document analysis	The information in the self-assessment is confirmed.	
Observations	The data collected through the external evaluation indicate that the information and social assistance activities within the service are considered irrelevant and are not directly applicable to the beneficiaries of this service who are seen as elderly, passive and in situations that cannot be improved. Despite their different profiles and life situations, beneficiaries are seen as being in need of care and assistance and not much else, except perhaps	

	specialized medical services. Some of the beneficiaries have indicated that they would like to receive more support in getting out and participating in events. Some have admitted that the pandemic situation makes it very difficult.
	The interviews with the beneficiaries have revealed that the staff treats them respectfully and is concerned about their wellbeing.
Standard 2: Person	nal care
Standard description	This standard refers to all the personal care activities that are aimed at assisting beneficiaries in maintaining their functional activities. It includes provisions for the types of activities that can be performed, the staff conduit, how the activities should be organized and documented, and the type of training that the staff should receive.
Self-assessment	All requirements are met according to the self-assessment done by the two providers, but not all the activities offered as options in the standards are offered by the service staff. The explanation is that the beneficiaries do not have a need for some of them.
Comprehensive evaluation: external evaluation, interviews, document analysis	This information is confirmed, with some additional explanations. They insisted that they do not offer medical services and do not have the qualifications to do so. Therefore, their service is limited to the support offered to beneficiaries in following the treatment prescribed by their medical providers, in particular, reminding them to take the medication.
Standard 3: Feeding	ng and hydration
Standard description	The standard contains requirements related to activities that ensure that the beneficiaries receive the needed assistance in preparing and eating meals.
Self-assessment	All requirements are met according to the self-assessment. As in the case of the previous requirements, not all the possible activities are offered, with the explanation "it is not the case."
Comprehensive evaluation: external evaluation, interviews, document analysis	Contrary to expectations, for one of the providers, the "support for feeding and hydration" activity was indicated as not being included in the staff's job description.

Standard 4: Social and civic integration and participation

Standard description	The fourth standard in the module indicates the activities and services aimed at ensuring the beneficiaries' participation in the life of the community. Besides procedural requirements, it lists a series of possible forms of assistance and support related to participating in cultural, sports, and leisure activities, as well as in using public transportation, voting, and participating in family events.
Self-assessment	The general requirements are met, but the list of services offered is rather short—for several of the possible activities, the service providers indicated that "it is not the case": activities in the community, cultural and sports events, accompanying beneficiaries at family events, and hobbies.
Comprehensive evaluation: external evaluation, interviews, document analysis	In addition to the conclusions of the self-assessment, the rest of the evaluation has revealed that neither the service provider nor the beneficiaries have the expectation that these kinds of activities be included in the services offered by the provider. The beneficiaries have indicated needs, but they feel that they themselves should be responsible for these activities, and some succeed. They feel that if these kinds of activities are not provided, it is just due to external causes or their own situation of disability or old age.

# Module 5. Protection and rights

The final module combines standards that refer to the beneficiaries' rights, their protection, questions of ethics, risk management, mechanisms for complaints, and also for measuring the beneficiaries' satisfaction.

Standard 1: Respecting beneficiaries' rights

Standard description	The standard comprises two requirements, of which only one is a verifiable requirement (the other one is a list of the rights beneficiaries have): that the service provider organizes staff training sessions about the beneficiaries' rights. Among the rights listed, there are provisions for respecting the beneficiary's dignity and privacy, as well as including the beneficiaries in making decisions about the service provision.
Self-assessment	According to the self-assessment, the service provider has organized 3 and 12, respectively, training sessions with the personnel about respecting the beneficiaries' rights.
Comprehensive evaluation:	The services did not provide documents that could attest that the training sessions took place (the training sessions that were

external evaluation, interviews, document analysis	documented were informational sessions about local laws and regulations). For one of the services, the beneficiaries indicated that they are constantly informed about their rights, and that they do not feel as if their rights are not respected by the service staff. However, from their declarations, it can be inferred that when they are mentioning rights about which they are informed, they are referring only to the legal and administrative rights they have in relation to other institutions.
Observations	Currently, standards do not stipulate the obligation of providing training to beneficiaries regarding their rights or information in accessible formats, nor about ongoing effective feedback and complaint mechanisms that can ensure access to prompt solutions and remedies. The standard does not include any requirement about ensuring that staff knows and respects beneficiaries' rights, such as recurrent evaluations of staff performance to assess their understanding and application at all times of the training content in relation with beneficiaries. There are also no specifications regarding the type of material used and the persons providing the mandatory trainings.
Standard 2: Risk m	anagement
Standard description	The standard enumerates what the risk management procedure should contain as well as the needed documentation in cases that required emergency intervention.
Self-assessment	All but one requirement in the standards are respected according to the self-assessment (for one of the service providers, the intervention in the risk situation is not included in the beneficiary's file).
Comprehensive evaluation: external evaluation, interviews, document analysis	Only one of the management procedures actually describes the risk situations that can occur, how to recognize a situation of crisis or risk, how the staff should act, and how they should follow up. The other procedure includes only contextual information (about laws, internal organization and procedures), but provides almost no information about risk situations and how to effectively manage them. Both procedures include a lot of additional, non-operational information that tends to bury the information that is actually useful in a situation of crisis or risk. In addition, one of the procedures considered is, in fact, for another service provided by the same provider, which means that the risk situations specific to home-care have not been taken into account.

Observations	The standard does not include any clear provision about training or other ways to provide such information on risk management to either service staff or beneficiaries.	
Standard 3: Code of	of ethics	
Standard description	The standard indicates that the provider should have a code of ethics, that this should have provisions for the equal treatment of beneficiaries, that the service should be provided in their best interest, and that professional ethics should be observed. The provider should also organize staff training sessions on the code of ethics.	
Self-assessment	According to the self-assessment form, the requirements are met by both services.	
Comprehensive evaluation: external evaluation, interviews, document	Both Codes of ethics are detailed and comprehensive—they are meant to be used in the larger organization that provides the service (GDSACP) and contain the elements that are required by the standard. One of the providers did not organize annual training sessions about the code of ethics in 2020, and stated that employees are instructed about the code when they are hired.	
analysis	There is no direct evidence that the employees actually know the provisions in the code of ethics, as the requirement indicates.	
Standard 4: Protect	ction against negligence, exploitation, violence, and abuse	
Standard description	The standard stipulates minimum requirements for assuring the beneficiaries' protection against situations of exploitation, violence, and abuse, such as the existence of a specific procedure that is known and applied by service staff, the annual training of staff on the topic, the obligation of staff to encourage and support beneficiaries to identify and report such situations, and the obligation of the SSPs' to identify, register, and take prompt action should such situations occur.	
Self-assessment	According to the self-assessment, all requirements in the standard are respected. The providers have indicated that they have organized three and four training sessions with the staff, respectively. The services reported that there were no cases of negligence or abuse in 2020.	
Comprehensive evaluation: external evaluation, interviews,	For one of the two providers, one of the procedures is very detailed and clearly offers information on what the situations of negligence, exploitation, violence, and abuse are; how to recognize them; and what the service staff should do in the event of encountering such a situation. The other procedure is mostly official information about laws and terms, some procedural	

document analysis	details related to internal organization and responsibilities, and close to no information about actual situations, how to recognize them, and how to act.
	One of the service providers has documentation of the staff being informed about the procedure, but not necessarily trained. This provider, however, has mentioned that the larger institution (GDSACP) has an extensive training program that uses internal experts to train all staff members, for other services, as well. The first provider indicated that they hold internal informational sessions and internal discussions on these issues with staff.
	None of the procedures contains details/provisions about administering medication, as the standard requires.
	There is no objective way to know from the documentation if the staff knows the procedure.
Observations	To ensure adequate protection from violence and abuse standards must include clear provisions on:
	<ul> <li>How services are expected to encourage and support beneficiaries to identify and notify situations of violence, exploitation, and abuse;</li> <li>Informing beneficiaries on how to identify and report situations of abuse, as well as ensuring protection from possible retaliation from perpetrators in case these are service staff or beneficiaries;</li> <li>Ensuring that beneficiaries are treated only with their informed consent and avoiding nonconsensual practices, such as involuntary administration of medication or physical restraints;</li> <li>Ensuring access of beneficiaries to such relevant services as psychological counseling or shelters, in the event of such situations;</li> <li>Ensuring access of beneficiaries to an independent, external mechanism for reporting and reviewing such cases, as well legal and counseling services and advocates.</li> </ul>
Standard 5: Protect Standard description	The standard indicates minimum requirements for assuring the protection against torture and cruel, inhuman, or degrading treatment: what the procedure should contain, how it should be applied, the resulting documentation, and that the staff should receive training in this matter.
Self-assessment	According to the self-assessment, all requirements are met, including the training sessions with personnel.

Comprehensive evaluation: external evaluation, interviews, document analysis	The procedures from both providers are vague about the situations of torture and cruel, inhuman, or degrading treatment: it does not contain information on what they are and how to recognize them, only information on the procedures that should be followed in case such a situation arises. Both procedures look more like a legal document than an operational procedure that can help the staff and the beneficiaries.
	As in the previous procedure for protection against negligence, exploitation, violence and abuse, only one provider appears to have organized actual training sessions, the other using only internal communication. There is no way to tell how much of the procedure is known by the staff, as the standard requires.
Observations	See Standard 4
Standard 6: Compl	aints
Standard description	The standard indicates that there should be a procedure for registering and solving beneficiary complaints, what the procedure should contain at the minimum, and some other requirements regarding documentation and archiving, as well as the possibility of using external mediation at the request of the service (not the beneficiary).
Self-assessment	According to the self-assessment, all requirements are met. In 2020 there was one complaint and it was successfully solved.
Comprehensive evaluation: external evaluation, interviews, document analysis	The procedure is very detailed and indicates the steps that a beneficiary should take in order to file a complaint. Although the requirement is respected, the actual procedure is almost impossible to follow. The beneficiary has to file a complaint in writing and send it electronically or through mail to the main office of the GDSACP, indicating identity details, including the exact address, what happened, and proof that it happened. The rest of the procedure indicates how the complaint will be handled internally.
	The other procedure is vaguer, but allows verbal complaints to be filed by staff in a special register. The staff also has the obligation of informing the beneficiaries how they can file a complaint.
Observations	There are no provisions in any of the procedures regarding how beneficiaries are protected in case they decide to file a complaint against one of the staff members.
_	Analyzing the procedures, it is quite unlikely that the beneficiaries will file a complaint, unless somebody else (maybe a member of the family or the personal assistant) will put in the

	effort on their behalf. The procedures are complicated and restrictive and are not designed actually taking into account the involvement of the beneficiary.	
Standard 7: Benefi	ciary satisfaction	
Standard description	This standard is meant to assure a mechanism for evaluating beneficiary satisfaction with the service provided. The SSP/mobile teams should apply questionnaires and include their analysis in their annual reports. The beneficiaries can ask for support from staff members, family, or the legal representative in filling out the questionnaires.	
Self-assessment	The requirements are not met, according to the self-assessment. One of the providers does not apply satisfaction questionnaires, and the other one does not include the results in the annual report.	
Comprehensive evaluation: external evaluation, interviews, document analysis	The comprehensive evaluation confirmed most of the information in the self-assessment (a general mention of the questionnaires was included in the annual report).	
	The questionnaire is not anonymous and requires filling out the full name of the beneficiary, which raises questions about the possibility for the beneficiaries to express their opinions openly and freely about the service. For the one service that applied questionnaires, the only request on the part of the beneficiaries was to extend the service over the weekend.	
	In the case of the provider that does not apply such satisfaction questionnaires, the coordinator indicated that they do not use them because they know the beneficiaries will not fill them in the elderly do not want to take responsibility for filling in a questionnaire because they are afraid of what might happen to them, possibly even their exclusion from the service.	
Observations	The provider that does not apply such satisfaction questionnaires did not see the situation (the beneficiaries' refusal to fill them in for fear of repercussions) as a problem that needs to be resolved in their relationship with the beneficiaries. This shows the trust that the beneficiaries have in the system and the situation of dependence and necessity that leaves them feeling vulnerable.	

## 2.3.4. Conclusions and recommendations

# Standards compliance and implementation

Most of the minimum requirements in the standards are followed, with some issues remaining regarding staff training in areas required by the standards and beneficiaries'

Several issues are worth mentioning and taking into account:

- Service 1 has invested more in training staff through organization-wide programs (at the level of GDSACP), involving staff from different types of services. The content of the training sessions can be updated and tailored to respond to the minimum requirements in the standards. Moreover, there is a need for an evaluation system to ensure that staff know the content of the requirements and procedures on which they have been trained, rather than just signing an attendance sheet or acknowledging that they were informed about these kinds of information. The practice of trans-service training and collaboration has potential and should be explored further (possibly extended as a model of best practice).
- Service 2 has a limited training program that works through informal discussions and briefings. This situation can certainly be improved.
- Several problems arise from the profile of current beneficiaries and the way that they are conceptualized by service providers. Beneficiaries are seen as relatively passive and in need of protection, not likely to improve (in particular the older ones), and having needs that are mainly about personal care, housework, and accessing medical services. More of beneficiaries' social, cultural, and political needs should be included in their Personalized Plans and more of these needs should be addressed in the service delivery. Beneficiaries have expressed having these needs, 140 but strangely they do not expect the service to be able to help with addressing them.
- Seeing beneficiaries as active partners in planning and delivering the service seems to be limited in some cases. One of the services does not use satisfaction questionnaires (or other forms of systematic feedback) out of the belief that the beneficiaries will not be interested in completing them and expressing their honest opinions. In some cases, beneficiaries are deliberately not included in the process of service planning and delivery, and instead, it is the person who the beneficiary has designated as the legal representative who is included. This practice seems to be a misunderstanding of the term "legal representative" used in the standards, which refers to a court-appointed legal representative and not a person delegated to sign legal and administrative papers on the behalf of the beneficiary.
- Most of the procedures are expressed in legal and formal terms with little regard to actual practical situations. Information about the question at hand (abuse, neglect,

<sup>&</sup>lt;sup>140</sup> For example, one beneficiary is very interested in knowing more and getting involved in issues around disability rights and is making efforts to access social networks and information sources that can assist her with this. She sees this pursuit as a personal effort and not something with which the service could help her. Other residents have expressed the need to be able to go out and access cultural and leisure events and spaces, but they are resigned to think of them as inaccessible because of their particular situation (and the pandemic).

torture, complaints, etc.) is buried in a mass of legal references, administrative terms, and internal procedures or is missing altogether. Services providers should find a way to rewrite the procedures and present them in a way that makes them usable and accessible for both the service staff and the beneficiaries.

#### Value and success of the service

Home care services are very valuable to both persons with disabilities and the community as a whole. Both beneficiaries and the service representatives have indicated that the need in the local community as well as in the surrounding region need is much higher, but that they do not have the funds and the institutional capacity to extend the service. Low pay is causing recruitment problems currently. More funds are needed to develop the service and increase the number of staff as well as provide adequate pay for the staff.

The service definitely has the potential of reducing institutionalization and offering beneficiaries a better life, closer to the community and their families. At the same time, several measures need to be in place to ensure the service also contributes to and does not prevent independent life in the community. First, beneficiary involvement, choice, and autonomy are crucial: beneficiaries should be actively involved in choosing the provider and the staff with whom they work directly and should be treated as active partners in service planning and provision instead of or in addition to the family/legal representative. Second, access to home-care service should be in addition to and not in place of access to other services in the community, if they are appropriate for needs and goals. Third, home-care service should actively assist beneficiaries in finding and accessing opportunities for community life: education, leisure opportunities, social networks and groups, and jobs or volunteering opportunities.

Although preventing institutionalization is a laudable objective in the current environment, in which institutionalization is seen as a solution when the needs exceed the service offer, such community services as home care should be seen as adequate tools in a set of options to assure independent life in the community. Public service providers have mentioned collaborations and integration with other services (both public and private), and these connections should be encouraged and naturally integrated in the service planning. High medical needs in particular have been mentioned as an obstacle in accessing or maintaining the service, so this conflict needs to be resolved so that there is no gap of service for particular categories of persons with disabilities, including by complementing home care services with medical services offered by other providers.

Beneficiaries value home-care services and appreciate staff and its involvement. Such gratitude is however also an indication the social and economic vulnerability these people are experiencing losing the home-care service would be a disaster for many of

them (and could mean institutionalization). The conclusion is that this vulnerability translates into a vulnerability toward the service itself—they are less likely to complain and more likely to accept conditions and forms of service that do not address their specific needs and, ultimately, in the worst of the cases, it opens up the possibility of neglect and abuse. Internally, this problem can be addressed through beneficiary involvement, creating mechanisms that reduce internal vulnerability, and orienting the service toward reducing the social and economic vulnerability of the beneficiary, through integration in social networks of support, accessing other services, informing beneficiaries of their rights, etc. At the level of public policy and community service planning, more effort should be put into developing a varied and extensive portfolio of community services that offer options and security for persons with disabilities who are in need of assistance. Finally, the relationship between the home-care service and the personal assistant service should be clarified in support of persons with disabilities. Although they overlap in most activities, current standards allow for access to both services, which allows for higher levels of care and synergy of services where appropriate. In practice, home-care services are sometimes considered redundant or a source of waste of public money, with some respondents, not understanding their role in addition to that of the personal assistant.

#### 2.4. Mobile Teams

This chapter offers a comprehensive evaluation of mobile team services with regard to compliance with the minimum quality standards provided by the Romanian national legislation. It first introduces the legal and institutional framework that regulates the provision of this service. Second, it provides an overview in terms of service and beneficiaries' profile. Third, it offers a comprehensive evaluation of the service in view of its compliance with minimum quality standards and proposes brief recommendations for the improvement of standards to ensure a better quality of service provision that is person-centered and ensures personal autonomy and self-determination.

## 2.4.1. Legal and institutional framework

The mobile team is defined by the Service Standards<sup>141</sup> as a type of social service that offers specialized interventions at the beneficiary's home, for a limited period of time, based on an individual evaluation. The service is aimed at adults with disabilities who do not have access to a day center or do not live near one, with the purpose of preventing institutionalization and developing the beneficiary's personal potential.

While the legal and institutional framework for mobile team services exists, they were not included explicitly in any national strategies until 2021. According to Law no. 448/2006, Art. 32, persons with disabilities can benefit from social services delivered to their homes planned and provided in accordance with their individual needs. Mobile teams are not mentioned explicitly but are implicitly included in services provided at home. Order no. 82/2019 mentions mobile teams explicitly and defines the minimum quality standards to be used in licensing and monitoring the service, while Government Decision no. 867/2015, which adopts the official classification list for all social services in Romania, lists mobile teams as one way of providing "home services aimed at adults with disabilities." The 2016-2020 National strategy for the special protection and social integration of persons with disabilities in Romania did not mention mobile teams explicitly either, but it mentioned the necessity of developing social services for persons with disabilities as part of the process of deinstitutionalization of persons with disabilities currently in residential centers. Among these social services are listed therapy and rehabilitation services to be provided at home.

In the new 2022-2027 strategy, <sup>142</sup> services through the mobile team are mentioned explicitly as part of addressing the objective of improving access to services in the community. There is currently only one mobile team service licensed in accordance with minimum mandatory quality standards and the number has remained the same since 2013, while the mobile team service started having beneficiaries only in 2018, and their number remained relatively unchanged until 2020 (22 to 20). The strategy

<sup>&</sup>lt;sup>141</sup> Annex 5 to Order no. 82/2019.

<sup>&</sup>lt;sup>142</sup> The "National strategy for the rights of persons with disabilities 2022-2027," still in the process of consultation.

recognizes the scarcity and lack of diversity in the services offered in the community, in particular mobile teams, despite the fact that the legal framework is in place and offers support for their functioning. The lack of home-based social services is attributed to lack of funding, county and local authorities not realizing the importance of these types of services, and lack of information that reaches potential beneficiaries.

# 2.4.2. Description of services

## Service profile

Although there is a need, currently there are only two mobile teams in Romania serving a total of 47 persons with disabilities. The services are public and relatively small, functioning under the coordination and funding of the respective GDSACP in the county they are located, one in west of the country (Oradea in Bihor county) and one in the South (Craiova in Dolj county). In principle, the service can be organized by both private and public providers, but no private services have been organized as such. At the moment, both mobile teams offer exclusively services for persons with physical or somatic disabilities. The orientation is the result of their particular histories and not necessarily a result of a decision to exclude beneficiaries with other types of disabilities. One of the services started in 2011 to respond to the local demand for rehabilitation and physical therapy for people who could not leave their homes due to mobility issues, many of them as a result of a stroke. The other service was founded initially through an EU-funded project for a similar service directed at children, and due to its success and the dedication of the team as well as the local need, the program was extended in 2018 into a service directed at adults. A summary of the main characteristics of the two services can be seen in Table 13.

Table 13. Mobile team services at a glance, in 2020

	Service 1	Service 2
Location	Craiova (Dolj country)	Oradea (Bihor county)
Area served	All country (both rural and	All country (both rural and
	urban)	urban)
Number of beneficiaries	30	17
(current)		
Total people served in	33	23
2020		
Total people served in	58	23
2019		
Frequency of service	Once a week	Twice a week or less
per beneficiary		
Average duration of	143 days	47 days
treatment per		
beneficiary in 2020		

Number of specialized staff	Service coordinator, plus 7 specialized staff members:     - 2 kinesiotherapists     - 2 physiokinetic therapists     - 2 social assistant     - 1 psychologist	Service coordinator, plus 4 specialized staff members: - 1 medical nurse - 1 social assistant - 1 kinesiotherapist - 1 psychologist
Number of vacancies	1 - speech therapist	0
Services offered	Kinesiotherapy, physical therapy, psychological counseling, social assistance, other support services.	Kinesiotherapy, physical therapy, psychological counseling, social assistance, medical assistance (administering treatments), other support services.
Equipment owned	2 vehicles 1 physical therapy equipment (machine) Other: physio-bicycle, stepper, etc.	None

Source: World Bank survey of mobile teams (2021).

Both services have indicated that due to budget limitations and lack of staff they are not able to provide the level of service they would like and that their beneficiaries need. Both mobile teams offer services only once a week to beneficiaries, for a duration ranging from one to two and a half hours, although some of the beneficiaries would need to receive therapy and do physical exercises every day (in particular in the first months after a stroke). Moreover, due to staff shortage, psychological counseling services are offered only once every two weeks for one of the teams.

In the context of material and staff shortage, family/personal assistants and more generally their caregivers become co-providers of the service. The staff have to rely on the family of the beneficiaries to help them with some of the exercises and therefore have developed ways of teaching and communicating with both beneficiaries and the personal assistants/family in order to assure the continuity of service. This need has become more acute during the COVID-19 restrictions, when the team was not able to visit the beneficiaries with whom they were working. In this context, families would film the exercises and recreate them when the team staff was not there, and beneficiaries used online or phone messaging applications, which the service team had set up and taught to some of the people, to communicate with their physical therapists about how to do their exercises.

As the only mobile team in the areas where they are located, each of the two services is forced to spread its efforts thin to serve people in both urban and rural areas. The need for rehabilitation and other types of services is high, in particular for people situated in remote, rural areas. Many of them have severe mobility issues, live in areas with infrequent or no public transportation, or live alone or with family members who cannot provide adequate transportation assistance. Most of them have financial problems, which makes access to private services and transportation impossible. The two mobile teams feel as if they have the obligation to help these beneficiaries, but at the same time they realize that this affects the total number of beneficiaries they can serve as well as the quality of the service they offer. In one case, the trip only can take two hours, in addition to the therapy time. This is particularly difficult for one team who needs to use public transportation or their own vehicles to reach the beneficiaries' homes.

Mobile teams are extremely important for the local community in the absence of other kinds of services. Although there are several other organizations offering services that could benefit persons with disabilities, they are insufficient, do not offer the services people would need (in particular to those with severe mobility issues), and in some cases they are located too far away, in a different town. In Dolj county there are two day-centers and one neuromotor rehabilitation center, all three public and in urban areas. In Bihor, there are several private providers in addition to the two public day centers in the county.

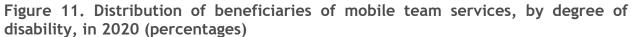
The relationship with the funder and organizer of the service (GDSACP) is crucial for the success and the experience of both service beneficiaries and staff. In one of the cases, the GDSACP is extremely supportive and does not see itself as separate from the service, but directly involved and responsible for its success. The close administrative, political, and financial support have made the continuation of the service possible. In the other case, the mobile team service is perceived as a burden by the institution, which translates into less funding and support, and the constant need to justify the service's existence through reports and paperwork. For example, no vehicles were assigned to the team, so the staff is forced to use public transportation or their own vehicles to reach beneficiaries, some of them in more remote rural areas. Moreover, some staff contracts were terminated, or staff was arbitrarily transferred to a different service (with other staff transferred to the mobile team), causing disruption and worry among both beneficiaries and staff.

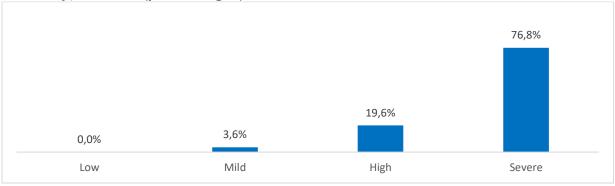
The most serious problem for both services are insufficient funding and budgetary limitations regarding expenses. Staff from both services have indicated that the need in the community is larger than they can cover with the resources they have. For one of the services, lack of money makes their mission extremely difficult. Not only do they not have a vehicle to reach beneficiaries, but they also lack the necessary equipment. They were told to find solutions and use what the beneficiaries have in their homes.

Some of the materials and "equipment" they use are improvised and received as donations from beneficiaries or even other members of the staff. For example, with the help of somebody who donated wooden boards, they improvised a device to help people get up from the bed into a sitting position. The other team is working with old vehicles (purchased for an earlier project) and insufficient equipment to address their clients' needs, and although they have the GDSACP support, they are faced with insufficient funds or rigid public acquisition rules that prevent them from acquiring the equipment they need. Another worry is that salaries are barely enough to retain the staff, some of whom are well trained and have extensive experience and would probably leave for private service providers if the 50 percent salary bonus would be cut.

# Beneficiary profile

Currently, most beneficiaries have physical, somatic, and associated disabilities, with only one having a mental disability. Also, a majority, according to the services' coordinators, have acquired a disability as a result of a stroke, which reflects to some degree the community need that the services are primarily trying to address. Over three quarters of all beneficiaries have severe disabilities, and a very small percentage have mild disabilities (see Figure 11). Their age distribution is fairly spread out, with a higher percentage of people in the older age groups: one third of them are over 70 years old (see Figure 12). The gender distribution is also fairly balanced: roughly half are male, and half are female. None of the beneficiaries of the service come from sheltered houses and none live on their own—most live with and are cared for by their family, a personal assistant, or a professional personal assistant. For a more detailed profile, see Annex-Table 4.





Source: World Bank survey of mobile teams (2021).

<sup>&</sup>lt;sup>143</sup> In this sense, the profiles of the beneficiaries in the two counties seem fairly different: while in Dolj most beneficiaries are cared for by their families, in Bihor most have a personal assistant or a professional personal assistant.

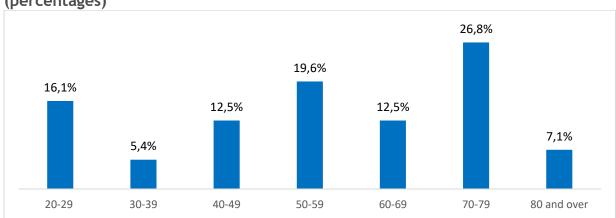


Figure 12. Distribution of beneficiaries of mobile team services, by age, in 2020 (percentages)

Source: World Bank survey of mobile teams (2021).

Beneficiaries come from both urban and rural areas. In the case of one of the services, the distribution is quite balanced; half of the beneficiaries come from the main urban area and a half from different villages in the county, while for the other (maybe due to the lack of team vehicles), most beneficiaries come from the urban area where the service is located. The need for mobile services in the rural areas is high—there are no community or professional services they could access, and many of the beneficiaries also have limited economic resources to travel or hire professionals to come to their homes.

With few exceptions, beneficiaries experience social isolation due to their disabilities, and the COVID pandemic has made the isolation even worse. The degree of isolation is perceived even more acutely by those who used to have a more active social life before the event that brought on the disability and by those who are older. Younger beneficiaries seem to be more integrated into other social networks, especially if they had attended school (mass education) or are employed. According to both beneficiary and staff interviews, receiving the mobile team service (in particular the psychological counseling and the help from the social assistant) and simply interacting with and receiving encouragement from the service staff has lessened the isolation to some degree. With support from their families and personal assistants, some beneficiaries started going out, if their mobility allowed for that.

Discrimination is a common experience of mobile team beneficiaries. Staff and beneficiaries reported that discrimination occurs both in relation to institutions and in daily interactions, from lack of physical accessibility to derogatory remarks and exclusion from various events or activities. What seems worrying is the experience with some health care providers, and in particular with family doctors, who, according to the interviewees, do not seem to be familiar with the needs and specific situation of the beneficiaries, and fill in the assessments and documents superficially, creating problems for beneficiaries and service teams who might interact with them.

All beneficiaries enrolled in the service have legal capacity, but most have delegated legal representation to a family member or rely heavily on their family members in administrative matters, with serious implications for their autonomy. For example, in Craiova, of the 30 beneficiaries currently accessing the service, 18 have delegated a representative. This might be a practical decision that reflects the bureaucratic and physical difficulties of dealing with the authorities or accessing a service (paperwork that needs to be taken from one office to another, staying in line to turn in an application, etc.). Mobile team staff have also reported that the family (implicitly the legal representative) and the personal assistant are important partners in providing the service, and that they rely on them greatly in making sure beneficiaries comply with the recommendations. Furthermore, some of the beneficiaries have expressed passivity, resignation, and preference to let family and in particular the legal representative deal with most aspects of the service, including paperwork and important administrative and legal information. According to the data reported by the coordinators of the two services, in 7 of the 47 cases (all 7 beneficiaries belonging to one of the services), beneficiaries cannot be involved in making decisions regarding their personal treatment plans and evaluation, due to "communication difficulties," and these decisions are made only with the consultation of the legal representative, without additional efforts for the beneficiaries' inclusion. This approach generates an excessive dependence on a third party and the partial loss of autonomy for the beneficiary. This situation requires increased attention and vigilance on the part of the service staff to ensure clear and effective communication with the beneficiary as well as true participation in the service planning, delivery, and evaluation.

Beneficiaries have multiple, complex needs, many of them resulting not from the disability itself, but from the larger social context in which they have to live. Some of these needs include dealing with bureaucratic procedures connected to obtaining or maintaining disability benefits (information about the procedures as well as going through the actual procedures, which might include showing up in front of a commission, presenting papers to a particular office, etc.), psychological counseling, participating in social life, medical treatments and procedures or just accessing medical service, or light housework that they themselves cannot do. The mobile team staff is proactive and supportive in helping them with these complex needs, but it cannot compensate for an entire social context, which puts the beneficiaries at a disadvantage.

#### 2.4.3. Standards compliance and implementation analysis

This section presents a detailed evaluation of the compliance with the minimum requirements in the standards, using both the service's self-evaluation and information gained from the external evaluation, interviews with service coordinators and beneficiaries, and the analysis of the documents that were offered by the services.

Module 1. Social Service Management

The first module ensures compliance with relevant laws and regulations regarding the organization and management of the service, more precisely founding the service, hiring and maintaining qualified staff, offering the service to particular kinds of beneficiaries, maintaining the proper internal administrative paperwork, and establishing relevant partnerships in the community.

Standard 1: Organization and functioning

Standard description	The standard details the general conditions for organizing the service and managing it; encouraging partnerships with other entities; offering training for the personnel in areas such as equality, preventing negligence, violence, and abuse; facilitating an independent life for the beneficiary, etc. The standards also indicate the minimum necessary documentation.
Self-assessment	According to the self-assessment form, most requirements are met, with the exception of the vehicle that service providers need to have (only one has vehicles).
Complex evaluation: external evaluation, interviews, document	One service coordinator also signaled the lack of dedicated vehicles that the service can use to reach beneficiaries. The service can borrow, in case of emergency, a vehicle from the larger institution of which they are part. They can also make a reservation in exceptional cases. In all other cases, the staff uses public transportation and personal vehicles.
analysis	In the area of staff training, the training sessions are not included in the annual plan and seem to be more of a formality provided by the service coordinator and documented only through an attendance sheet and no other instruction materials.
Observations	The standard does not specify aspects in regard to the number of required equipment (only that there is a vehicle, regardless of the number of beneficiaries), how many of the staff have to be trained, who, how often (the standard can be met with only one member, for example).

## Module 2. Accessing the social service

Module 2 offers a framework for accessing the service, from informing potential beneficiaries about the service and admitting them, to managing their information and the final termination of service. The module standards and requirements place special emphasis on the administrative paperwork that is related to these processes, and in particular its transparency and compliance with the law.

### Standard 1: Information

Standard description	The standard is meant to assure full and adapted access to information about the service to interested persons with disabilities who could benefit from the service. It requires that materials are published and comply with particular requirements. No provisions are made as to how the materials are to be distributed to those who are interested.
Self-assessment	According to the self-assessment form, almost all requirements are met, with the exception, in the case of one service of particular kinds of information about the termination of the service and the rights and obligations of the beneficiaries that is not included in the information directed at prospective beneficiaries.
Complex evaluation: external evaluation, interviews, document analysis	The two services use leaflets that they hand out to the evaluation commission for adults with disabilities, and post in medical offices, public institutions, or other places that can be accessed by persons with disabilities, but most people find out through informal networks from friends and other beneficiaries). No leaflets were offered for consultation, so they were not evaluated, but they seem to be only text-based with no other accessible format. One of the services is interested in proving information online through a website, but they depend on GDSACP to offer human resources for that since the IT specialist has been on leave for a long time.
	Some beneficiaries reported that they received all relevant information upfront, while others said that the information was not presented to them in the beginning, but they were informed once they asked.
	There might be inaccurate information offered to the beneficiaries. One of the service providers has indicated that the beneficiaries only have the right to one community service and this is why this particular service cannot be integrated with others, even if there is currently no legislation that forbids the simultaneous provision of multiple community-based services to persons with disabilities.
Observations	It is unclear if the information reaches all or the majority of people who could benefit from these services. The information is not accessible to all outside of these institutional contact situations. Once the service develops, it will need to also develop its information materials and contact methods.

Standard description	The standard details the requirements for admission, in particular informing and involving the beneficiary and the legal representative in the process, the contents of the admission file, the procedure, and using a contract.
Self-assessment	According to the self-assessment form, the admission documents and procedures comply with the standard minimum requirements. Both services indicated that there was no need for a contract and paperwork in an accessible format.
Complex evaluation: external evaluation, interviews, document analysis	According to the external evaluation, the standard is respected. The service providers have indicated, however, that the admission procedure (the necessary paperwork) is cumbersome, requires a lot of resources, and can discourage potential beneficiaries. Some of the necessary documents have to be obtained from other institutions and require travelling, staying in line, appearing in front of a commission, waiting to see a particular kind of functionary, etc. Some staff of the mobile team have indicated that they sometimes help beneficiaries with this kind of work, especially when the documents have to be renewed.
Observations	Streamlining the admission procedure would greatly help the accessibility of the service, in particular in reducing the number of trips or the number of different institutions beneficiaries have to interact with in order to obtain the necessary paperwork.
Standard 3: Benefi	ciary's personal file
Standard description	All beneficiaries should have a personal file. The standard details the conditions under which it can be consulted by various people.
Self-assessment	Both services comply with the minimum requirements.
Complex evaluation: external evaluation, interviews, document analysis	It is interesting to note that no beneficiaries have ever asked to see their personal files.
Standard 4: Service termination	
Standard description	The standard stipulates that terminating the contract can be done in conditions of transparency and in three forms: unilaterally (by the service provider), through mutual agreement, and at the beneficiary's request.

Self-assessment	The services comply with the minimum requirements. One service provider indicated an additional way of terminating the contract, through the beneficiary's death.
Complex evaluation: external evaluation, interviews, document analysis	The standards is respected.  Once the beneficiary regains mobility and is able to access other services in the community, the staff recommends service termination since he or she is no longer eligible.

# Module 3. Evaluation and planning

The third module ensures that the service is provided on an ongoing basis in accordance with beneficiary's needs, through proper evaluation and monitoring and a personalized plan. Requirements focus on procedures as well as on the resulting documentation.

## **Standard 1: Evaluation**

Standard description	The standard details the requirements for the procedure of evaluation (what is to be evaluated, how, by whom, and what documentation to use). There is a separate requirement that the beneficiary is involved in the process.
Self-assessment	Most of the minimum requirements are respected by both service providers, but:
	<ul> <li>For one of the services, the evaluation procedure does not include all required information (methods of evaluation, information regarding assistive devices);</li> <li>For one of the services, not all beneficiaries are involved in the process of evaluation, due to "difficulties in communication," and instead a mediator the beneficiary has designated as legal representative.</li> </ul>
Complex evaluation: external evaluation, interviews, document analysis	There is a mismatch between how the service provider and the beneficiaries see their involvement in the evaluation process and, implicitly, planning. The external evaluation has shown that, although many formal requirements are met, the opinion of the beneficiary (what is important for him/her, what kind of support they would like, etc.) is not formally taken into consideration and documented. For some of the beneficiaries, priority is given to the opinion of the legal representative.
	Informally, however, according to beneficiaries' interviews, the formal evaluation, as well as the informal, on-going evaluation, takes the desires and the opinions of the beneficiaries into account. The interviews have shown that beneficiaries are

	constantly involved through feedback and communication. In the case of one provider, the staff has indicated that they always take the opinion of the beneficiary into consideration, but they do not write it down separately in the file.	
	The frequency of evaluation varies between providers, from every three months to one year.	
Observations	There is confusion as to what "legal representative" actually means, and this affects beneficiary involvement in the service. The standards clearly define legal representative as the person representing a beneficiary who has lost legal capacity, but the service providers seem to use it to refer to someone who has the right to represent the beneficiary in some legal and administrative matters and thus involve this person and not the beneficiary in the treatment plan, depriving the beneficiary of his or her right to self-determination. Further clarification explanation in the standards would help clarify this aspect.	
Standard 2: Person	Standard 2: Personalized plan	
Standard description	All beneficiaries should have a Personalized Plan that is the result of the complex evaluation. The standard indicates the content of the plan and that the beneficiary should be involved in elaborating or updating it.	
Self-assessment	Most requirements are respected by both services with some exceptions:	
	<ul> <li>Not all Personalized Plans include the modality of involving the family in the service, and in the case of one provider, no plan offers this possibility.</li> <li>For one of the services, not all beneficiaries are involved in the process of evaluation, due to "difficulties in communication;" instead a mediator, someone who the beneficiary has designated as his/her legal representative, is used.</li> </ul>	
Complex evaluation: external evaluation, interviews,	Some of the beneficiaries who were interviewed know their Personalized Plans and had a copy nearby, others did not know and have not even read it or seen it—instead, the family member who acts as a legal representative has the plan and is aware of its content.	
document analysis	The same issues as in the case of evaluation apply in terms of beneficiary involvement. In addition, one of the service providers has declared that if the beneficiary (or legal representative) has signed the plan, this means he/she agrees with it and that can be considered proof of involvement.	

Observations	See Standard 1. Evaluation.
Standard 3: Monito	pring
Standard description	The standard lays out what the minimum requirements are in terms of monitoring the actual implementation of the services indicated in the Personalized Plan, as well as the required documentation. No provisions are made to include the beneficiaries.
Self-assessment	All requirements are met, according to the self-assessment form.
Complex evaluation: external evaluation, interviews, document analysis	All requirements seem to be met.

## Module 4. Services and activities

Module 4 indicates the standards and minimum requirements for the specific activities that services have to provide. In the case of the mobile teams, these are Information and social counseling/social assistance, psychological counseling, facilitating the beneficiary's independence, and developing personal mobility. These services and activities constitute the core of the service provision.

Standard 1: Information and social counseling/social assistance

Standard description	The service provider is required, through this standard, to offer a wide array of services and activities related to accessing mainstream and specialized services in the community: information and support in accessing the service, mediation in the relationship to other entities (administration, employers, etc.), support with integration in social networks, support for social and cultural activities.
Self-assessment	According to the self-evaluation, all minimum requirements are met. The service provider employs social assistants that can provide these services and activities.
Complex evaluation: external evaluation, interviews,	The collected data indicated that the mobile teams, in particular the social assistant, put a lot of effort into assisting the beneficiaries with obtaining information about their rights and accessing them. In some cases, they do the actual work for the beneficiaries, especially when it comes to paperwork that needs to be moved from one office or commission to another.

document analysis	
Observations	Many of the activities are done to compensate for the difficulties that the different systems create for the beneficiaries: convoluted procedures and paperwork, services and procedures that are disjointed or not integrated. In other cases, the social workers have to act as mediators and advocates when different institutions or people refuse beneficiaries their rights or refuse to help them.
-	ological counseling
Standard description	Psychological counseling is offered to all beneficiaries who are evaluated as having a need for support. The standard is meant to assure the psychological and emotional security beneficiaries need in their everyday life as well as in supporting other specific services and activities offered by the provider.
Self-assessment	All minimum requirements are met according to the self-assessment form. The service providers employ a psychologist to provide the service.
Complex	All minimum requirements are met.
evaluation: external evaluation, interviews, document analysis	Psychological counseling is seen by both the mobile staff and beneficiaries as having great value, both for the general wellbeing of the beneficiaries and as support for the success of the other therapies and forms of assistance. The interviewed beneficiaries could not specify the content of the counseling sessions, but they have indicated that even just having someone to talk to and being encouraged is of great help.
	Both the mobile teams and the beneficiaries have indicated as insufficient the level of counseling that is offered, due to the fact that there is only one psychologist per team (which means visits every other week), or none (for one of the team, the psychologist was moved to a different service, and the new psychologist hadn't arrived yet). More sessions are needed.
Observations	Beneficiaries have indicated that the emotional support they receive from the other members of the mobile team is also akin to psychological counseling. It is obvious that there is a great need for this type of services.
	ating the beneficiary's independence
Standard description	The standard contains requirements that are meant to assist the beneficiary and facilitate independence. The services and

	activities indicated refer to information, instruction, analysis, and offering solutions.
Self-assessment	Most of the requirements in the standard are met, in particular those referring to the activities and services offered, according to the specific needs of the beneficiaries. There is no information, however, on whether the activities are documented in the beneficiary file (and all interventions acknowledged and signed by the beneficiary) and how the staff interacts with the beneficiary.
Complex evaluation: external evaluation, interviews, document analysis	The requirements in terms of services and activities are met, in accordance with the specific needs of the beneficiary.
Observations	The mobile teams seem to have extended the meaning of the requirements of the standard and see their role as encouraging and creating opportunities for the beneficiaries to integrate in the community, to get out of the house, and engage in various activities.

Standard description	The fourth standard in the module indicates the activities and services aimed at developing personal mobility, which members of the staff are involved, how this support is offered (in relation to evaluation, monitoring, the personalized plan), as well as what documentation needs to be done.
Self-assessment	Most requirements are met, with one exception in the case of one of the services that does not have the needed technologies and devices.
	Also, there is no information, however, on whether the activities are documented in the beneficiary file (and all interventions acknowledged and signed by the beneficiary) and how the staff interacts with the beneficiary.
Complex evaluation: external evaluation, interviews, document analysis	According to interviews and the external evaluation, the requirements are met, even though there are difficulties due to lack of equipment (in the case of one team, complete lack). Developing personal mobility is seen as the main purpose of the service, mainly because in the profile of the beneficiaries it is their main rehabilitation need.

# Module 5. Protection and rights

The final module combines standards that refer to beneficiaries' rights, their protection, questions of ethics, risk management, mechanisms for complaints, and also for measuring the beneficiaries' satisfaction.

Standard 1: Respecting beneficiaries' rights

Standard description	The standard comprises two requirements, of which only one is a verifiable requirement: that the service provider organizes staff training sessions about the beneficiaries' rights. The other requirement is a list of beneficiaries' rights.
Self-assessment	The requirement regarding training sessions is met. One service provider has organized one session, the other eight during 2020.
Complex evaluation: external	Although the beneficiaries' rights seem to be generally respected, the external evaluation and the interviews have revealed several issues:
evaluation, interviews, document analysis	<ul> <li>The staff conduit is based rather on their own sense of responsibility, empathy, and efforts rather than on procedures, training sessions, or any external support. While in most cases this is enough, in others it is not. For example,</li> </ul>

	there is no clear understanding of what informed consent is					
	and the procedure for obtaining it.					
	<ul> <li>While involving the family and the personal assistants is</li> </ul>					
	important, in some cases their will and options substitute					
	those of the beneficiaries. This can affect the exercise of the					
	beneficiaries' rights to decide on the services and how they are provided.					
Observations	Better training of staff, access to information for both beneficiaries and the staff, as well as clear procedures, would be helpful.					

Standard 2: Risk m	
Standard description	The standard enumerates what the risk management procedure should contain as well as the needed documentation in cases that required emergency intervention.
Self-assessment	All requirements are met according to the self-assessment form and no emergency situations occurred in the past year.
Complex evaluation: external evaluation, interviews, document analysis	Only one of the centers uploaded the procedure for risk management. This procedure does not contain the information required by the minimum standard in terms of examples of risk situations, details of handling them, how situations of violence or aggressivity on the part of the beneficiary should be handled, etc. The procedure is instead a very long document of 15 pages of tables, administrative details, names of laws, and general information. Only a half-page addresses the actual procedure of risk management. which is very generally worded and only indicates that the team should evaluate the risk, involve the family, call 112 if necessary, and fill out the appropriate reporting paperwork. No information on what is recommended, what actions are allowed and not allowed in these situations, what the priorities are, etc.
Observations	The procedure should be a useful document that can actually uniformly guide the team's actions in situations of risk. The existing procedure seems to have been created for the benefit of others (inspectors, supervisors) than the team and the beneficiaries.
Standard 3: Code of	of ethics
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Standard	The standard indicates that the provider should have a code of
description	ethics, that this should have provisions for the equal treatment
	of beneficiaries, that the service should be provided in their best
	interests, and that professional ethics should be observed. The

	provider should also organize staff training sessions on the code of ethics.
Self-assessment	All requirements are met. One service provider has organized one session, the other eight during 2020.
Complex evaluation: external evaluation, interviews, document analysis	No codes of ethics were so far provided by the mobile teams.
	tion against negligence, exploitation, violence, and abuse
Standard description	The standard stipulates minimum requirements for assuring the protection against negligence, exploitation, violence, and abuse: what the procedure should contain, how it should be applied, the resulting documentation, and that the staff should receive training in this matter.
Self-assessment	All requirements are met according to the self-evaluation. No cases of negligence, exploitation, violence, or abuse were registered in 2020.
Complex evaluation: external evaluation, interviews, document analysis	According to the self-evaluation, only one of the procedures respects all the content requirements. It is not clear how the beneficiaries are informed about their rights and the procedure (some of the requirements in the standard are presented in ways that are unverifiable).
Observations	The procedure should be written in a user-friendly format. Also, there should be materials directed at the beneficiaries and their families/personal assistants (that they can keep as a reference in case of need), so they can recognize cases of negligence, exploitation, violence, and abuse.
	The standard does not require this, but there should also be an independent system of reporting these kinds of cases other than calling 112.
Standard 5: Protec	tion against torture and cruel, inhuman, or degrading treatment
Standard description	The standard indicates minimum requirements for assuring protection against torture and cruel, inhuman, or degrading treatment; what the procedure should contain; how it should be

-	applied; the resulting documentation; and that the staff should receive training in this matter.
Self-assessment	All requirements are met according to the self-evaluation. No cases of torture and cruel, inhuman, or degrading treatment occurred.
Complex evaluation: external evaluation, interviews, document analysis	According to the external evaluation, all verifiable minimum requirements are met. However, it is not clear how the beneficiaries are supported and encouraged to report such cases, and if there is a simplified, accessible format for the procedure. The procedure stipulates that there should be informational sessions with the beneficiaries, but no reference materials are addressed to them. The procedure does not indicate how the beneficiaries will be protected in these kind of cases from the perpetrator if he/she is a member of the staff, and how they will be protected from retaliation or changes in the service received.
Observations	The procedure should be created, worded, and presented in a friendly, accessible manner, for the benefit of both staff and beneficiaries. There should be materials beneficiaries can use as a reference.
	Beneficiaries might feel discouraged from reporting such cases for fear of losing the service, so efforts should be made to ensure this is not the case and that beneficiaries do not think their service will be affected.
	An independent, external mechanism for reporting and reviewing such cases should be made available to the beneficiary.
Standard 6: Compl	aints
Standard description	The standard indicates that there should be a procedure for registering and solving beneficiary complaints, what the procedure should contain at the minimum, as well as some other requirements regarding documentation and archiving as well as the possibility of using external mediation at the request of the service (not the beneficiary).
Self-assessment	All requirements are met according to the self-evaluation. No complaints have been filed.
Complex evaluation: external evaluation, interviews,	In fact, according to the external evaluation, one of the services does not have a procedure for complaints (beneficiaries are informed verbally that they can file complaints), and none have a list of external mediators that could intervene, if needed.

document analysis	
Observations	The same recommendations as in the cases of standards 4 and 5: simple, accessible procedures, the protection of the beneficiaries, and access to independent mediators or mechanisms of complaint.
Standard 7: Benefi	ciary satisfaction
Standard description	This standard is met to assure a mechanism for evaluating beneficiary satisfaction with the service provided. The mobile teams are required to apply questionnaires and include their analysis in their annual reports. The beneficiaries can ask for support from staff members, family, or the legal representative in filling out the questionnaires.
Self-assessment	Both providers apply questionnaires, but only one included their analysis in their annual report. In the case of one provider, no beneficiaries have asked for support in filling out the survey, but in the case of the other, 23 have asked in the past year.
Complex evaluation: external evaluation, interviews,	None of the services assure the anonymity of the beneficiaries who fill out the questionnaires. One of the services explained that beneficiaries "should take the responsibility" for what they are saying in the questionnaires, because otherwise, the staff could fill them out instead.
document analysis	One of the questionnaires has items about the respect offered to the beneficiaries, if their complaints were solved, or if they received other kinds of assistance.
Observations	The questionnaire system, in particular a very short, multiple- choice kind of questionnaire, does not provide a sufficient evaluation of the experience of the beneficiaries.

### 2.4.4. Conclusions and recommendations

## Standards compliance and implementation

Most of the minimum requirements are respected by both mobile teams, with minor problems in the content and form of the documents used or issued. The most relevant problems are the lack of required vehicles and equipment for one of the teams and problems with some of the procedures (they are missing or lack certain provisions).

There are, however, other issues that cannot be just considered under "standards compliance," but are closely connected to their implementation:

o Requirements and the resulting documentation and procedures should be designed to help the design, management, and implementation of the service rather than to create additional burdens. The requirements, documentation, and

to some degree procedures, exist as a parallel system to the actual practice of the service. Considerable effort is put into formally complying with the standards on paper and producing the necessary documentation, without this actually helping the successful functioning of the service. Some of the requirements seem to be designed and implemented for the benefit of inspections and bureaucracy, as well as having documents that fit a particular form. The success of the service on the other hand largely relies on the dedication, vocation, intuition, and effort of the staff and not on how the system is designed and regulated.

- Procedures should be useful and in an accessible, user-friendly format. Procedures are in a form that makes them mostly unusable. The reader has to search through 17 pages of cumbersome content about laws, names of documents, and administrative terms to get to the two paragraphs that indicate what needs to be done in a particular situation. Procedures should be written in a user-friendly format that makes them accessible and useful. A separate simplified procedure should be made available to beneficiaries as reference material for these kinds of situations, a yearly information session is not enough.
- Beneficiaries and not the family or the personal assistant should be the main partner of the service provider. Although the service provider relies greatly on the beneficiaries' families and personal assistants and treats them as partners and coproviders, this can seriously limit the beneficiaries' right to self-determination as well as the person-centered aspect of service provision. Some of the beneficiaries prefer to delegate many of the personal decisions to family members, but the service staff should try to engage the beneficiary rather than to enable passivity and loss of self-determination.
- There is a need for further clarification as to what the "legal representative" is. Although the standards clearly define what a "legal representative" is as being appointed through a court order to represent a person who has lost legal capacity, the service staff seem to use the term to refer to the person who the beneficiary has delegated to sign documents or represent him/her in administrative matters, even if the beneficiary has not lost legal capacity. Since the standards indicate the legal representative as the person who will sign the paperwork, be informed, and be involved in making decisions, the mobile teams' staff work with this person, to the detriment of the beneficiary, which raises issues of confidentiality, personal autonomy, and self-determination.

### Value and success of the service

Mobile teams operate in Romania rather as services meant to compensate for a landscape of insufficient and inaccessible social services for persons with disabilities at the level of community. Their users do not have access to community services either because these services do not exist or because the general and service infrastructure does not allow this. In contrast, in the UK, mobile teams work as a form of intermediate care, which is designed to help people recover more quickly and avoid needless hospitalization and admission to long-term residential care. There, intermediate care is a supplement to, not a replacement for, specialized clinical treatment and rehabilitation (see Box 15). In addition, mobile services can provide support for a variety of physical and psychological needs.

## Box 15: Types of mobile services in the UK

In the UK, mobile team care services can take different forms.

- (1) Rapid Response Teams provide persons in need with quick access to a variety of competent specialists who can help with physiotherapy and occupational therapy, medication prescribing and reviews, and being well-fed and hydrated. This type of service is highly effective in helping people regain or maintain their independence. Also, it is more cost-effective than providing care in hospitals, because it allows beds there to be available to people who require them more promptly.
- (2) **Crisis Resolution Teams** offer short-term, intensive home therapy to people who are undergoing an acute mental health crisis.

Sources: Clift (2015), Mental Health Today (2014), Mind (2018), Spencer & Stevenson (2002).

In Romania, services provided through the mobile team both support and compromise access to independent living for persons with disabilities. First of all, mobile teams provide services at home, allowing beneficiaries to live in the community and with their families, preventing their institutionalization. They do not act as institutions that regulate all aspects of someone's life, but only provide needed services, unbundled from other constraints and requirements. However, at the same time, mobile team services might actually play a role in keeping persons with disabilities isolated in their homes and further segregating them from the rest of the community, especially if these services make up for the lack of other services in the community and are not actually complementary to them. As the evaluation has shown, the choice of service and beneficiary involvement can be problematic when the beneficiary's family or legal representative is taken as the partner in service planning and provision, rather than the beneficiaries themselves.

Given the disability services landscape in Romania, services provided by mobile teams are, according to both providers and beneficiaries, of great value. They can be seen as an intermediary step toward transforming community services and infrastructure to be inclusive and appropriate for persons with disabilities. More resources and institutional support should be directed at developing these kinds of services, and the experience and approaches developed by the two teams should be, in many aspects, replicated in other parts of the country as examples of good practice. More resources would mean vehicles, equipment to be used in the delivery of the service, and financial resources meant to attract and retain highly qualified staff.

## 2.5. Day Centers and Outpatient Neuromotor Recovery Service Centers

This chapter summarizes the findings of a comprehensive evaluation of services offered by Day Centers (DCs) and Outpatient Neuromotor Recovery Service Centers (ONRSCs) with regard to their compliance with the minimum quality standards provided by the Romanian national legislation. The chapter first introduces the legal and institutional framework that regulates the provision of this service. Second, it provides an overview of the services in terms of service and beneficiaries' profile. Third, it presents a comprehensive evaluation of the service in view of its compliance with minimum quality standards and proposes brief recommendations for the improvement of standards to ensure a better quality of service provision that is person-centered and ensures personal autonomy and self-determination.

## 2.5.1. Legal and institutional framework

According to Law no. 448/2006, services provided in day centers represent a protection measure for adults with disabilities. 144 Day centers are a type of non-residential services that are provided in order to prevent, limit, or eliminate marginalization or social exclusion of beneficiaries. Day centers for persons with disabilities are a particular type of community-based services that comprise a set of activities carried out at different times of the day to meet the individual specific needs of adults with disabilities in order to overcome difficult situations, to develop their personal potential and to prevent institutionalization, and/or offering specialized interventions focused on neuromotor recovery to meet the individual needs, identified by the assessment, of adults with disabilities, in order to maintain/develop personal potential and prevent institutionalization. 145

Day centers differ depending on the profile of activities they offer to beneficiaries. According to current legislation, <sup>146</sup> day centers can be licensed either as: (i) day centers that offer activities related to psychological counseling, habilitation and rehabilitation (speech therapy, massage, kinesiotherapy, physiotherapy, hydrotherapy, balneotherapy, thermotherapy, occupation therapy, and so on); support for developing independent living skills and developing job skills and for job retention, social and civic integration, and participation, or (ii) outpatient neuromotor recovery service centers that offer rehabilitation activities, such as physical therapy, massage therapy, physiotherapy, relaxation therapies, and so on.

Day centers are one of the most widely developed community-based services in Romania. According to the NARPDCA data, in March 2021, there were 48 day centers.

<sup>&</sup>lt;sup>144</sup> Besides personal assistance or personal professional assistance, home-care services, services in residential centers. Law no. 448/2006. Art. 5. 23^1.

<sup>&</sup>lt;sup>145</sup> Order no. 82/2019, Annex 6, Specific minimum quality standards for social services organized as day centers for Adults with Disabilities and Outpatient Neuromotor Recovery Service for adults with disabilities.

<sup>146</sup> Ibid.

However, even though in 2016 NARPDCA launched the Program of National Interest to fund services in the community, including day centers, <sup>147</sup> there has been only a slight increase in their number over the past 5 years, from 47 centers in 2015 (see Table 14). The National Disability Strategy 2022-2027 aims to further increase the number of day centers as well as of their beneficiaries as the outcome and output indicators for measuring the improvement of access for persons with disabilities to community-based social services necessary for independent living. <sup>148</sup>

Table 14. Number of day centers and their beneficiaries, 2013-2021

	201	201	201	201	201	201	201	202	Marc
	3	4	5	6	7	8	9	0	h
									202
									1
Day centers	20	19	19	20	23	24	25	25	24
Beneficiaries	687	982	710	752	667	568	525	579	668
Outpatient	29	28	28	29	28	29	29	25	24
neuromotor recovery									
service centers									
Beneficiaries	825	1,50	1,00	1,26	1,31	1,32	1,25	1,06	879
		4	8	9	4	9	8	6	
Centers with	2	2	2	2	1	2	2	2	2
occupational profile									
Beneficiaries	60	49	49	51	29	64	66	60	57

Source: NARPDCA statistical bulletins (2013-2021).

Day centers are considered a type of community-based service that can facilitate independent living and can prevent institutionalization. The European Expert Group of the Transition from Institutionalized to Community-Based Care indicates day-care centers for adults and elderly persons with disabilities as an example of services in the community meant to prevent institutionalization, as well as to support the reintegration and transition back to the community. These services may provide advice, support, meals, and some aspects of personal care, as well as social and cultural

<sup>&</sup>lt;sup>147</sup> "Establishing day center type social services, respite/crisis centers and sheltered houses for the deinstitutionalization of persons with disabilities from old types of institutions and for preventing the institutionalization of persons with disabilities in the community." The PNI was approved through the Government Decision no. 798/2016.

<sup>&</sup>lt;sup>148</sup> Operational Plan for the implementation of the National Strategy on the rights of persons with disabilities 2022-2027 (in the consultation process at the time of writing this report). Specific objective 5.3. Improving the access to social services in the community necessary for independent living. Measure 5.3.5. Providing social services such as day centers for adults with disabilities, by setting up, including with funding from European funds, and/or contracting them and carrying out awareness-raising actions among persons with disabilities and their relatives about their existence and purpose.

<sup>&</sup>lt;sup>149</sup> European Expert Group on the Transition from Institutional to Community-based Care (2012: 93).

activities. <sup>150</sup> Nevertheless, there is concern that the development of day centers may reproduce the segregation of persons with disabilities rather than promote community inclusion and independent living. Community-based services can reproduce forms of institutional care in the community, in cases where beneficiaries have little contact with other persons or activities in the community and spend the entire day or only part of it in the centers only with other persons with disabilities, <sup>151</sup> even if the service buildings may be located in the community. <sup>152</sup>

## 2.5.2. Description of services

## Service profile

The general profile of the day center type services evaluated shows that small and very large centers in terms of the total number of beneficiaries are spread out in the whole country, but mostly in urban areas. The 34 evaluated services out of the total 50 existing services are unevenly distributed nationwide, with many counties lacking centers, and some having from one to three centers, except Bucharest, where seven centers are located. The distribution of the 2,700 beneficiaries reported by the day centers included in the evaluation for 2020 is more uneven across counties, given that most centers have more than eight beneficiaries, the minimum stipulated by the legislation, with 5 out of 34 day centers concentrating two-thirds of the total number of beneficiaries. Bucharest along with two counties (Dolj and Ialomița) concentrated more than half the total number of beneficiaries of day centers in 2020, with relatively equal distributions (see Annex-Table 7). Only one out of the 34 day centers in the sample is located in a rural area.

<sup>&</sup>lt;sup>150</sup> Ibid.

<sup>151</sup> Ibid.

<sup>&</sup>lt;sup>152</sup> International Disability Alliance (IDA) (2012).

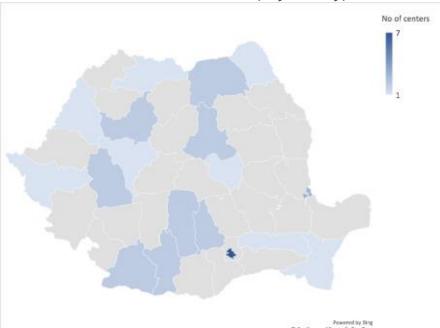
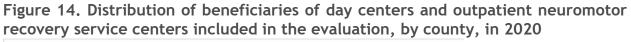
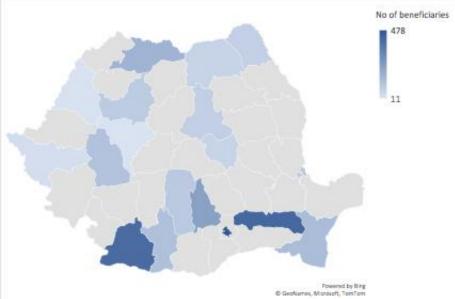


Figure 13. Distribution of day centers and outpatient neuromotor recovery service centers included in the evaluation, by county, in 2020

Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).





Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).

Day centers offer a combination of socializing activities and activities directed at recovering and rehabilitation, as well as at developing and maintaining independent

living skills. Recovery and rehabilitation activities such as kinesiotherapy, physiotherapy and massage are the main activities provided in both DCs and ONRCs. While not a mandatory activity, psychological counseling is also provided in ONRSCs, besides other rehabilitation services such as laser therapy, electrotherapy, balneotherapy, and psychological counseling. Day centers are more oriented toward providing activities that support beneficiaries to develop their occupational/employment and independent living skills, including learning how to read and write and develop their social skills, IT courses, workshops where beneficiaries paint or make jewelry, as well as socialization activities, either in the centers or in the community.

The frequency of access to the service varies depending on the needs of beneficiaries, as well as on how centers organize their service provision. ONRSCs provide services to their beneficiaries either over longer periods with a daily frequency or a few times per week, or for shorter lengths of time: such as four weeks every six months with more intensive sessions of activities daily. These patterns impact the beneficiaries' relationship with the staff as well as with other beneficiaries. More frequent access to services creates stronger bonds and community-like feelings. In the case of DCs, the pattern of attendance is somehow similar, either daily attendance or several days per week or alternating two weeks of daily attendance with the other two weeks of pause. Some beneficiaries have been using the service for a few months while others used them for more than 10 years. The average number of hours of services provided per day to beneficiaries in 2020 was 3.7 in the case of DCs and 2.3. in the case of ONRSCs, decreasing only slightly from 2019.

Beneficiaries' needs are not always satisfied by the frequency of service use. In almost one-third of centers, there is a need for current beneficiaries to access the service more often. The most common difficulties that limit a more frequent use (besides the restrictions related to COVID-19 restrictions) are related to either the long distance between the centers and the beneficiaries' home coupled with lack of access to public transportation, and insufficient specialized staff, spaces, and equipment.

The number of beneficiaries decreased in 2020. In 2020, the number of beneficiaries accessing the services, of those admitted to each type of services as well as the average number of days of service provision, slightly decreased most probably because of the pandemic restrictions that forced some day centers to suspend their activities (see Table 15). In some cases, according to interviews with services coordinators and beneficiaries, some of the activities (socialization, psychological counseling, kinesiotherapy) were either provided at beneficiaries' home, online, or in parks. In addition, the average number of days per year of service provision also decreased in 2020 compared to 2019.

Table 15. Evolution of the number of beneficiaries in DCs/ONRSCs included in the evaluation, from 2019-present

	Day centers		Outpatient neuromotor	
			recovery centers	service
Year	2019	2020	2019	2020
Total number of beneficiaries accessing the service	1,330	1,345	2,663	1,555
Total number of beneficiaries admitted to the service	677	484	921	576
Average number of days per year of service provision	111.6	77.6	60.2	49.3
Average number of hours per day of service provision	4.2	3.7	2.6	2.3

Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).

Day centers offer services to beneficiaries who live in the community or in residential services for adults with disabilities. More than two-thirds of day centers (both DCs and ONRSCs) offer services preponderantly to persons with disabilities who live in the community and are cared for by their families. However, there are significant percentages of centers that offer services to beneficiaries who live either in sheltered houses (16 percent of all DCs) or in residential centers (14 percent of all ONRSCs). <sup>153</sup> In some counties, all beneficiaries of day centers are either from sheltered houses (all 138 beneficiaries of the only DCs in Constanţa) or from residential centers (all 104 beneficiaries of the only ONRSC in Olt).

The dyads "sheltered houses - day centers" might slow down deinstitutionalization efforts. The current quality standard for sheltered housing states that specific activities should take place preponderantly in a day center (and not in the sheltered house), which, in some cases, led to the opening of day centers for sheltered houses to be licensed as social services. Some day centers were set up as a stage prior to the establishment of sheltered housing and function as part of a larger service complex that includes other services offered by GDSACPs, sometimes even in the same building or the same yard: sheltered houses, residential centers, or outpatient neuromotor recovery service centers. Although the intention was to push service providers to help connect beneficiaries to services in the community, the unintended effect was that the service arrangements, characteristic to residential service centers, such as segregation, physical separation from the community, containment, and no need to be out in the

<sup>&</sup>lt;sup>153</sup> No ONRSC offers services to persons living in sheltered houses, while only approximately 5 percent of DCs have beneficiaries who live in residential centers for adults with disabilities.

community, are being partially recreated. Thus, some service coordinators indicated that day centers were opened specifically for beneficiaries of sheltered houses, that they are using a quota system for admitting beneficiaries from the community, and that people from sheltered houses do not access other community services. This conclusion was further supported by the reluctance of DCs coordinators to admit other persons with disabilities from the community (and resentment when they are forced to, especially if there are no extra "EU" funds), their poor opinion of other community services (and possibly reluctance to recommend them to the beneficiaries of sheltered houses they coordinate), as well as their attempts to segregate the schedule (provide services to persons from the community in one separate part of the day).

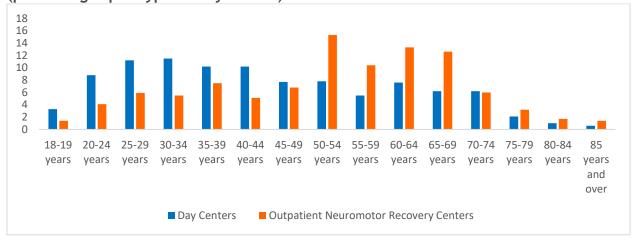
The profile of service staff generally reflects the difference between the activities offered by the two types of centers. There are currently 162 full-time and 1 part-time employee in DCs and 69 full-time and 1 part-time employee in ONRSCs. DCs have more social workers and psychologists, as well as education and ergotherapy instructors, ONRSCs tend to have more physicians, physiotherapists and massage therapists. Medical assistants, nurses and kinesiotherapists are common to both services. DCs must offer psychological counseling as well as activities related to social and civic participation, rehabilitation (including physical and psychological), independent living, employment skills, and job retention. ONRCs must offer exclusively neuromotor recovery activities, in addition to more general activities of social information and counseling. Generally, both types of services have vacant positions for specialized staff, with higher rates of vacancies in DCs for positions of psychologists (23 employees out of 33 existing positions), medical assistants (17 full-time employees and 1 part-time, out of 22 fulltime and 1 part-time) and kinesiotherapy specialists (15 employees out of 22 existing positions). More than half the number of all centers (63 percent of DCs and 45 percent of ONRSCs) reported that the number and training of staff do not match the number and assessed needs of beneficiaries, and there is a need to employ more staff for all types of specialized positions.

## Beneficiary profile

Profiles of beneficiaries of both types of centers are different in terms of age, types and degree of disability, legal capacity, and institutionalization/living situation. The difference has implications for beneficiaries' expectations regarding services, how they use them, and for the importance the services have for them.

• Age. DC beneficiaries are younger than those of ONRSCs: half of the former are concentrated in the 24 to 44 age range, whereas half of the ONRSC beneficiaries are in the 50 to 69 age range (see Figure 15). This also correlates with the fact that many of those who come to ONRSCs have acquired the disability later in life (often as the result of a stroke).

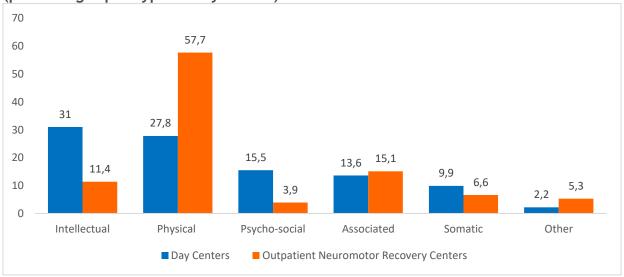
Figure 15. Age distribution of beneficiaries in day centers and outpatient neuromotor recovery service centers included in the evaluation, in 2020 (percentages per type of day center)



Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).

Type of disability. ONRSC beneficiaries are less diverse in terms of disabilities than DC beneficiaries. For example, more than half of beneficiaries in ONRSCs have physical disabilities, but not all; 15 percent have associated disabilities, and 11 percent mental disabilities. In day centers, almost one third have mental disabilities and almost one third physical disabilities. Also, those with associated, psychic and somatic disabilities make up from 10 to 16 percent of the total number of day center beneficiaries (see figure below).

Figure 16. Distribution of beneficiaries of day centers and outpatient neuromotor recovery service centers included in the evaluation, by type of disability, in 2020 (percentages per type of day center)



Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).

- Degree of disability. Although both types of centers serve beneficiaries with all degrees of disability, persons with accentuated and high degrees of disability (87 percent in DCs compared to 77 percent in recovery centers) are overrepresented.
- Legal capacity. DC beneficiaries are more than twice as likely to lack legal capacity than those in ONRSCs (17 percent compared to 7 percent). Although quality standards indicate that the staff should be preoccupied with involving beneficiaries and listening to their opinions in the process of developing and implementing their personalized plan of services, beneficiaries are represented in all these instances by a legal representative. The latter becomes not just a proxy for obtaining information and consent, but also the main actor, by signing papers and being directly involved in evaluation, planning, and monitoring.
- Living situation and institutionalization. More than a fifth of those coming to DCs are or have been institutionalized (16 percent live now in sheltered houses, and a further 5 percent live in residential centers). For those in ONRSCs, the proportion is smaller (15 percent live in residential centers and none in sheltered houses). The difference in the two categories might be due to the requirement that all sheltered houses should be connected to a day center. Similar proportions live with their families in the case of both types of centers (around 70 percent), although DC beneficiaries are twice as likely to not have a family at all compared to those in ONRSCs (21 percent compared to 10 percent, respectively).

Day centers are experienced as safe spaces where beneficiaries feel welcomed and accepted. Beneficiaries see their participation in centers' activities as a form of socialization and experience the centers as spaces of acceptance that can mitigate their experience with discrimination and social isolation in their everyday lives. Many interviewed beneficiaries indicated that they are severely socially isolated: for many, the only social contacts are family and service staff. Being in a public space or interacting with the general population is emotionally taxing and avoided as much as possible. They recounted experiences in mass transportation or commercial spaces where they were made to feel excluded: people did not have patience, pushed them aside, made them feel slow, in the way, and so on. Some hide their disability as much as they can, especially if it was acquired later in life or due to a degenerative condition. Especially those coming to day centers see the center and the time there as an opportunity to socialize. Beneficiaries make friends among the rest of the beneficiaries, especially if they come several times a week. They speak fondly of just hanging out, talking, and having a cup of coffee or tea in the center.

Day centers can also be experienced as isolated places that separate persons with disabilities from the rest of the community. While day centers are designed as disability-specific services where persons with disabilities can benefit from a variety of activities - from psychological and vocational counseling to rehabilitation and social activities - the concentration of service provision for persons with disabilities in one

space may reproduce segregation. Some of the beneficiaries interviewed understand that, in the end, socializing and spending time with other persons with disabilities in a segregated space is also a form of social isolation. This experience has been reported in other contexts and has led to proposals to rethink and redesign day services, in line with more individualized models.<sup>154</sup>

For beneficiaries, the difference between those who come from inside the protection system (residential centers and sheltered housing) and those from outside of it (live with the family or independently) is significant. The significance of this difference is also evident in the language and labels used by the beneficiaries: people come from or live "outside" or "inside". Coming from a residential center or a sheltered house can be stigmatizing and may affect the relationships developed with other beneficiaries, also as a result of the practical implications of being institutionalized (or quasi-institutionalized). For example, a beneficiary who lived "outside" dated someone from "inside," but the relationship was broken off because "they were not for each other," as they could not spend time in town or doing other kinds of activities. In the end, the beneficiary decided to date someone from the outside, more like her/himself. However, the beneficiaries do not want to be segregated and both categories believe that segregation is a bad idea. In one case, one of the day centers is about to be re-organized, so that beneficiaries from the community will come separately from those from the sheltered housing complex. The beneficiaries that were interviewed hope this will not happen.

Beneficiaries have expressed the need for more psychological counseling. Part of the need is directly related to having a disability and the social isolation and discrimination they experience. Some beneficiaries have expressed having other anxieties, phobias, and even suicidal thoughts. Also, the need for psychological counseling is related to the lack of other forms of formal or informal support. This is why, for some of the beneficiaries, the content of the counseling is sometimes less important than the fact that they feel they have support and someone to talk to. They greatly appreciate the service, where it is offered.

Beneficiaries have low expectations on offered services and have expressed the need for both more activities and having the option to choose themselves out of a list of activities. Overall, beneficiaries feel grateful to have access to services and do not have expectations that could be subsumed under some of the compulsory services offered by the centers (for example, work and employment-related skills, support for adapting the home and the workplace, support in their relationship with employers.). Their expectations are more closely tied to the core of the service (habilitation/rehabilitation and neuromotor recovery) and to maintaining a space for socializing. Beneficiaries need more control over their day-to-day activities: they have

<sup>&</sup>lt;sup>154</sup> Fleming et al. (2016).

suggested that the activities should be more varied and that even though they cannot come up with ideas for activities, they would like to be able to choose from a list.

#### Box 16: Beneficiaries' voices

## Life in the community

"I would like to get out of the house, to be able to move, but it is crowded, people do not have patience with those who have needs like us, they push us... it happened to me on the bus many times, they push you so you fall down. They do not... do not accept those needs."

"And the illness makes you close up, you do not think someone will understand you."

"Since I've had this problem, I isolated myself in the house. All I want to do is watch TV and get into bed and sleep. (...) Because first of all, they do not have patience. Why should I bother X that I walk so slowly and everybody else is running? (...) I do not want to bother the other, that's what I'm saying."

"Before my illness, I went to work, in other words, I had a normal life. After I retired because of my illness, life forces you...since you do not have face-to-face relationships anymore... since you're ill, you do not even want to socialize anymore, you think nobody will understand you."

### Information about the center/services

"Nobody tells us about these facilities. I found out about a part from the internet, and we looked up more information."

"Now [with the changes in the center, being transformed from a residential center into a day center] with the new changes they said they would inform us, but we didn't have this training at the center, we didn't know what the center would do, what my obligations would be, but I went to the center because I had nothing to lose anyway, I have nothing to lose. But I would like to be told what we can do, what can be done for us."

## Accessing the center

"We have to walk 2 km to the street, and from there to take the bus that goes to the neighborhood where the center is, it comes every 30 minutes, so we really have to catch the bus to come, otherwise we would be late a half an hour."

### Experiences with the center

"My physical progress was very big. Counseling helped me get over difficulties more easily." [they talk to us] as equals, it depends also on how they feel, they also have family problems."

"They explain things to us, they do not consider us patients, but their colleagues."

"We are like a family, the staff are like my friends."

"The center wasn't built a long time ago, but it was made by someone smart. Maybe there are people who can complain about something, but I haven't found anything [...] inside it is easy to move around so that even persons with severe disabilities do not have problems."

"I am most pleased with the bathroom; the bathroom is really good for us. The toilets with those things that I can lift myself so easily, I said where can I find them for myself? The halls are very good for us. They were made for our cases, I guess."

"Well, psychological counseling and socialization, these are the services that they offer at the moment. Because sometimes I need to be energized, you know, this illness is not so pleasant."

"But it helped me a lot because I started socializing. At the center, I was 30, 30-something at the time, the first time, and I started talking to one or another, it was really good you could say. If I hadn't gone to the center, it would have been really hard to start my activities again."

"I had to come, I couldn't move my hand, my fingers, I can move them now."

"You have to know that the idea with the computer courses was really good for many of us, the internet was like a window for us, a window to society, to the community. What I watch YouTube videos, I escape my problem, I feel joy for the positive things I see, and in addition, they teach you a lot of things on YouTube, they teach you a lot of tutorials, and audiobooks."

"I got from walking really badly to running. You can imagine. I run, I walk and I play football with my children, they are happy, too."

## Wishes about the center-desegregation

"I would tell you something, it was good if healthy people came to this center, too, so they can see that we are not that different from them, to know us, to understand us, so we can exchange a word with healthy people as well, not just with sick people like us. Do you understand what I am saying? This would be a gain for us, if healthy people from the community could come, so that they understand us, and we can talk, but they do not come because it is forbidden for them to come into this center, it is only for those with disabilities. But if they had an open house day, but this is a one-day event...yeah, this would be real social inclusion, for the society to see us how we are, and that as people we are not that different, it is just that we have an illness." Source: World Bank interviews with beneficiaries of day centers (April-May 2021).

## 2.5.3. Standards compliance and implementation analysis

This section presents a detailed evaluation of the compliance with the minimum requirements in the standards, using services self-evaluation, information gained from the external evaluation, interviews with 4 service coordinators and 28 beneficiaries, and the analysis of documents offered by the centers.

## Module 1. Social Service Management

The first module seeks to ensure compliance with relevant laws and regulations regarding the organization and management of services, particularly establishing the service, hiring and maintaining qualified staff, offering services to particular groups of beneficiaries, maintaining proper internal administrative paperwork, and establishing relevant partnerships in the community. This module also establishes minimum

requirements related to assuring the comfort and safety of beneficiaries in terms of spaces, physical access, accessibility and adaptations, materials and equipment. There are two additional standards for DCs, one referring to feeding, care, and assistance, and one referring to health assistance.

Standard 1: Organi	zation and functioning
Standard description	The standard details the general conditions for organizing and managing the service; encouraging partnerships with other entities; offering training for personnel in areas like equality; preventing negligence, violence, and abuse; facilitating an independent living for beneficiaries, and so on. The standard also indicates the minimum necessary documentation. Moreover, the standard stipulates who can benefit from the service and what the minimum capacity for the service should be (40 hours a week for a minimum of 8 beneficiaries a day).
Self-assessment	Only a very small percentage of centers respect all minimum requirements in the standards (2 DCs and 1 ONRSC) and only a small proportion of beneficiaries benefit from services in centers that fully comply with the standard (4 percent of all beneficiaries in DCs and 8 percent in ONRSCs). The areas that seem to pose problems for most of the centers are (1) the annual report and (2) issues related to the personnel. The annual report, for over two thirds of the centers, does not include all elements mentioned in the minimum requirements. In terms of personnel, there are several important aspects. About 20 percent of the centers do not have a coordinator that complies with the requirement in terms of needed qualifications. Moreover, for around half of the centers, there are problems of including all required professional trainings in the annual training plan (equality; diversity; encouraging independent life and autonomy; recognizing and preventing exploitation, violence and abuse), as well as holding the required training sessions. One of the centers has less than the minimum required number of beneficiaries per day.
Comprehensive evaluation: external evaluation, interviews, document analysis	Data from external evaluation has confirmed the insufficient training provided to personnel reflected in the absence of annual training plans and actual annual training sessions. In addition, one of the service coordinators explained that not all staff has the necessary formal education, but that their experience makes up for this lack. He said that the staff is interested in attending training sessions, but that those they can usually access are formal and nonengaging, generally with information about laws

or redundant information that they already know, and that they would appreciate more courses that equip them to deal with

	concrete, practical situations. All centers have reported carrying out annual performance evaluations of staff regarding fulfillment of their tasks and responsibilities in the job description. Service coordinators are most often the persons carrying out these evaluations.
Observations	There is no provision in the standard indicating the persons responsible for training personnel or the material used, as well as the involvement of persons with disabilities as trainers for modules related to respecting their rights. In addition, it is unclear how services make sure that staff do acquire the training content and apply it appropriately in relation to beneficiaries.
Standard 2: Safety	and comfort for beneficiaries
Standard description	The standard indicates the minimum requirements that should ensure the safety and comfort of the beneficiaries: details about the placement of the center; the spaces; their accessibility, equipment, and materials, and general environmental and sanitary conditions.
Self-assessment	None of the day centers respect all of the minimum requirements in the standard. Some of the issues revealed by the self-assessment are common to both DCs and ONRSCs. For example, only about a third of DCs and less than a fifth of the ONRSCs have the adaptations for persons with disabilities required by the law (in the case of bathroom adaptations, the proportion is around half for both). Also, one third of DCs and two-thirds of ONRSCs offer the required safety features.
	There are also differences between the two types of centers. While all outpatient recovery centers have the needed spaces and equipment (for their activities), only about one fifth of the day centers do so.
	The centers are very different in size, with about one third offering less than 100 square meters for activities with beneficiaries (for the smallest 7 centers, 6 DCs and one ONRSC, the average surface area is under 50 square meters).
Comprehensive evaluation: external evaluation, interviews, document analysis	The external evaluation and interviews with beneficiaries have generally confirmed the self-evaluations. The majority of centers had accessible routes to the building entrance, access ramps and most or all of the following adaptations of the building: wide-opening doors, no stairs and interior sills, access ramps or inclined planes, handrails. Only 2 DCs had almost none of these adaptations. Beneficiaries who participated in the study indicated that in some day centers spaces are not adapted, but that they

are not necessarily bothered. What upset many is that sidewalks and entrances to centers and sometimes ramps are blocked by parked cars which made access difficult. Where spaces and in particular bathrooms were adapted, they generated immense appreciation from beneficiaries, a sign that the adaptations were a sharp contrast to the world outside of the center.

Many beneficiaries have indicated that spaces in the center are insufficient, larger spaces with more rooms would be of help, and more equipment is needed. Some have indicated the precise type, others said that even simple static equipment (mattresses or other basic gym equipment like a trellis) would improve their experience. One beneficiary, however, said that instead of expensive equipment, he would appreciate more having someone to guide and assist him in the gym activities.

According to the external evaluation, most centers are situated either in the center of the locality or between the center and the periphery, while only a few are located on the very periphery (3) DCs and 2 ONRSCs). Even if only one ONRSC is located in an area with no easy access to public transportation, for some of the beneficiaries, reaching the center poses difficulties even though there is access to public transportation. Some beneficiaries have to use several different buses to go to the center and deal with a public space that is rarely accessible for persons with disabilities. Others depend on the weather conditions, and in the winter it is difficult for them to travel. Some beneficiaries and even service coordinators have suggested that this problem could be addressed if centers had available vehicles. Data from the external evaluation indicates that some centers do have access to vehicles they request from GDSACPs (15 DCs and 6 ONRSCs), while only a few centers have their own vehicles (4 DCs and 2 ONRSCs). Up to 50 percent of vehicles provided by GDSACP to DCs are not adapted to transport persons with physical disabilities or limited mobility. It is however unclear how these vehicles are used to ensure beneficiaries access to the service or to facilitate their activities. Alternatively, a transportation community service could also help.

The general state of service buildings was satisfactory\* in most centers that were externally evaluated. Only a few centers had some (8) or all (1) the following problems: broken windows, windows that do not close, seepage and mold, broken floors, and perforated roof. Almost all centers provide the following safety and accident prevention elements: secured windows, insulated

electrical installations and cables, doors with locking systems accessible to beneficiaries and staff, equipment and materials to prevent landslides, falls, stings or cuts. One DC did not provide any of these safety aspects. Generally, centers did provide beneficiaries with a comfortable temperature and natural lighting, permanent supply of cold and hot water, and clean spaces (activity rooms, bathrooms, common areas, outdoor spaces). Only one DC did not provide a temperature of at least 20 degrees, and natural lightning was rather insufficient in 3 DCs. In two centers (one DC and one ONRSC) the toilets were not equipped with consumables (toilet paper and soap), while more than a third of all centers did not have adapted bathrooms for each gender.

\*Results from external evaluations identified fewer centers that did not comply with requirements regarding infrastructure aspects meant to ensure the safety and comfort of beneficiaries than those that resulted from centers' self-evaluation. This may have to do with limitations imposed on external evaluations carried out via online applications that may not have allowed the evaluators to identify all irregularities signaled by the centers.

#### Observations

While not stipulated in the standard, access to a vehicle is a need signaled by beneficiaries as well as service coordinators and it may be of great use to ensure that beneficiaries reach centers easily and have access to a broader spectrum of activities.

## Standard 3: Feeding, care, and assistance

Staridard 5. I CCdii	ig, care, and assistance
Standard	The standard details the minimum requirements in terms of care
description	and assistance (for both types of centers) and offering meals (for the Day Centers), including equipment, staff training, and responsibilities. The requirements are slightly different for the two types of centers. In the case of Day Centers, the requirement is that food should be offered to all beneficiaries who spend more than 4 hours at a time in the center. All staff should be trained in the area of respect for dignity and privacy. Training sessions can be offered in the area of first aid.
Self-assessment	About two thirds of DCs and ONRSCs comply with all the minimum requirements in the standard.
	Of the 13 DCs that have beneficiaries who spend more than 4 hours at the time in the center, only 6 offer meals, as required by the standard. All DCs, however, have equipped kitchens, plates, and utensils for the beneficiaries. Thirty out of 33 centers

provide information and assistance to their beneficiaries about healthy eating habits and choices.

For both types of centers, about a quarter do not organize the required training sessions regarding privacy and dignity. Moreover, the proportion of staff that has participated in these training sessions is even smaller (about a fifth for day centers and a quarter for recovery centers). The requirement for organizing first aid training sessions is optional, and only half of the recovery centers and about one third of the day centers do so.

Only a small proportion of beneficiaries (about 11-18 percent of beneficiaries of DCs and 22-33 percent of ONRSCs) are offered support with either dressing/undressing, personal hygiene, transfer and mobilization, indoor/outdoor travel, and so on. Nurses are most often the staff involved in these activities, but in some centers, recovery and ergotherapy instructors are also involved.

Comprehensive evaluation: external evaluation, interviews, document analysis

Interviewed beneficiaries have confirmed that the care and assistance part of centers' activities is a very small part of the overall service. Most beneficiaries do not need assistance with dressing, personal hygiene, and so on.

Only a few centers offer a meal per day to their beneficiaries (6 DCs and 1 ONRSC), and in most cases, centers have been evaluated as not providing a familial environment where food can be served (almost two thirds of DCs and all but one ONRSC). Several beneficiaries have indicated that, even though they might not be entitled to a meal in the center (activities last less than 4 hours), they would really appreciate being offered coffee or tea as part of socializing or just the general experience of being in the center. As of now, centers do not usually provide this, so beneficiaries have to bring them from home.

Several beneficiaries have mentioned that they really appreciate information and advice on healthy eating habits and choices and that this is something that can assist their independent living.

## Standard 4: Health assistance

Standard description

The main requirement of the standard refers to assisting beneficiaries to understand their health status. In addition, support can be offered through specialists on topics like sexual and reproductive health, sex and intimate relationships, and HIV/AIDS. In case of needing medical assistance, service staff will use the medical emergency services.

Self-assessment	All but two centers comply with all requirements in the standard. Still, only about 40 percent of the centers offer to their beneficiaries, through partnerships with specialists, informational support for health-related themes. In particular, only 5 provide information on HIV/AIDS, 6 on intimate relationships and sex, 3 on family planning, and 14 on other health-related topics.
Comprehensive evaluation: external evaluation, interviews, document analysis	Beneficiaries highly appreciate the support they receive with understanding their health status, especially the younger ones. Medical nurses seem to be more involved in providing health assistance (rather than the physician), and these kinds of training/informational sessions seem to normalize and make these topics like HIV/AIDS, relationships and sex, and family planning more accessible to the beneficiaries. Only 8 beneficiaries in 5 centers needed emergency health care in 2019 and 2020, and services reported no difficulties in accessing such services.
	Data from the external evaluation indicated an even lower number of centers than those reported through self-assessment provide beneficiaries with information on health-related topics in 2020, such as sexual and reproductive health (6 DCs and 3 ONRSCs), sex and intimate relationships (9 DCs and 3 ONRSCs), or HIV/AIDS (6 DCs and 3 ONRSCs). Only 3 DCs offered beneficiaries information on COVID-19 prevention.

# Module 2. Accessing the social service

Module 2 offers a framework for accessing services, from providing potential beneficiaries with relevant information about the service and admitting them to managing their information and terminating the provision of service. This module place special emphasis on administrative paperwork related to these processes and in particular its transparency and compliance with the law.

## Standard 1: Information

Standard description	The standard is meant to assure full and adapted access to information about the service to interested persons with disabilities. It requires that materials are published (on paper or electronically), and that they comply with particular requirements. No provisions are made as to how the materials are to be distributed to those who are interested.
Self-assessment	About a third of the centers comply with all minimum requirements in the standard. The most significant issues seem to be:

0	Two centers of	do not have	any in	formation	al ma	terials a	at all,
	and more tha	n half do no	ot have	adapted r	nateri	ials;	
				<b>-</b>			

 Three centers use images of beneficiaries without the proper consent measures (written).

Comprehensive evaluation: external evaluation, interviews, document analysis

Most beneficiaries that were interviewed found out about the service either through friends and family, by seeking out information (online or calling up GDSACP) or even accidentally. Only a handful of beneficiaries were reached directly by the service or GDSACP though informational materials, suggesting that the presence of the service in the community is timid and only part of potential beneficiaries find out about it. From the perspective of service coordinators, the situation looks the same for the most part. Only one declared making efforts to make the service known in the community (through leaflets, partnerships with family physicians, campaigns). There are not clear roles regarding advertising and passing out information about the service, but usually services seem to simply rely on being part of a GDSACP for both disseminating information and using resources for this.

Once beneficiaries reached centers for a visit, they were offered all the information they asked for about the center and the services offered. This was also confirmed by service staff during the external evaluations of the centers. All but four centers that offered beneficiaries information regarding at least the conditions of admission, services and activities offered, conditions for cessation of services, and rights and obligations of beneficiaries before their admission () also provided them with the opportunity to meet the staff. While all but one DC had information materials about the service, external evaluation identified more centers where these materials did not include all previously mentioned aspects required by the standard (7 DCs and 4 ONRSCs). In general, most centers provide information materials in an easy-to-read format (17 DCs and 10 ORSCs), and only a few in audio-video format with subtitles (4 DCs and 1 ONRSC), Braille (1 DC and 1 ONRSC) or in sign language (1 DC).

## Standard 2: Admission

Standard description

The standard details the requirements for admission, contents of the admission file, the procedure, and using a contract, in particular, informing and involving beneficiaries and legal representatives in the process. The procedure should have a number of mandatory elements (application for admission, copy

	of identity papers and disability certificate, PIS and PIRIS, proof of income, social investigation report).
Self-assessment	Most centers comply with the requirements, but there are also aspects that are not met. The most significant discrepancy concerns the documents in the admission files - 14 out of 33 centers do not include all documents in the standards. Two centers do not have all the information provided for in the admission procedure and one recovery center does not issue an admission decision that needs to be included in the personal file.
	Only one center indicated that they encountered a situation that required an adapted format for the admission procedure. The center was not able to provide the procedure in an appropriately adapted format.
Comprehensive evaluation: external evaluation, interviews, document analysis	For all beneficiaries interviewed, the admission process was a positive experience: they had the admission process and the contract explained to them clearly, and they were given further clarifications and explanations when needed.
	However, data from external evaluations indicated that in more than a third of all centers there were beneficiaries who did not use the service as a result of their personal choice. The reasons are multiple, including that the choice either belonged to legal representatives, or beneficiaries have a high level of support needs for decision-making and communication.
Observations	The fixed-term contract (one, six, or twelve months) seems to be a source of confusion for some beneficiaries. The beneficiaries do not understand why they need to go through the same procedure and sign a new contract periodically. They see it as unnecessary bureaucracy. Moreover, some see the contract itself as an unnecessary part of a bureaucratic process and not one that stipulates and guarantees their right to a particular service ("nobody has ever asked me for my contract").
	Some service coordinators have indicated that they are inclined to not accept persons with psychosocial disabilities that they might deem "problematic" and think might cause problems for the rest of the beneficiaries. They complain that private providers take "all the good beneficiaries" and that they would like to know someone's HIV status before admission (without denying it), in the name of protecting other beneficiaries (the regulations allow them to ask for a medical bill that states the beneficiary has no contagious diseases).

	There is a need to ensure decision-making support for all prospective beneficiaries, as well as information materials in accessible formats, to ensure that they access the service with their full and informed consent.
Standard 3: Benefi	ciary's personal file
Standard description	All beneficiaries should have a personal file. The standard details the conditions under which it can be consulted by various people.
Self-assessment	There are no issues regarding personal file requirements, with the exception of three-day centers. In one center, for example, the file can be consulted by someone from the social protection system without someone from the center being present, and another, there is no record of the archives of personal files.  In only 4 centers beneficiaries asked to see their personal files.
Comprehensive evaluation: external evaluation, interviews, document analysis	No other issues were indicated by the comprehensive evaluation.

# **Standard 4: Service termination**

Standard description	The standard stipulates that terminating the contract should be done in conditions of transparency and may be the result of three options: unilaterally (by the service provider), through mutual agreement, and at beneficiaries' request.
Self-assessment	All but one center complies with the regulation; one of the centers allows the termination of a contract in other conditions than those indicated in the standard.
Comprehensive evaluation: external evaluation, interviews, document analysis	The interviews have shown that some contracts were terminated because the health status of the beneficiary has worsened to the point that he or she could not physically come to the center. However, there are few situations in which the beneficiary has requested the termination of the contract.
Observations	One of the causes for terminating the contract with the beneficiaries from residential social services is their transfer to

another residential social service that is not in the vicinity of the DC/ONRSC.

An issue that has come up in the interviews with center coordinators is that the prolonged use of center's services is seen as service dependency. This frame is used to describe

coordinators is that the prolonged use of center's services is seen as service dependency. This frame is used to describe beneficiaries as "not willing to get better" (including improve their disability status through the use of prostheses or wanting to seek employment). One coordinator mentioned that they were trying to convince some beneficiaries to stop coming because they were no longer eligible, but the beneficiaries wouldn't give up.

#### Module 3. Evaluation and planification

The third module seeks to ensure that services are constantly provided in accordance with beneficiaries' needs, through proper evaluation and monitoring and a personalized plan. The requirements focus on procedures as well as on the resulting documentation.

#### **Standard 1: Evaluation**

Standard description	The standard details the requirements for the procedure of evaluation (what is to be evaluated, how, by whom, and what documentation to use). There is a separate requirement that the beneficiary be involved in the process.
Self-assessment	According to the self-evaluation, most of the requirements are met. There are problems, however, with including some of the required items in the evaluation process—six centers have indicated that they do not include them all.
	The standard states that service staff should be "preoccupied" with including beneficiaries in the evaluation process and listening to their opinion. All centers reported doing so. However, 95 beneficiaries in 12 centers are not involved in the evaluation process, and the opinions of 66 beneficiaries in 8 centers are not included. The reasons mentioned are low comprehension or communication skills or low mental capacity, medical issues, lack of legal capacity, and lack of discernment. The total number of beneficiaries who lack legal capacity is actually larger (310 in total), which means that a good proportion of them are not included in the evaluation process.
Comprehensive evaluation: external evaluation, interviews,	The interviews with most beneficiaries have confirmed that evaluations take place and that they involve multidisciplinary teams. Most beneficiaries remember this initial evaluation, with the exception of those coming from one particular center, where the beneficiaries do not even know if they have a case manager

### document analysis

(it was later confirmed that the case manager does not meet the beneficiaries in this center).

External evaluations of a sample of beneficiaries' files from all services confirmed that most beneficiaries (with the exception of those at one DC and one ONRSC) had been evaluated within five days of the approval of their admission to the center, as stipulated by the standard. Most evaluation fiches contained the aspects stipulated by the standard (information about the evaluation, identified needs, short and medium-term objectives, the specialized staff involved in the evaluation, and their signatures as well as those of beneficiaries or of their legal representatives). Two DCs and two ONRSCs did not comply with the requirement for having the evaluations signed by the beneficiaries.

It is not clear how the multidisciplinary teams involve beneficiaries during the evaluation process and considers their opinions, even though this is a mandatory requirement of the standard. Less than one quarter of all DCs and all ONRSCs have evaluation fiches included in all files evaluated that describe what beneficiaries consider important and what kind of support he or she needs. While this is not a requirement of the standard, some services reported that the absence of mentions regarding beneficiaries' wishes and preferences reflects the lack of beneficiaries' involvement in their evaluations due to either the prioritization of the opinion of the evaluation teams, physicians, or legal representatives, or beneficiaries' high support needs for understanding and communicating. In other cases, services reported that beneficiaries' signatures are proof of their involvement, even if the evaluation fiches do not include a description of how this is being carried out or that beneficiaries are indeed involved in the evaluation without necessarily being asked what they need or consider important for themselves.

In addition, although the evaluation should cover a series of mandatory aspects, some centers (particularly more ONRSCs, between 27 to 72 percent) do not evaluate their beneficiaries regarding one of the following: (i) their general status as well as their level of autonomy and communication; (ii) recovery and rehabilitation needs; (iii) independent living skills; (iv) education and cultural needs; (v) possible risks and addictions; and (vi) vocational interests and work skill.

#### Observations

In the case of outpatient recovery centers, no beneficiaries have a copy of their PIS or PIRIS included in their file (a personalized plan for services), so it is unclear what initial plan the evaluation process builds on.

Depending on how the center runs its activities (for example, through more intensive sessions of two weeks every few months or twice or three times a week), beneficiaries remember the evaluation process differently. Those who visit centers frequently do not have a precise recollection of the moment of the evaluation, but instead remember it as constant interaction with the staff or multidisciplinary team, when their needs and progress are constantly assessed. For those who come every several weeks or months, the evaluation process seems to be a more formal event that is remembered with more precision.

Standards must further detail how the multidisciplinary team can best ensure that the beneficiary is involved in the evaluation process and that his or her opinion is prioritized.

#### Standard 2: Personalized plan

## Standard description

All beneficiaries should have a personalized plan that is the result of a comprehensive evaluation, updated at least every 6 months. The standard indicates the content of the plan and that beneficiaries should be involved in elaborating or updating it. The plan should include at least three of the activities offered by the center.

#### Self-assessment

Almost 60 percent of all centers declared they meet all the requirements in the standard. Out of the rest, four centers do not have all the necessary elements in the plan. The elements that are missing are: the signature of the beneficiary or legal representative, the time length of the intervention, the materials/equipment necessary, the date of the next revision, and conclusions. Three centers do not offer a copy to the beneficiary every time it is revised, and nine centers (around a quarter) do not include in the personalized plan how the family or support system will be involved (or whether it exists).

Multidisciplinary teams should include beneficiaries and their opinion during the elaboration of the plan. However, 138 beneficiaries are not at all involved in preparing their Personalized Plan and for 171 their opinion is not considered. The reported reasons for this practice are lack of legal capacity, low capacity for comprehension/communication, and "high degree of affectation." Thirteen DCs and five ONRSCs have beneficiaries that do not have legal capacity.

Comprehensive evaluation: external evaluation, interviews, document analysis

Although all centers declared that they revise Personalized Plans every 6 months, when probed further, only 25 (less than three quarters) have done so in the past 6 months.

The interviews with the beneficiaries revealed that only a small portion of them know what the Personalized Plan is and whether the activities they are doing correspond to those in the plan. In addition, service staff reported during the external evaluations that only in 15 out of 22 DCs and 5 out of 11 ONRSC beneficiaries had a copy of the last revised Personalized Plan, as required by the standard.

From the discussions with both beneficiaries and service coordinators, it became apparent that in some cases there is a mismatch between Personalized Plans and what beneficiaries are interested in or willing to engage in. Some beneficiaries indicated that they are forced to do activities that they do not want to do (one beneficiary mentioned that he was told to "exercise" but in reality, he was carrying firewood at one of the staff's home). Some service coordinators reported that beneficiaries are "uncooperative" and that unfortunately there is no way to force them to do all the activities in the plan (and since they are not doing them, their needs are not met).

The sample of beneficiaries' files from the large majority of services confirmed that most services had Personalized Plans for beneficiaries, which included all mandatory aspects, such as activities and services offered to the beneficiaries, short and medium-term objectives, duration and scheduling, materials, and equipment necessary, individual or group activities, date of next revision, conclusions, type of staff involved in the evaluation, their signatures, as well as that of beneficiaries' or legal representatives.

It is not clear how multidisciplinary teams involve beneficiaries during the process of elaborating and revising their Personalized Plan and how they consider beneficiaries' opinion, even though this is a mandatory requirement of the standard. Only up to four services of each type have Personalized Plans included in all files evaluated, which describe how beneficiaries' opinions were taken into account regarding each of the following aspects: what beneficiaries consider important in the short- and long-term, type of support to address their needs, what has been functioning and what has not, and what has to be changed. Similarly, very few services have Personalized Plans that clearly mention how preferences of beneficiaries were taken into account. While these

	are not requirements of the standard, services reported not involving some of beneficiaries in elaborating or revising their Personalized Plans, because of similar reasons they do not involve beneficiaries in the evaluation process - due to either the prioritization of the opinion of the evaluation teams, physicians, or legal representatives, or beneficiaries' high support needs for understanding and communicating
Observations	The process of developing and revising Personalized Plans should be more responsive. More effort should be put into involving beneficiaries in the development of their Personalized Plans and in particular in helping them understand to what they are agreeing (what the activities entail in terms of time, effort, effects, and so on). Furthermore, any mismatch between the plans and what beneficiaries need and want should trigger a revision of the plan (instead of waiting for multidisciplinary teams to meet/be available). Providing access to a person that may offer support in decision making to beneficiaries or may act as a facilitator for beneficiaries during the evaluation or revision of a Personalized Plan can ensure the involvement of beneficiaries more effectively. Currently, only 10 centers offer this option.
Standard 3: Monitor Standard description	The standard lays out the minimum requirements in terms of monitoring the actual implementation of services indicated in Personalized Plans, as well as the required documentation. No provisions are made to include beneficiaries in the process.
Self-assessment	Only over half of all centers fully comply with all the requirements in the standard. Moreover, none of the requirements is met by all centers. While all requirements are important, it is particularly concerning that in 5 centers there is no case manager assigned to each beneficiary, and 21 percent of beneficiaries of DCs have no case manager. The rest of the compliance problems are connected to: (1) improper documentation, (2) insufficient supervision on the part of the center (that the case is handled correctly and in accordance with the general standards), and (3) most importantly, insufficient or improper monitoring of beneficiaries' progress through monthly meetings and discussions between service teams and the corresponding case manager. In approximately 64 percent of DCs and 67 percent of ONRSCs case managers met with the multidisciplinary team at least 6 times during the past 6 months. In terms of how SSPs make sure the case manager is fulfilling the obligations in terms of implementation, evaluation, and

monitoring, the most frequently mentioned method was by consulting various documents (monitoring and evaluation fiches, activity reports, action plans), and the second most frequent was through periodic visits of inspectors from the case management services and social monitoring department. Talking to the beneficiaries was only mentioned two times, in relation to verifying the evaluation of the implementation of the Personalized Plan by the case manager.

Comprehensive evaluation: external evaluation, interviews, document analysis

During the external evaluation, services reported 69 case managers in centers where beneficiaries have case managers, 53 in 19 DCs and 16 in 11 ONRSCs. Most centers have only one or two managers that monitor changes in the situation of beneficiaries: seven DCs and nine ONRSCs. However, there are centers where there is more than one case manager, up to seven case managers in two DCs. Most beneficiaries meet with their case managers at least monthly. However, while more beneficiaries in DCs than in ONRSCs meet with their case managers every month, a larger part of beneficiaries in ONRSCs that in DCs meet their cases managers only once every few months (approximately one quarter) (see Annex-Table 9).

Despite the high proportion of centers that reported at least a monthly frequency of meetings between beneficiaries and case managers, interviews with beneficiaries revealed that many do not know if they have a case manager or who that case manager is, in particular when the service is provided continuously (every day or a few times a week). Sometimes, they confuse him or her with the social assistant. This does not mean that the case manager is not present in these cases, just that his or her role is unclear to the beneficiary.

In addition, data from the external evaluation indicated that in eight DCs and three ONRSCs managers do not comply with their monthly responsibility of writing down the progress made by beneficiaries in the monitoring fiches. Moreover, in some centers, monitoring fiches do not include mandatory aspects stipulated by the standard, either the description of beneficiaries' progress (8 DCs and 3 ONRSCs), or comments on how beneficiaries are provided with a safe environment in terms of protection against exploitation, violence and abuse, or protection against torture and cruel, inhuman or degrading treatment (15 DCs and 6 ONRSCs).

Observations

The standard does not require that beneficiaries should be involved in the monitoring process. In addition, SSPs rarely

involve beneficiaries in the process of evaluating the activity of case managers. This needs to be improved because personcentered service provision cannot be achieved without the involvement and feedback of beneficiaries.

#### Module 4. Services and activities

Module 4 indicates the standards and the minimum requirements for the specific activities that the services have to provide in the case of the Day Centers and Outpatient Neuromotor Recovery Service Centers: information and social counseling, habilitation and rehabilitation, independent living skills, work skills development, preparation for employment, job retention support, social and civic integration and participation, and outpatient neuromotor recovery. These services and activities constitute the core of the service provision and vary depending on the type of center.

Standard 1: Information and social counseling/social assistance

Standard 1: Inform	ation and social counseling/social assistance
Standard description	Services are required to provide beneficiaries with information about their rights and social benefits. This information may include aspects related to medical facilities and rehabilitation services, transportation services, alternative and complementary services provided by private SSPs, assisted employment, and so on. Services have to be offered by a social assistant employed by the service.
Self-assessment	According to the self-assessment, although the general requirements are met by the majority of centers (for example, issues regarding the monitoring of activities by the case manager and documenting the activities in the beneficiary files for a couple of centers), none of the centers offer all types of activities recommended in the standard. The main activities offered are:  Information and counseling concerning general social services and benefits,  Support in maintaining relationships with family and friends, and  Information and support in accessing certain medical services. For the rest of services, support provided in the form of information, counseling, or direct support, is minimal. The lowest level of support is in the area of analyzing the workplace and conditions and intervening with employers to help them understand the rights of persons with disabilities and support and information in adapting their home. For the ONRSCs, strangely, the level is very low: only a quarter of the centers do so and they are the smallest ones).  Another point that generates lack of compliance is that although the standard requires that the activity is carried out by a social

assistant, this is not the case in four centers. In addition to the social assistant, other types of staff carry out information and social counseling, the highest frequency being psychologists, medical nurses, physicians, and kinesiotherapists.

Comprehensive evaluation: external evaluation, interviews, document analysis

The comprehensive examination has confirmed the fact that this activity does not constitute a priority for either of the types of centers.

Beneficiaries have mentioned that centers' staff supported them in some cases by finding a job, while finding a home is not necessarily one of the areas where they have received assistance (largely because it is unrealistic given the lack of social housing). Some beneficiaries know some of their rights, but do not associate this information with the information they receive from the center. Also, some beneficiaries have indicated that they would like to find support groups (even if they are just online), but that they have not received support from the centers in finding or accessing them.

These types of activities are not a priority from the perspective of the centers. The interviews with service coordinators showed that a part of them consider that beneficiaries are not interested in finding and maintaining a job even if they would be capable, because it is easier to just receive social benefits. This is why some centers are reluctant or slow to offer support in this direction. Also, centers rarely recommend or direct beneficiaries toward other (complementary) services in the community because they either see them as of low quality (treating the beneficiaries poorly or infantilizing them) or because of the competition (especially when there is a perception that their own funding and institutional support is vulnerable).

#### Standard 2: Psychological counseling

Standard description	Psychological counseling is offered to beneficiaries who are evaluated as having a need for support. The standard is meant to assure the psychological and emotional security beneficiaries
	need in their everyday lives as well as in supporting other specific services and activities offered by the provider. The standard is compulsory for the Day Centers, but optional for the Outpatient Neuromotor Recovery Service Centers.
Self-assessment	According to self-assessments, 19 out of 22 DCs are complying with all requirements. Also, 5 out of 12 ONRSCs do so, although they need not comply with the standard to be licensed as a social service for persons with disabilities.
-	-

3 centers do not offer the service of psychological counseling at all and about 40 percent of beneficiaries of DCs do not benefit from this service. Despite not being specifically required by the standard, 16 percent of beneficiaries of ONRSCs receive psychological counseling, concentrated in 5 centers.

Moreover, in two DCs that do offer psychological counseling, the service is provided by someone with a qualification different from what is required in the standard, psychologists or psychotherapists. Three DCs, while it is required by the standards, do not have a separate space for psychological counseling, while seven ONRCs have one, even though it is not specifically required by the standard.

Comprehensive evaluation: external evaluation, interviews, document analysis

Where they exist, psychological counseling services are extremely valued by beneficiaries. In some cases, they mentioned this service as among the most important aspects of the center. Psychological counseling helps them deal with some of the difficulties that arise in everyday life. Such support has helped beneficiaries with issues regarding their self-confidence, coping with anxieties and phobias, and generally feeling supported. However, in many centers, and in particular in ONRSCs, there is no psychological counseling at all, and interviewed beneficiaries indicated that they need access to such a service. A service coordinator, however, mentioned a desire to have another psychologist on staff.

Despite the need for additional psychological counseling signaled by beneficiaries, only a very few centers reported during the external evaluations the lack of specialized staff for psychological counseling (three centers), lack of specifically designated space (one), and of necessary equipment (one). While only 3 centers reported a need for more specialized staff for psychological counseling, more centers have vacant positions for this type of staff- there are currently 10 vacant positions (one third of total available positions) concentrated in 8 DCs and 1 vacant position in ONRSCs. There is currently one position of psychotherapist in the organizational charts of all centers (in one ONRSC) which is still vacant.

#### Standard 3: Recovery and rehabilitation

Standard description

The standard describes the activities that should take place in the center to support beneficiaries to develop their autonomy and functional potential. The center should offer at least three activities to each beneficiary, out of the indicated list which lists speech therapy or psychotherapy; massage or kinesiotherapy or

	physiotherapy; hydrotherapy or balneotherapy or art therapy (modeling, sculpture, painting or drawing, decorations on various materials, crafts, dance, music, theater) or music therapy; psychosensory motor stimulation; occupational therapy; and vocational or occupational activities. Also, the activities should include assisting beneficiaries to learn how to use assistive technologies and devices. The rest of the standard detail the staff that can be involved and the corresponding documentation and administrative procedures.
Self-assessment	Only about half of the DCs and three out of four ONRSCs comply with all the requirements in the standards. Three centers (out 34) do not offer to each beneficiary three activities from the required list, and 11 DCs (half of all) are not equipped with the assistive devices and technologies needed for the activities they offer. Only one ONRSC lacks such technologies.
	Activities profile is different for the two types of centers. All ONRSCs offer physical/kinesiotherapy/massage, and half of them instructional activities for assistive technologies and devices. In the case of DCs, almost three-quarters offer occupational therapy, and almost half physical therapy/kinesiotherapy/massage or one activity from a more heterogenous category (everything from hydrotherapy to handmade art and theater). Speech therapy/psychotherapy is the least-offered activity in both types of centers. In 2020, some centers offered the majority of listed activities to beneficiaries in their homes.
Comprehensive evaluation: external evaluation, interviews, document analysis	Only a reduced number of centers reported during the external evaluations the lack of specialized staff and adequate spaces and equipment needed for each type of recovery and rehabilitation activity, no more than one or two centers per each type of activity. However, activities of recovery and rehabilitation (kinesiotherapy, massage, physiotherapy, balneotherapy and so on.) were most-frequently mentioned in the 17 centers that reported lack of access to certain services that beneficiaries may need.
Observations	One of the requirements in the standard states that each beneficiary should be offered at least three activities from the list, but since the list is organized in categories, it is unclear if the activities can come from within the same category or from different ones. For example, one category comprises, among other activities: hydrotherapy, making handmade objects, theater, and music therapy. Another category has both speech

therapy and psychotherapy. They should probably be listed in different categories, more appropriately grouped around types of needs they are addressing or therapeutic approaches, and the standard should be clearer as to how the activities can be chosen.

#### Standard 4: Independent living skills

## Standard description

The standard lists a range of activities that can be offered at the center, outdoors, or at beneficiaries' home that can help beneficiaries to develop their independent living skills. The standard also includes minimum requirements related to documentation and procedures. For DCs, the standard is obligatory, while for ONRSCs it is not.

#### Self-assessment

A little over a quarter of DCs and one third of ONRSCs comply with all the requirements in the standards. While most categories of requirements pose problems for many centers, the requirement with the lowest compliance regards training the staff and beneficiaries about assistive technologies and devices, to ensure independent living, through the collaboration with providers from the community or NGOs. Thus, only 27 percent of DCs and 33 percent of ONRSCs comply with this requirement.

The profile of activities offered in the two types of centers reveals not only different beneficiary and service profiles but also different visions of what is needed in order to live an independent life as a person with disabilities. The activities offered by DCs are geared primarily toward developing social, emotional, and cognitive skills necessary for social integration and managing everyday life. Between a third and a half of all beneficiaries of DCs are provided some type of support for basic learning, improving concentration, organizational skills, management, crisis management, behavioral self-control. communication relational and conversational skills, personal hygiene, balanced diet, personal safety, and basic economic transactions, as well as for developing educational abilities.

In contrast, the activities offered by most ONRSCs have a strong physical component and, secondly, might be aimed at developing some practical cognitive and motor skills. More than two thirds of all beneficiaries are provided with activities for increasing their physical mobility and motor coordination and around one-third for learning the benefits of a balanced diet and physical activity. The difference is reflected also in the profile of the staff involved in providing these activities: primarily social assistants and

psychologists in the case of DCs and kinesiotherapists, nurses, and physicians in the case of the ONRSCs.

Comprehensive evaluation: external evaluation, interviews, document analysis

Interviews with beneficiaries confirm the two profiles and visions. Beneficiaries who use DCs' services understand the importance of independent living skills, making references to everyday life skills and emotional management, as well as general knowledge (financial management, phones, and the internet, and so on.). On the other hand, some of the beneficiaries from the ONRSCs that were interviewed viewed independent living as something out of their immediate reach that cannot really be achieved. They felt that it was more appropriate to orient their efforts toward physical recovery and slowing down the loss of some of their physical abilities.

The perspectives of service coordinators seems to be conflicting. On the one hand, some of them consider independent living to be incompatible with using services for persons with disabilities, they see using services for persons with disabilities as a form of dependence. Therefore, the goal of providing these services should be independent living and, in consequence, reducing dependence on and the use of their services. On the other hand, developing independent living skills is a very serious goal for some service coordinators; they complained that some private service providers infantilize beneficiaries and offer them services more appropriate for children rather than adults.

Decision-making support leads to increased skills for independent living, but it is unclear how it is provided. All but one DC have reported during external evaluations that they could offer decision-making support to beneficiaries who might need it. However, only about half of the centers could indicate a document in which this type of support is stipulated. The current standard does not detail the steps of ensuring support in decision making, nor does the mandatory training of staff in this area. Nevertheless, 39 percent of all beneficiaries of DCs concentrated in 19 centers received this type of support at the time of the external evaluation. In addition, 10 out of 33 centers consider that beneficiaries cannot make their own decisions even with adequate support, referencing either the legal capacity status of beneficiaries who benefit from a protection measure of being placed under guardianship and cannot thus decide for themselves or alleged lack of mental capacity.

Currently 16 DCs and 4 ONSRCs offer beneficiaries support to further their education, either as support for learning how to read

and write (9 DCs and 4 ONRSCs) or to facilitate education enrollment (3 DCs), or for continuing a form of education (7 DCs and 2 ONRCs). However, centers cannot provide this type of support to all beneficiaries who may need it, either due to lack of specialized staff or the profile of the center, which is specialized on neuromotor recovery, or due to the high level of support in the case of beneficiaries with psychic or mental disabilities.

Standard 5: Work skills development, preparation for employment, employment retention support

## Standard description

Centers can offer activities and assistance to help beneficiaries develop their skills and preparedness for work, as well as legal and employment counseling, organizing sheltered workshops and work activities for beneficiaries, and facilitating partnerships with institutions and firms that may offer practical training or internships. There are also provisions about the staff involved, documentation, and administrative procedures. The standard is mandatory for Day Centers, but not for Outpatient Neuromotor Recovery Service Centers.

#### Self-assessment

None of the centers are complying with all requirements. It is important to note that although it is a requirement, none of the centers have partnerships with an institution or company that can offer internships, practical training, or volunteer opportunities to the beneficiaries for the purpose of developing their work skills or preparing them for work in general.

There are problems with the rest of the requirements as well. Less than a quarter of the centers took on activities that involved employers or workplaces (raising awareness about the work rights of persons with disabilities, facilities in hiring persons with disabilities, workplace adaptations, and so on). Only six DCs have spaces for organizing vocational or creative-therapeutic workshops. Among the workshops that were organized, the most common were art therapy, woodwork, and making objects out of paper. Only two centers signed partnerships with outside providers that offered services in the area of professional and career counseling and orientation.

# Comprehensive evaluation: external evaluation, interviews,

Data from the external evaluation support self-assessments that helping beneficiaries in developing work skills and assisting them in their job-seeking endeavors is not a priority for centers. Nearly a quarter of DCs and more than half of ONRSCs do not evaluate

## document analysis

their beneficiaries' vocational interests and work skills, even though this is a requirement of the standard.

Interviews with both beneficiaries and service coordinators show a more complex picture. Not all beneficiaries are interested in having a job, but some are, and have made efforts to either find one or to keep the one they have. Unfortunately, many beneficiaries have difficulties in finding jobs that are appropriate for their skills and conditions.

Service coordinators indicated that employment is really important and is an indicator of success for the service. However, efforts on the part of the centers are rather informal and not a formal, organized approach in compliance with the standard. Beneficiaries indicated that they were supported individually by service staff in finding jobs or directed toward certain opportunities (like job fairs or job openings). At the same time, the interviews with service coordinators showed that they consider beneficiaries to be reluctant in seeking or keeping a job and accuse them more or less directly of preferring to access day center's services.

A number of barriers that hinder beneficiaries' access to jobs were mentioned by centers. Sometimes, the service coordinators suggest, even though the beneficiaries might wish to find a job, their families might oppose it, either to protect them or to keep the benefits. Lack of working places that can ensure reasonable accommodations (shorter working hours, flexible tasks, and so on) was also mentioned as a barrier to employment as well as a lack of collaborations with local employment agencies, employers, or other organizations.

#### Standard 6. Social and civic integration and participation

Standard	The standard indicates activities and services aimed at ensuring
description	beneficiaries' participation in the community. Besides procedural requirements, it lists a series of possible forms of assistance and support related to participating in cultural, sports, and leisure activities; using public transportation; voting; and participating in family events.
Self-assessment	Activities of social and civic integration and participation are more common in DCs than in ONRSCs. On average, almost half of beneficiaries from more than two-thirds of DCs benefit from activities characteristic to the social environment, learning adequate behavior in different social contexts, and recreation and leisure activities, visits, and so on. In contrast, only a third

of all ONRSCs offered such activities to their beneficiaries in 2020. Among the activities that can be offered in day centers as part of the standard, beneficiaries are the least involved in cultural, artistic, and sports activities in the community (only 18 percent of beneficiaries from DCs and 5 percent from ONRSCs).

Social workers and psychologists are the specialized staff most often involved in providing such activities in 14 DCs and 12 ONRSCs. However, social and civic activities are also provided by staff that is not mentioned by the standard as appropriate, such as nurses and medical assistants. About 82 percent of all beneficiaries in DCs and 44 percent in ONRSCs are provided such activities by specialized staff mentioned explicitly by the standard.

Comprehensive evaluation: external evaluation, interviews, document analysis

Beneficiaries' participation in cultural or civic activities in the community often reflects the size of the community where the center is located. The bigger the city, the more diverse the activities and the possibilities for cultural activities and recreation. While the pandemic restrictions limited socializing activities in the centers as well as in the community and some beneficiaries could not keep in touch with service staff or with other beneficiaries, this was in some cases rather an occasion for beneficiaries to spend more time in open spaces. Leisure activities consisted mostly of trips by train or bus to nearby places or farther away in the country. Some beneficiaries also went to public gardens, movies, opera, theater, book fests, football matches, Special Olympics, folk dance performances, and other events. This is also confirmed by data reported by services: a large majority (28 out of 33) reported that in 2019 and 2020 beneficiaries had the opportunity and were supported to participate in recreational, leisure, and cultural activities within the community. Only five centers supported their beneficiaries with information about elections and voting procedures.

Forty percent of DCs and fifty percent of ONRSCs reported during the external evaluations that beneficiaries are not encouraged and supported to continue or become equal citizens actively involved in community life by participating in civic activities and groups (for example, through volunteering, participating as members of local organizations or initiative groups, participating in public meetings on citizenship issues, and so on.) Only a few beneficiaries from a small number of centers attend, for instance, pensioners' clubs or support groups. The motives for limited civic participation have to do with lack of involvement of local

communities, as well as the lack of such activities in the community, accommodations for persons with psychic and mental disabilities, insufficient staff to accompany beneficiaries, and access to public transportation.

#### Standard 7: Outpatient neuromotor recovery

## Standard description

The standard stipulates that centers should offer neuromotor recovery services in accordance with beneficiaries' Personalized Plans and make available dedicated spaces for these activities. The standard also indicates the procedures and the necessary documentation.

#### Self-assessment

Most ONRSCs (11 centers) comply with all requirements covered by the standard, in terms of: (i) necessary facilities for neuromotor recovery activities; (ii) the daily recording of beneficiaries who are provided such activities as well as of activities provided (by the hour); and (iii) the mandatory monitoring activities of the beneficiaries' progress carried out by the case managers through monthly discussions with the service staff involved in service provision. Only one ONRSC fails to fully comply with the standard, since no meetings between case managers and service staff was organized in the past six months to discuss the situation of beneficiaries.

The majority of beneficiaries of ONRSCs are being provided kinesiotherapy and massage therapy (82 percent and 84 percent, respectively), while almost half benefit from physiotherapy and close to one guarter from relaxation therapy. ONRSCs also provide other types of recovery activities to close to one third of beneficiaries, such as speech therapy, psychopedagogy, orofacial mobilization/sensorimotor stimulation, thermotherapy/electrotherapy, combined therapies/hydrotherapy/galvanotherapy/lymphatic drainage, and paraffin applications. All ONRSCs have kinesiotherapists who provide such activities, while in a few centers this type of activity is provided by other types of specialists, such as masseurs (in five centers), physiotherapists and physio-kinesiotherapists (in three), medical doctors and recovery educators (in one). In some centers, the activities are provided by specialized staff who are not mentioned by the standard as the type of staff who can provide such activities, social workers and psychologists, while other types of specialized staff mentioned by the standard are entirely missing from ONRSCs (for example ergotherapy instructor or occupational therapist).

	While ONRSCs have a specific profile for offering neuromotor recovery activities, beneficiaries from DCs are also being provided such activities. In 2020, 14 percent of beneficiaries received kinesiotherapy; 10 percent, massage therapy; 12 percent, physiotherapy; and 11 percent, relaxation therapies.
Comprehensive evaluation: external evaluation, interviews, document analysis	Most interviewed beneficiaries appreciate recovery activities provided by centers, stressing their impact on regaining mobility, mood improvement, and quality of life generally. Some problems with service delivery do stand out nevertheless, such as the need for additional recovery procedures or equipment, as well as larger spaces for therapy. Some beneficiaries also suggested the need for additional specialized staff that may ensure better recovery than using the equipment on their own, for instance. The lack of kinesiotherapists in centers where there is infrastructure for kinesiotherapy activities is a common problem in many centers, as indicated by some coordinators of day centers. Data from external evaluations has also confirmed the problems identified by beneficiaries regarding service provision, such as the lack of necessary staff; adequate spaces; or equipment for providing kinesiotherapy, physiotherapy, and massage therapy.

#### Module 5. Protection and rights

The final module combines standards that refer to beneficiaries' rights, their protection, questions of ethics, risk management, and mechanisms for complaints and for measuring beneficiaries' satisfaction.

Standard 1: Respecting beneficiaries' rights

Standard	The standard must ensure that beneficiaries' rights are respected
description	by making them known to service staff through training sessions. Among the rights listed, there are provisions for respecting beneficiaries' dignity and privacy, as well as including beneficiaries in making decisions about service provision. While the list of rights is a mandatory requirement besides compulsory training sessions, the standard has no other provision to ensure that the listed rights are respected.
Self-assessment	More than 90 percent of all centers have reported full compliance with the standard. About 96 percent of all DC beneficiaries access centers that fully comply with the standard, while this is the case for only 78 percent of beneficiaries in ONRSCs. Despite the minimum requirement about yearly mandatory training for service staff regarding beneficiaries' rights, this was not respected by 2 DCs and 1 ONRSC; in 2020 12 centers provided more than two such training sessions. In 2020, no notifications or

complaints were registered regarding beneficiaries' rights, such as: (i) human rights and fundamental liberties; (ii) provision of information about social rights and services provided; (iii) the right to participate in the decision-making process regarding service provision; (iv) confidentiality rights; (v) beneficiaries' right to dignity and intimacy; (vi) the right to be protected from abuse and neglect; and (vii) beneficiaries' right to freely express their opinions regarding the services received.

Comprehensive evaluation: external evaluation, interviews, document analysis

Only very few interviewed beneficiaries did not have the notion of "rights" or did not know their rights. However, relatively few persons could in fact enumerate their rights, such as the right to work, the right to social benefits (pension, social services), free transportation, the right to express an opinion regarding service provision, and so on. Beneficiaries did complain of discriminatory attitudes from other persons in the community or barriers to access various public services, as well as about the lack of more substantial information about their social benefits as persons with disabilities.

Services must ensure that beneficiaries have access to information about their rights at all times, in addition to relevant information being offered at the moment of admission. Currently, only around half of DCs and two thirds of ONRSCs offer information materials about beneficiaries' rights as service users in accessible formats and in places on service premises where beneficiaries may easily access them.

#### Observations

Although the standard includes mandatory training sessions with service staff on the topic of beneficiaries' rights, it does not stipulate a similar obligation of providing information to beneficiaries in accessible formats, nor about ongoing effective feedback and complaint mechanisms that can ensure access to prompt solutions and remedies. Currently, the standard does not include any requirement about ensuring that staff knows and respects beneficiaries' rights, such as recurrent evaluations of staff performance to assess their understanding and application of the training content in relation to beneficiaries at all times. There are also no specifications regarding the type of material used and the persons providing the mandatory trainings.

#### Standard 2: Risk management

Standard description

The standard covers aspects related to the management of risk situations, such as the existence and content of a specific procedure that is known and accordingly applied by the service.

#### Self-assessment

Close to 64 percent of DCs and 75 percent of ONRSCs comply with the standard. About 78 percent of beneficiaries access DCs and ONRSCs that fully comply with the standard. Some minimum requirements seem particularly problematic with regard to their implementation. Only 15 out of the 20 DCs and 9 out of 12 ONRSCs that have a procedure for managing risk situations are also complying with the requirements about mandatory aspects the procedure must include. Most often missing are aspects related to details about behaviors requiring intervention and post-risk situation measures (in case of ONRSCs), as well as interventions in cases of aggression or in cases beneficiaries leave unannounced. No emergency situation was registered in 2020.

Comprehensive evaluation: external evaluation, interviews, document analysis

Most risk management procedures submitted by centers contained the mandatory aspects stipulated by the standards. Out of 33, 27 submitted specific procedures, while 2 submitted procedures for sheltered houses. There are however significant differences regarding the content of the procedures and how mandatory aspects are detailed:

- Most procedures cover only psychosocial risk factors (such as behavioral unrest, aggression), while very few mention other types of risk that may endanger the health and safety of beneficiaries while on the center premises (such as improper infrastructure, storage of hazardous substances, and so on). In addition, a large number of procedures do not detail the types of psychosocial risk factors and situations that may occur.
- Only some procedures stipulate prevention measures such as: (i) mandatory analysis of risk factors by multidisciplinary teams together with beneficiaries and their families (one procedure mentioned a special document called Behavioral Support Plan); (ii) training personnel on how to identify the first signs of crisis situations by paying close attention to behavioral changes and on how to further relate to beneficiaries to prevent risk situations; or (iii) provision of materials with information on how to avoid and prevent risk situations.
- Only some procedures mention de-escalation measures by giving clear indications on how to relate to beneficiaries, the type of personnel that should relate to beneficiaries (such as staff who knows beneficiaries best), and so on.
- Very few procedures include measures to be taken after emergency situations to support beneficiaries other than calling the emergency service 112, such as psychological counseling or medical care (in the center or at the hospital).

0	Very few procedures mention how and when beneficiaries ar	
	informed regarding the management of risk situations, while a	
	small number mention that beneficiaries are to be informed	
	verbally at the moment of admission.	

- A few procedures recommend physically restraining beneficiaries, not as a punitive measure, but to prevent selfharming, harming other persons, or destroying the center infrastructure and material resources.
- Very few procedures describe in detail how service staff are expected to relate to beneficiaries in crisis situations, while several procedures do stand out by centering the selfdetermination and autonomy of beneficiaries in crisis situations who choose and implement the solutions themselves with the support of service staff who must at all times respect the wishes and preferences of beneficiaries.

#### Observations

Given the variety of procedures analyzed, standards provide further instructions on how to manage a crisis situation and require that services implement specific measures to prevent and manage risk situations that respect beneficiaries' rights, including autonomy and bodily integrity.

Risk management requires adequate know-how about deescalating emergency situations rather than appealing to solutions that could aggravate beneficiaries' state. The standard does not include any clear provision about training or other ways to provide such information to service staff and beneficiaries. In addition, the minimum requirements regarding the content of procedures do not include any provisions on ensuring the informed consent of beneficiaries in any risk situations that may lead to forced treatment or interventions without the beneficiary's consent, such as physical restraint. For example, through planning in advance the interventions the beneficiaries might want or not want to experience in the event they might not be able to give consent.

#### Standard 3: Code of ethics

Standard description	The standard indicates that centers should have a code of ethics, which should have provisions for the equal treatment of beneficiaries and requires that services should be provided in their best interest and that professional ethics should be absented. Centers should also erganize staff training sessions on
	observed. Centers should also organize staff training sessions on the code of ethics.
Self-assessment	The rate of full compliance is 100 percent in the case of ONRSCs, and all but one DC. The missing requirements of the single DC are related to the content of the ethics code. For example, provisions

	regarding equal treatment of beneficiaries and nondiscrimination, providing services exclusively in the beneficiaries' interest and respecting professional deontology, and the annual mandatory staff training regarding the provisions of the ethics code. More than a quarter of centers (6 DCs and 3 ONRSCs) provided two or more annual training sessions.
Comprehensive evaluation: external evaluation, interviews, document analysis	Most codes of ethics submitted by centers (3 services did not submit their codes) did include the minimum requirements stipulated by the standards, such as equal treatment and provision of services in the interest of beneficiaries. However, most codes mention these aspects rather briefly as principles, with no further detail on how these principles are to be implemented in practice or what their violation could entail. In fact, more than one third of all codes submitted do not specifically regulate the activities of a particular center, but rather the activity of all staff at the level of GDSACPSs.
Observations	Some procedures provide a section regarding the service staff responsibilities in relation with beneficiaries which stipulates that staff is allowed to limit beneficiaries' self-determination whenever the latter's choices contradict professional ethics or whenever their present or future actions may endanger themselves or other persons. The procedures do not give any clear example about such situations, and in the absence of any provisions in the standards regarding clear steps for ensuring the informed consent of beneficiaries, including through provision of decision-making support, there is a risk that beneficiaries' rights could be limited arbitrarily.
Standard 4: Protect Standard description	The standard covers minimum requirements that are needed to ensure the beneficiaries' protection against situations of exploitation, violence and abuse, such as the existence of a specific procedure that is known and applied by service staff, the yearly training of staff on the topic, the obligation of staff to encourage and support beneficiaries to identify and report such situations, and the obligation of the SSPs' to identify, register and take prompt action should such situations occur.
Self-assessment	Less than half of DCs and two thirds of ONRSCs are fully compliant with the standard. About 63 percent of all DC beneficiaries access centers that fully comply with the standard, while this is the case for only 48 percent of beneficiaries of ONRSCs. Only a few centers reported no compliance with some of the minimum requirements (for example, the existence of a specific procedure or recording

of cases in a special register), but approximately half of the centers did not have a specific procedure that included all aspects stipulated by the standard (11 DCs and 5 ONRSCs). In particular, the aspects most often missing from the procedures are those related to the administration of medication and management of beneficiaries' assets and money. In addition, while only four centers (three DCs and one ONRSC) did not organize their annual mandatory staff training, there were also centers that organized more than one training session in 2020 (five DCs and three ONRSCs).

Comprehensive evaluation: external evaluation, interviews, document analysis

Document analysis showed that specific procedures include clear responsibilities of staff and SSPs for identifying and reporting cases of violence, exploitation, and abuse, as well as concrete actions. There are however significant differences between specific procedures used by services to ensure the protection of beneficiaries against exploitation, violence, and abuse.

- o Beneficiaries may themselves report situations of violence and abuse, verbally or in writing, through questionnaires administered by service staff or by filing complaints to a box especially designed for this purpose. However, only one procedure stipulates that beneficiaries may notify the SSP directly or call the police or other independent organizations.
- Very few procedures provide a clear timeline for acting in cases of violence and abuse.
- Not all procedures stipulate the mandatory provision of information to beneficiaries regarding protection against negligence, violence, and abuse. In cases where such stipulations exist, it is not always specified when and how beneficiaries are to be informed. Some centers do mention the organization of yearly or quarterly training sessions, while others provide information to beneficiaries upon request or through information materials available in the center.
- Very few procedures mention the possibility of offering postabuse counseling provided by service staff or other organizations, and, generally, procedures do not include instructions on how service staff must interact with victims and perpetrators to avoid causing secondary trauma.
- Very few procedures make reference to the administration of medication, as required by the standard, as well as to the management of beneficiaries' money. However, some procedures exclude from the list of situations of violence and abuse the administration of medication according to doctors'

instruction in the absence of beneficiaries' consent. The same procedures also exclude physically restraining beneficiaries from the list of violent and abusive practices.

Although all services that were externally evaluated reported that they support and encourage beneficiaries to identify and report cases of violence, exploitation, and abuse, most centers do so by providing beneficiaries with information (formally or informally) about the procedure, their rights, or other relevant themes. Only a few provide psychological counseling as a form of support or encouragement in such situations or support beneficiaries to report the abuse to competent institutions.

#### Observations

To ensure adequate protection from violence and abuse, standards must include clear provisions on

- How staff should encourage and support beneficiaries to identify and notify situations of violence, exploitation, and abuse;
- Informing beneficiaries on how to identify and report situations of abuse, as well as ensuring their protection from possible retaliation from perpetrators in case these are service staff or beneficiaries;
- Ensuring that beneficiaries are treated only with their full and informed consent, and that nonconsensual practices are avoided (such as involuntary administration of medication or physical restraints);
- Ensuring access of beneficiaries to relevant services in the event of such situations; for instance, psychological counseling, shelters, and so on; and
- Ensuring access of beneficiaries to an independent external mechanism for reporting and reviewing such cases, as well as to legal and counseling services and advocates.

#### Standard 5: Protection against torture and cruel, inhuman, or degrading treatment

standard 5: Protection against torture and cruei, innuman, or degrading treatmen		
Standard 5. Trotect Standard description	The standard covers minimum requirements needed to ensure the beneficiaries' protection against situations of torture and cruel, inhuman, or degrading treatment, such as the existence of a specific procedure that is known and applied by service staff, the	
	yearly training of staff on the topic, the obligation of staff to encourage and support beneficiaries to identify and report such situations, and the obligation of the SSPs to identify, register, and take prompt action should such situations occur.	
Self-assessment	Approximately 82 percent of DCs and 92 percent of ONRSCs reported full compliance with all minimum requirements included	

	in the standard. About 80 percent of DC and 78 percent of ONRSC beneficiaries access centers that fully comply with the standard. A few centers do not comply with some of the specific requirements, including: (i) a specific procedure regarding the protection against torture and cruel, inhuman, or degrading treatment (one DC); (ii) yearly staff training on aspects relevant to the standard (three DCs and one ONRSC); and (iii) a register for recording such situations (two2 DCs). One DC also reported that it does not encourage and support beneficiaries to identify and report such cases. In addition, while only four centers (three DCs and one ONRSC) did not organize annual mandatory staff trainings, there were also centers that organized more than one such training session in 2020 (four4 DCs and three ONRSCs).
Comprehensive evaluation: external evaluation, interviews, document analysis	Generally, centers use a similar format and structure for specific procedures required by Standard 4 and Standard 5. Similar results from the comprehensive evaluation for Standard 4 apply.
Observations	See Standard 4
	cations and complaints
Standard description	The standard indicates that there should be a procedure for registering and solving beneficiary complaints, what the procedure should contain at the minimum, and some other requirements regarding documentation and archiving as well as the possibility of using external mediation at the request of the service (not the beneficiary). The procedure also includes aspects about informing beneficiaries on how to submit notifications and complaints.
Self-assessment	Approximately 80 percent of both DCs and ONRSCs reported compliance with the standard. About 91 percent of all DCs beneficiaries access centers that fully comply with the standard, while this is the case for only 67 percent of beneficiaries of

Approximately 80 percent of both DCs and ONRSCs reported compliance with the standard. About 91 percent of all DCs beneficiaries access centers that fully comply with the standard, while this is the case for only 67 percent of beneficiaries of ONRSCs. The minimum requirement with which both types of services reported the least compliance (a little over 80 percent) is the possibility to appeal to external mediators to find adequate solutions in case of complaints No complaints were registered during 2020.

Comprehensive evaluation:

Document analysis indicated that evaluated day services have a variety of procedures for registering and solving beneficiaries'

external evaluation, interviews, document analysis complaints. Beneficiaries can lodge complaints directly with the service coordinator or GDSACP/DSA directors in writing, indicating their name and details about the reason for the complaint, write down the complaint in a public register available for all beneficiaries on the center premises, placing the complaints in a box especially assigned for this purpose on the center premises, or through questionnaires administered by service staff. In some centers, the complaint reaches the GDSACP's directors or other authorities (county councils) if no satisfactory solution could be found by the service staff or coordinators or in the case of more serious issues. Police or prosecutors may also be called on in cases of serious misdemeanors reported by beneficiaries. Some procedures provide beneficiaries with the option to voice their complaints directly to service staff, in which case the reporter may also be receiving the solution verbally.

Although the majority of procedures give clear indications as to how beneficiaries can file complaints, not all mention the timeline for resolving the complaints and only a few detail the aspects of service provision about which beneficiaries can lodge complaints.

The practice of informing beneficiaries also varies according to the procedures analyzed. Beneficiaries are either informed about the possibility to submit complaints upon their admission to the center or at various times throughout their time spent as beneficiaries. Some centers keep a register with all the information sessions (five, according to the external evaluation). In addition, three services also provide beneficiaries with information materials, and nearly a third of all centers reported that they inform beneficiaries about these aspects informally with an unspecified frequency. Only eight DCs and four ONRSCs reported that they make the procedure for recording and solving complaints available to beneficiaries in accessible places in the center.

In some cases, procedures stipulate that beneficiaries are to be guaranteed protection against possible retaliation, but do not further detail how this protection is ensured.

#### Observations

Standards should include clear provisions on informing beneficiaries about the procedures for recording and solving complaints and the timeline and persons responsible for processing and addressing complaints. Beneficiaries should be provided with the specific procedure on lodging complaints in

accessible formats. In addition, the procedure on notifications and complaints should also include more provisions on how to avoid any consequences that may occur in the event of complaints submitted verbally or in writing by beneficiaries.

#### Standard 7: Beneficiary satisfaction

## Standard description

This standard is meant to assure a mechanism for evaluating beneficiary satisfaction about services provided. Centers are required to apply questionnaires and include their analysis in their annual reports. Beneficiaries can ask for support in filling out the questionnaires from staff members, family, or their legal representatives.

#### Self-assessment

Only 73 percent of DCs and 58 percent of ONRSCs are fully compliant with the minimum requirements included in the standards, while these centers offer services to approximately 68 percent and respectively 44 percent of the total beneficiaries. Some of the standard's requirements are met to a lesser extent. For instance, some services did not administer questionnaires to beneficiaries at all (three DCs and one1 ONRSC), while others did so only partially. Other requirements also proved to be challenging for some centers, including: (i) the use of a box for placing filled in guestionnaires was not implemented by five DCs and two ONRSCs; (ii) lack of analysis of questionnaires in the annual activity reports of seven centers; and (iii) lack of support to beneficiaries to fill out questionnaires. About 38 percent of beneficiaries in DCs received support to fill in questionnaires compared with 38 percent in ONRSCs, which may be explained by the higher percentage of beneficiaries with psychic and mental disabilities in DCs.

Comprehensive evaluation: external evaluation, interviews, document analysis

The practice of evaluating the quality of service provision in DCs and ONRSCs was confirmed by the majority of interviewed beneficiaries who filled in satisfaction questionnaires. Some beneficiaries from DCs filled in the questionnaires with support from service staff, while all interviewed beneficiaries of ONRSCs did so autonomously. Data from the external evaluation also confirmed that more beneficiaries from DCs have received support. While most ONRSCs offered support to only up to 20 percent of their respective beneficiaries, 5 out of 11 DCs offered support to more than 60 percent of their beneficiaries.

It is unclear how results were processed and used for improving quality of services, given that document analysis indicated that less than 20 percent of centers included the results from the satisfaction questionnaires in their annual activity reports. Only

two centers offered a detailed analysis of how data was collected and analyzed, as well as of the degree of beneficiaries' satisfaction on particular aspects of service provision. This is in contrast with data reported by centers themselves, according to which 27 out of 33 services included this analysis in their yearly activity reports.

Beneficiaries made suggestions and complaints for the improvement of the quality of services in almost two thirds of the centers (13 DCs and 7 ONRSCs). The most common complaints were related to insufficient space dedicated to activities, lack of materials or equipment (for kinesiotherapy or electrotherapy, air conditioning, and so on.), and only very few related to insufficient opportunities social, cultural, and sports activities such as trips, competitions, visits to museums, or concerts, maintenance, lack of specially designated parking spaces, or the large size of working groups for specific activities. Some of these reported shortcomings were reported by services as having been addressed.

Questionnaires are not the only method beneficiaries use to give feedback on services provided, as some given informal verbal feedback directly to service staff. Generally, beneficiaries reported that they felt safe and listened to by staff members who treat them more as colleagues and family members than beneficiaries. While building an informal environment may lead to feelings of safety and trust for beneficiaries, it may also jeopardize the possibility of addressing complaints, especially those regarding the attitude or behavior of service staff.

#### Observations

Feedback is essential for ensuring that beneficiaries have control over services provided, but the effectiveness of this process is dependent on conditions of anonymity, safety, and trust. Standards need further improvement to ensure these conditions, either through providing additional requirements or by detailing how current ones are to be further implemented.

Although the standard stipulates that beneficiaries are provided support for filling in the questionnaires (either from the service staff, legal representatives, or family members), it does not further specify the reasons why beneficiaries might need such support. This is particularly problematic since the support offered by service staff might lead to a breach of confidentiality, conflict of interest, and undue influence, given that staff performance and behavior is part of the service provision that beneficiaries are expected to evaluate. Analysis of questionnaires used by centers

indicated that more than two thirds of all day centers in the sample use questionnaires that include questions to evaluate how service staff interacts with beneficiaries, including questions about possible abuse and punishment of beneficiaries by personnel. Approximately the same proportion of services use questionnaires that do not ensure beneficiaries' anonymity because beneficiaries are expected to write their names down. It is possible that support is also offered due to lack of questionnaires in accessible formats: Only a little over half of all centers (13 DCs and 4 ONRSCs) reported having questionnaires in easy-to-read formats, Braille, or audio-video formats with subtitles.

In effect, the evaluation of service provision by beneficiaries must be anonymous by providing questionnaires in accessible formats such as easy-to-read, Braille, audio-video with subtitles. In addition, the evaluation must involve independent evaluators who can offer support to beneficiaries both for filling in the questionnaires and ensuring that overall data collection and analysis is carried out in a way that does not compromise the accuracy, completeness, and reliability of information provided by beneficiaries and that keeps them safe from any negative consequences or retaliation.

#### 2.5.4. Conclusions and recommendations

#### Standards compliance and implementation

Overall, as the detailed comprehensive evaluation above shows, there are issues with compliance in most areas, in both modules and standards. A few of these issues are related to improper documentation and more formal aspects of service provision, but some are connected to more substantive issues such as staff provision and training, services and activities, material conditions, and involving beneficiaries in the process of service planning and provision, as well as in the feedback process regarding service use.

In light of these issues, some comments and recommendations are worth mentioning:

The choice and control over service provision need to be further ensured for current and prospective beneficiaries. More effort should be put into communicating and publicizing existing services to all potential users. Most beneficiaries have found out about the existence of centers through informal channels (friends, family, or other persons with disabilities) and very few through more formal or institutional channels. Although service capacity is low and ensuring access for anyone who may need day services might not seem important at this time, as day centers are being further developed it is crucial that information reaches all

potential beneficiaries. Moreover, information about all aspects related to service provision should be made available to all beneficiaries before admission and throughout the time spent as beneficiaries of the service, either through information sessions or by making available information materials in accessible formats. In addition, feedback procedures on the quality-of-service provision should be anonymized by providing feedback instruments in accessible format and possibly by involving independent evaluators to avoid conflict of interest and undue influence from service staff.

- o A great deal of care should be taken in making sure there are no discriminatory or nonconsensual practices in admitting beneficiaries into a service. Certain DCs practice quota systems for admitting beneficiaries from the community (keeping spots for those in residential centers and sheltered houses). In at least one center, beneficiaries are required to take a HIV test, which, even if HIV status does not condition admission, is a discriminatory practice that could limit the access of persons living with HIV to centers. Moreover, service coordinators seem to divide potential beneficiaries into "good"/"desirable" beneficiaries "bad"/"undesirable" beneficiaries, variously based on their potential for recovery and entering the labor market or on their docility. In some of these cases certain types of psychosocial forms of disability are grounds for denying admission, citing the need to protect the other beneficiaries from alleged aggressive behavior. Private service providers are blamed for seeking the best beneficiaries. In addition, some beneficiaries are accessing services as a result of decisions taken by their legal representatives, families, or authorities. Decision-making support should be provided so that neither the alleged lack of mental capacity of beneficiaries nor their legal capacity status can be invoked to limit their opportunity to freely chose a given service.
- The person-centered dimension of service provision needs further regulation. Personalized Plans should be more responsive and reflect closer and more dynamically beneficiaries' needs and options. Service providers should make more efforts for including the beneficiaries in the process of service planning and delivery. The assessment carried out for this report has revealed that beneficiaries are not always involved in these processes. Some service coordinators complained that beneficiaries "are not cooperative" and refuse to or fail to do the recommended activities. At the same time, beneficiaries have expressed boredom and the desire for some variation. All of these indicate a lack of true correspondence between the beneficiaries' interests and desires and the personalized plans.
- Centers must provide a broader spectrum of services to ensure the development of beneficiaries' potential and their full inclusion in the community.
  - More variety in activities and control should be offered to beneficiaries. Many beneficiaries have mentioned that they would like to do other activities than

those they have been doing, in some cases, for years. Some offered examples from other centers they have heard about, while others admitted that they are not able to come up with ideas, but they would like to be offered a list they can chose from. It is possible that after a while activities cease to be stimulating and engaging and people get bored and less interested in pursuing the activities in their plan.

- Psychological counseling services should be extended. All beneficiaries who had access topsychological counseling services have indicated the immense value it has on their general well-being, and those who were not able to access these types of services suggested that they would appreciate being able to receive them.
- The socialization and leisure function of the centers could be formalized. The standards currently do not indicate these kinds of activities directly, although some of the habilitation or rehabilitation activities can be taken as such. Reconceptualizing space and activities to be more conducive to socializing and enjoyment could greatly enhance the experience of most beneficiaries.
- Centers should encourage and facilitate access to other services in the community. At the moment, this does not happen, or it happens sporadically. Furthermore, some service coordinators discourage beneficiaries from accessing other services, which they consider low quality, infantilizing beneficiaries, or even treating them poorly. In addition, service providers should make sure that all beneficiaries have access to education and employment opportunities, by promoting partnerships with local authorities, local employment agencies, employers, and other organizations.
- More resources should be invested in building the capacity of centers' staff. It is clear that a well-trained, highly motivated, and well-paid staff has a direct impact on the quality of services provided as well as on the experiences of the beneficiaries. This evaluation has revealed that there are problems in the specific training provided to staff (required by the standards), as some lack the necessary qualifications. One service coordinator indicated that formal education is not that important and that practical experience can make up for it. There also is a significant number of vacancies, particularly in DCs.

#### Value and success of the service

Beneficiaries' level of satisfaction with services is high, both as reported by centers and as indicated directly by beneficiaries themselves in the interviews. Beneficiaries value the services they receive, in particular the habilitation/rehabilitation, recovery, and psychological counseling services. They feel these services have made a great deal of difference in their lives, physically, emotionally, and socially. Some were able to start working, have enough self-confidence to go out into the community, and initiate

and sustain social relationships. At the same time, they had relatively low expectations of the rest of the services that centers are offering.

Some of the high levels of satisfaction with services comes from experienced centers as a safe place where beneficiaries can socialize and feel accepted and valued. For many beneficiaries, centers are the only place they go when they leave their homes. It is the place where they made friends and spent time. Furthermore, beneficiaries do not necessarily perceive centers as specialized services, but rather as leisure/hanging out/general activities. They speak fondly of the time spent there, chatting, doing activities, and drinking tea and coffee.

At the same time, the high level of satisfaction with the centers might also reflect the lack of alternatives in the community both in terms of specialized services and services for the general population and spaces that persons with disabilities could access. A review of the literature of users' satisfaction with day centers (in particular day centers for persons with intellectual disabilities) showed that those who used day centers in the present were more likely to evaluate them positively and not say they would like to change what they do in their daytime. Those who moved on to activities and services in the community evaluated day centers more negatively and found them stigmatizing. Beneficiaries that were interviewed for this report are aware that, as valuable as these centers are, they are ultimately a form of segregation, and what they ultimately want is to have full access to the "outside" world and be treated with dignity and respect.

The current shortage of services can be turned into an opportunity. Day Centers in particular and also Outpatient Neuromotor Recovery Service Centers should be extended and made available to a much larger number of beneficiaries. At the same time, they should be redesigned as spaces of integration, where persons with and without disabilities can socialize, participate in various activities, and improve their lives. This might require rethinking the centers as places of preparation for employment or adult life, or spaces for leisure and the arts, of personal care, and so on. One solution is to design them as community centers; for example, in Sweden, there are two types of centers, one that is more employment-related and one that functions more like a meeting and socializing place. What should not happen in the development of the system is to invest in and solidify a system that continues to segregate persons with disabilities, to address them only as persons with disabilities, and to limit their opportunities for a life in the community.

<sup>&</sup>lt;sup>155</sup> Cole et al. (2007).

<sup>&</sup>lt;sup>156</sup> Lundqvist et. al (2018).

#### 2.6. Personal Professional Assistance

This chapter offers a comprehensive evaluation of the personal professional assistance (PPA) service with regard to compliance with the minimum quality standards provided by Romanian national law. It first introduces the legal and strategic framework that regulates provision of this service. It then provides a comprehensive evaluation of the service in terms of its compliance with minimum quality standards, and proposes recommendations to improve the standards and ensure higher quality service provision in line with independent living principles.

#### 2.6.1. Legal and strategic framework

According to Law no. 448/2006, personal professional assistance is one of the protection measures for adults with disabilities. 157 This measure is instituted by the committees that evaluate adults with disabilities at the county or local level for the Bucharest municipality, and is directed at adults with disabilities who have no access to housing or income, or have income below the national medium wage. 158 The PPA is employed by the social service provider-either General Directorate for Social Assistance and Child Protection (GDSACP) or private, accredited social service providers (SSPs)—while GDSACPs are in charge of monitoring and controlling PPAs' activity. 159 GDSACP specialists are obligated to provide counseling and support to PPAs so they can best care for and protect adults with disabilities. 160

The service is provided by public or private SSPs, at the request of beneficiaries, by designating a PPA compatible with them. PPAs are certified by the assessment committee of adults with disabilities at the GDSACP level, upon a thorough evaluation of conditions with which PPAs must comply. 161 Shortly thereafter, the comprehensive assessment service matches a PPA with a beneficiary. During this process, beneficiaries must be continuously consulted and supported to actively participate in the implementation of the measure. 162 PPAs are employed by SSPs (public or private) and must sign an engagement letter as an addendum to the employment contract that requires them, among other things, to implement all activities and services specified

<sup>&</sup>lt;sup>157</sup> Besides personal assistance, home-care services, and services provided in day centers or residential centers. Law no. 448/2006. Art. 5. 23<sup>1</sup>.

<sup>&</sup>lt;sup>158</sup> Law no. 448/2006, Section 3. Personal professional assistant. Art. 45 (1). Unlike the service of personal assistance, the close family (wife, husband, children, grandparents) cannot apply for the position of personal professional assistant. Art. 45 (1^1).

<sup>&</sup>lt;sup>159</sup> Ministry of Labor and Social Justice Order no. 1690/2018 for the approval of the procedure of monitoring and control of the activity of personal professional assistant.

<sup>&</sup>lt;sup>160</sup> Law no. 448/2006. Art. 47 (a).

<sup>&</sup>lt;sup>161</sup> Government Decision no. 548/July 27, 2017 regarding conditions for obtaining the certificate, certification procedures, and the statute of personal professional assistant.

<sup>&</sup>lt;sup>162</sup> Government Decision no. 548/July 27, 2017 Art. 10 (1) and (2).

in the Individual Program of Rehabilitation and Social Reintegration (IPRSR) and Individual Plan of Services (IPS). 163

Personal professional assistance is considered a type of community-based service that can facilitate independent living and prevent reinstitutionalization. 164 Romania's approved list of social services currently states that personal professional assistance is one of two community-based services for adults with disabilities, 165 besides the service for assistance and support. 166 Personal assistance is a key community-based service that can ensure independent living as stipulated by Art. 19 of the CRPD on *Living independently and being included in the community*. The European Strategy for the Rights of Persons with Disabilities 2021-2030 refers to personal assistance as part of the differentiated landscape of the community-based services needed to ensure independent living. 167 In addition, Romania's current disability strategy aims to increase the number of PPAs and revise and complete the regulatory framework for this service as measures to improve beneficiaries' access to community-based services and ensure independent living. 168

Providing assistance for persons with disabilities at the PPA's home may pose challenges to beneficiaries' choice and control over the service, as well as the autonomy needed to live independently. Personal professional assistance is designed to offer housing to persons with disabilities, in addition to other activities and services aimed at supporting independent living. The CRPD committee highlights that services for persons with disabilities should not be provided as "package solutions" that link the

<sup>&</sup>lt;sup>163</sup> According to Law no. 448/2006. Art. 5 (24) (25). The IPRSR is elaborated by the evaluation committee of adults with disabilities and includes the activities and services the person with disabilities may need in the process of social inclusion; the IPS establishes the short-, medium-, and long-term objectives, specifying the types of intervention and support needed, specific to the activities and services included in the IPRSR. While Law no. 448/2006 does not specify the institution/person responsible for elaborating the ISP, Order no. 1218/2019 for the approval of the minimum mandatory quality standards for the application of the case management method regarding the protection of adults with disabilities established with Standard 3 that the ISP is the case manager's main instrument, and this can be elaborated either by the evaluation committee or by the multidisciplinary team in the case of a residential system.

<sup>164</sup> Government Decision no. 548/2017, Art. 2.

<sup>&</sup>lt;sup>165</sup> Government Decision no. 867/2015 for the approval of the classified list of social services, as well as of the framework regulations for organizing and operating social services. Service code 8899 SC-D-I.

<sup>&</sup>lt;sup>166</sup> Regulated by Order no. 82/2019, Annex 7. The law stipulated that *Services for assistance and support for adults with disabilities* comprise a set of activities provided so as to meet the specific individual needs of adults with disabilities and family members or their representatives, in order to overcome difficult situations and to prevent institutionalization.

<sup>&</sup>lt;sup>167</sup> European Commission (2021). Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. COM (2021) 101 final. 7. Developing independent living and reinforcing community-based services.

<sup>&</sup>lt;sup>168</sup> Operational Plan for the implementation of the National Strategy on the rights of persons with disabilities, 2021–27. Specific Objective 5.3. Improving the access to social services in the community necessary for independent living. Measures 5.3.10 and 5.3.11. Currently in the consultation process.

availability of one service to another 169—in the case of the PPA, of linking housing to the provision of professional personal assistance, and that such practice is not in line with Art. 19. This idea has been emphasized by the first models of personal assistance, which envisioned a service that can facilitate independent living but is not provided in the same package as housing. 170 The separation between housing and support has also been reiterated by the European Expert Group of the Transition from Institutionalized to Community-Based Care as a design principle of community-based services, to ensure that individuals do not lose access to personal assistance should they decide to change their living arrangements. 171

Personal professional assistance has been promoted as a service that can facilitate the deinstitutionalization of persons with disabilities. During the 2014-2020 programming period, the Romanian government assumed the obligation to ensure the transition from an institutionalized care system to one that facilitates independent living through access to alternative community-based services. As an outcome indicator, 1,300 persons with disabilities would be deinstitutionalized during 2015-2023, of which 516 people through funding from European funds, and the rest through national funding. 172 As a community-based service, PPAs are expected to facilitate access to all resources and facilities in the community, including those related to health, education, occupation, culture, leisure, and social relationships. 173

PPA services are unevenly developed at the national level. In August 2020, there were 238 PPA positions in the organizational charts of 16 GDSACPs; however only 2 counties had 21 PPAs employed at the time. 174 Interviews with GDSACP directors and representatives mainly highlighted the lack of local budget for PPA positions, as well as a lack of interested persons to apply for these positions in counties where they do exist. Despite local authorities' attempts to launch information campaigns about the existence of such services and related employment opportunities—including those aimed at staff of residential centers—there is still little interest in such jobs; most often, former professional maternal assistants (PMAs) apply to become PPAs (see Box 17).

#### Box 17: Challenges to developing the PPA service

"When the institution of personal professional assistant was established, it was a really good idea and it was conceived in a similar was as the maternal assistant. When it was included in the legislation, it was similar to the PMA, regarding remuneration

<sup>&</sup>lt;sup>169</sup> CRPD Committee (2017: para. 17).

<sup>&</sup>lt;sup>170</sup> Ratzka (ed.) (2004).

<sup>&</sup>lt;sup>171</sup> European Expert Group on the Transition from Institutional to Community-based Care (2012: 84).

<sup>&</sup>lt;sup>172</sup> Substantiation note. Government Decision no. 548/July 27, 2017 regarding conditions for obtaining the certificate, certification procedures, and the statute of personal professional assistant.

<sup>&</sup>lt;sup>173</sup> Substantiation note. Government Decision no. 548/July 27, 2017 regarding conditions for obtaining the certificate, certification procedures, and the statute of personal professional assistant.

<sup>&</sup>lt;sup>174</sup> World Bank (2021: 189).

rights and housing rights for the person with disabilities which were the state's responsibilities, just as is the case with the PMA. Eeee... but in 2018 things changed and this is not the state's responsibility, it is now the county's. And the county does not have money. If the county was assigned with the task to build [the service], in addition, you also burden it with this, you also assign it the employees from the GDSACP structure, how could we possibly employ other people? We could not employ anyone last year and neither will we employ this year, because we have no funding. Why did not they keep the similarity with the funding from the state?" -GDSACP Deputy director

"We did a study regarding the PPAs, we only had one request, an intention in fact." -GDSACP director

"I here return and say if you really want these persons to exist, besides the aspects concerning the needs or the availability and willingness to get employed, let's try through a cost standard as is the case with other services, to fund the PPAs, and in that situation perhaps the County Council might be more willing to open more positions and then through campaigns, mass-media, we could find persons for this service. You should carry out a research at the national level, how many persons want to take home persons with disabilities, to take care of her, you need to have a home, availability. The maternal assistant is a different story, it is about a child. You may take care of a person with disabilities only if have a certain availability, how to put it, a sort of psychiatric availability, otherwise, it is extremely difficult." -GDSACPdirector

"We have had it for a long time in the organizational chart but this service hasn't been developed [...] we are in the phase of establishing the working procedures and criteria, in the summer we will start informing the community for the selection." -GDSACP Head of case management service

Source: World Bank interviews with GDSACP directors (March-April 2021).

#### 2.6.2. Assessment of personal professional assistance

This section presents a detailed evaluation of compliance with the standards' minimum requirements, using the service's self-evaluation, information gleaned from the external evaluation, interviews with service coordinators and beneficiaries, and the analysis of documents offered by the services.

The analysis focused on two services at the level of two GDSACPs that coordinate the PPA activity at the county level. Only one service has been organized as a distinct department at the GDSACP level since 2019. As of April 2021, only around a third of vacant PPA positions had actually been filled. For the department established as a distinct service, most beneficiaries of the PPA service were admitted in 2020 (8 out of 9), while for the other service, the majority of current beneficiaries were already being provided services on January 1, 2020; just one beneficiary had their contract for service suspended in 2020.

Table 16. PPA positions (open and filled) in the two GDSACPs

Number of available PPA Number of filled positions positions

Service 1	24	8
Service 2	30	9

Source: World Bank survey of personal professional assistance services (2021).

Beneficiaries of PPA services have both accentuated and high degrees of disabilities and are overwhelmingly youth from the child special protection system. All PPA service beneficiaries are youth between 18 and 29 years old, and all have been previously placed in the care of a PMA. The majority have a degree of disability and mental disabilities according to their disability certificate, while a few have psychic and associated disabilities. None were deprived of their legal capacity at the time of data collection. Regarding their family situation, there is a significant difference between beneficiaries at each GDSACP level—in one county, none of the beneficiaries have known families, while in the other the majority do. Similarly, in one county, most beneficiaries live in rural areas, while the opposite is true in the other county. Most beneficiaries are young men (see Annex-Table 6).

#### 2.6.3. Standards compliance

#### Module 1. The service that ensures care and protection by the personal professional assistant

The first module covers the minimum conditions that SSPs are expected to implement regarding the service's organization, including the structure and qualification of staff, and relevant procedures and instruments; recruiting PPAs and promoting the service at the community level; training, monitoring, and evaluating PPAs' activity; partnerships with other organizations; and annual public reporting of PPA activities, including recommendations to improve service quality.

Standard 1: The service that ensures care and protection of adults with high or accentuated disabilities by the personal professional assistant

	y the personal professional assistant	
Description	This standard covers aspects related to ensuring the care and protection of adults with disabilities by PPAs in terms of the standards, procedures, and instruments used in service provision, as well as recruiting and training PPAs.	
Self-assessment		

	equal opportunities; preventing exploitation, violence, and abuse; respect for diversity; and respecting and encouraging individual autonomy.  One GDSACP identifies and recruits PPAs through information provided on their website, while the other does not recruit PPAs proactively, but on an as-needed basis, and only when there is a request from a potential beneficiary in accordance with his/her needs. This may considerably limit beneficiaries' options and the control they have over the service, since it is the SSP that chooses the PPA.  One SSP reported that overall, some regulations that pertain to the organization of the PPA service are not respected.  None of the SSPs promote partnerships with NGOs or other relevant specialists, and had no such partnerships in 2020.
Comprehensive	External evaluations indicated that PPAs in one county
evaluation: external	were not provided with annual trainings as required by
evaluation, interviews,	the standard. In addition, all PPAs are former PMAs that
document analysis	requested by law to transition to PPAs, and their
	recruitment was the result of their own request to
	transition.
Observations	The standard does not currently include any provision
	regarding the person(s) responsible for annual PPA
	trainings, nor the materials used, and in effect cannot be
	used to measure the quality of training PPAs receive or
	their level of knowledge.

# Module 2. Accessing the service

The second module covers a series of requirements related to providing information about the service (admissions, PPA activity, rights and obligations, monitoring and control), including information in accessible formats for potential beneficiaries, the admissions procedure, the content of beneficiaries' personal files and confidentiality, as well as suspension/cessation of the service contract.

# **Standard 1: Information**

Description	This standard is meant to ensure access to information about all aspects related to service provision (admission conditions, PPA activity, rights and obligations, interinstitutional relations, monitoring and control), on paper or online to anyone interested in the service. The information materials are to be regularly updated.
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Self-assessment	According to the self-assessment form, some requirements were not respected:
	<ul> <li>Information materials must also be provided in accessible</li> </ul>
	formats (easy-to-read, Braille, audio-video presentations,
	sign language interpretation). However, only one SSP
	provides accessible information in an easy-to-read format.
	<ul> <li>One of the SSPs includes beneficiaries' personal data in information materials about the service without the latter's</li> </ul>
	consent.
Comprehensive	External evaluations of PPA services and interviews with
evaluation: external	beneficiaries indicated that only one beneficiary had access to
evaluation,	information about the PPA service, but this was not provided
interviews,	in accessible formats. All PPAs evaluated were former PMAs,
document analysis	and some SSPs only verbally informed the beneficiaries that the PMA service was transforming to PPA service.
Observations	PPA beneficiaries were also not informed of other services in
Objet vacions	the community, including other PPAs at the time of their
	admission, which raises questions about their informed choice
	of the current service.
Standard 2: Admission	n
Description	This standard covers mandatory aspects of the admission
	procedure elaborated by the SSP, the content of the procedure
	(eligibility criteria for beneficiaries, admission process and
	necessary documents, service contract, including the rights
	and obligations of beneficiaries) and provisions about the service contract, including the SSP's obligation to explain the
	content of the contract to beneficiaries or their legal
	representatives.
Self-assessment	Both services comply with the standard.
Comprehensive	External evaluations and interviews indicated that
evaluation: external	beneficiaries were only partially involved in the admission
evaluation,	process, regardless of their support needs for understanding
interviews,	and communication. Rather, it was the PPAs who requested to
document analysis	be certified as PPAs for beneficiaries for whom they had
	previously been PMAs. While data from self-assessment
	instruments shows that none of the beneficiaries benefit from
	a protection measure of being placed under guardianship,
	during the external evaluations, all five interviewed PPAs reported that their beneficiaries did indeed have a legal
	guardian who was either a representative of local authorities
	(including the Guardianship Authority) or themselves. This
	raises further questions about issues of legal representation
	that may affect beneficiaries' active involvement and
	participation in all aspects of the admissions process.

Observations	Clearer specifications are needed to ensure that beneficiaries are fully and actively involved in the admissions process, by providing them with decision-making support whenever necessary, to ensure the service is accessed with full informed consent.	
Standard 3: Personal	file	
Description	This standard covers mandatory aspects of the beneficiaries' personal files (admission disposition, identity papers in copy, the case manager's contact details, the service contract, the IPRSR and IPS), as well as issues related to confidentiality and beneficiaries' ability to consult their file.	
Self-assessment	All requirements are complied with. No beneficiaries asked to consult their files in 2020, despite this being their right as per the standard.	
Standard 4: Suspension/cessation of service		
Description	This standard refers to issues pertaining to the service contract's suspension/cessation, related procedures and documents, as well as the SSP's responsibilities.	
Self-assessment	Both services comply with the standard.	

# Module 3. Care and protection of adults with high or accentuated disabilities by the **PPA**

The third module comprises eight standards related to monitoring PPA activity regarding the implementation of the IPRSR and IPS, the support the SSP is expected to provide for implementation, as well as aspects that must be included in a beneficiary's evaluation whenever plans are updated.

Standard 1: Individual program for rehabilitation and social reintegration (IPRSR) and individual plan of services (IPS)

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Description	This standard pertains to the support that SSPs are obligated
	to give to PPAs to ensure IPRSR and IPS implementation, and
	the obligation of SSPs to make sure that any evaluation of
	beneficiaries relates to all of their needs and ensures they can live independently in the community.
Self-assessment	According to self-assessments, personal files of all beneficiaries included both IPRSR and IPS, and the evaluation for the updated version of the documents covered all aspects required by the standard (personal, family and medical situation, behavior and integration into the family and the community, independent living skills, and specific needs. In addition, GDSACPs reported that they offered support to PPAs to implement the plans.
Comprehensive	Data from the external evaluation of PPAs showed that four
evaluation: external	out of five either had never heard of IPS or IPRSR or had heard
evaluation,	but were unfamiliar with their content. The only PPA with

interviews, document analysis	knowledge of these documents did not consider them relevant to the beneficiary in her care, and had her own views about what the beneficiary might need. In addition, one SSP could not provide an anonymized/standardized version of the IPS included in beneficiaries' personal files, even though they reported all beneficiaries had such plans.
Observations	It is unclear how case managers and SSPs ensure that the PPAs implement the IPS and IPRSR, given that most PPAs evaluated had no knowledge of these documents. The standard should include specific provisions on the case manager's monitoring activity with instruments and measurable assessment indicators.
Standard 2: Housing,	accessibility, and hygiene
Description	This standard requires the SSP to ensure that the PPA's home provides beneficiaries with living conditions that are comfortable, safe, and hygienic.
Self-assessment	According to the SSPs, self-assessment all PPAs under their coordination respected the minimum requirements regarding living conditions, and no complaints or irregularities were registered about any such aspects in 2020.
Comprehensive	External evaluations and interviews indicated overall
evaluation: external	compliance with the standards. All PPAs evaluated were
evaluation, interviews,	located in rural areas, and housing was provided in family-type houses that, according to external evaluators, provided
document analysis	standard living conditions. However, one PPA did not have
accument unavysis	access to tap water, while in another situation, the toilet, bathing facilities, and kitchen were located in a different building in the same courtyard.
Standard 3: Food and	feeding
Description	This standard requires that SSPs make sure that PPA beneficiaries are provided with proper, healthy food that meets their nutritional needs.
Self-assessment	None of the SSPs registered any complaints or irregularities regarding minimum requirements about: (i) food storage; (ii) quality or quantity of food provided to beneficiaries; (iii) beneficiaries' involvement in shopping-related to food preparation, menu preparation, and cooking; and (iv) recommended diets.
Comprehensive	External evaluations and interviews indicated that the
evaluation: external	standard is partly complied with, with the exception of
evaluation, interviews,	beneficiaries' involvement in shopping and cooking, which in most cases remained the exclusive task of PPAs.
document analysis	most cases remained the exclusive task of FFAs.
Observations	Data from external evaluations and interviews point to a rather
	overprotective attitude of PPAs, who would rather not involve

	beneficiaries in domestic tasks regardless of their support needs. This situation leads to a relative state of dependency of the beneficiary and might lead to perpetuating the lack of independent living skills.
Standard 4: Health an	nd mobility
Description	This standard includes requirements for maintaining the health and mobility of beneficiaries, as well as ensuring their emotional needs.
Self-assessment	Both SSPs reported compliance with the standard regarding: The content of the procedure for ensuring beneficiaries' health (including aspects related to medication, managing critical situations and undesirable behaviors, respecting the beneficiary's choice of treatment, and types of interventions for cases of neglect, substance addiction, and emergency situations).  All PPA beneficiaries reported having access to a family doctor and undergoing an annual psychological evaluation in 2020. In the case of one SSP, none of the beneficiaries admitted during 2020 had undergone the mandatory annual medical evaluation at the time of data collection. Only one SSP reported having included the consent of all 9 PPA beneficiaries for exceptional treatments in their personal files. The standard does not specify, however, to what these exceptional treatments refer. Both SSPs reported that they conduct home visits to assess the hygienic conditions of PPAs and beneficiaries; one SSP conducts such visits every month, while the other SSP included the results of such assessments in their reports.  Both SSPs reported that they make sure that PPAs know about and comply with doctors' recommendations regarding a beneficiary's health, by filling in the fiche for monitoring beneficiaries' health (in one case), and by merely checking the administration of medication (in the other case).  Both SSPs offers specialized support on topics such as HIV/AIDS, intimate relationships and sex, reproduction and family planning, and substance addiction that are tailored to
Comprehensive	beneficiaries' age and disabilities.  Data from external evaluations and beneficiary interviews
evaluation: external evaluation, interviews, document analysis	showed that:  PPAs supported beneficiaries by accompanying them to medical appointments or offering basic care at home, as well as giving them information about medication, etc. While all PPA beneficiaries have access to a family doctor, only two had a comprehensive medical evaluation in 2020, consisting of blood tests only; one beneficiary received a psychiatric consultation and an abdominal ultrasound.

Beneficiaries of 4 PPAs were being administered psychotropic medication, 2 of whom were receiving it without their informed consent due to their severe disabilities and inability to understand, according to PPAs. In the case of others, the administration had become a long-term practice, and PPAs reported that beneficiaries had become accustomed to taking medication and knew "they had to take it." It is unclear whether and how informed consent is or if it can be ensured regarding the administration of medication. Even though most PPAs reported knowing the steps of informed consent, they could not refer to a document or procedure that stipulated the provision of such information. Besides being administered psychotropic medication, not all beneficiaries had access to psychiatric or other mental health services.

Most PPAs reported that SSPs had not informed beneficiaries about other medical services in the community, or of rehabilitation and recovery services, etc., and some highlighted the need for more support from SSPs.

Dental care was most often cited as the medical service to which beneficiaries lack access, either due to high costs or because doctors refuse to offer services to persons with mental disabilities.

PPAs in one county reported that in 2020, beneficiaries did not receive information regarding HIV/AIDS, intimate relationships and sex, reproduction and family planning, or substance addiction.

In general, neither PPAs nor beneficiaries discriminatory attitudes while accessing medical services. Only one PPA did notify the SSP of a discriminatory situation and alleged degrading treatment from a pediatrician who suggested the beneficiary be euthanized.

#### **Observations**

Data from external evaluations and interviews conflicted with that from self-assessments, and indicated that not all minimum requirements of Standard 9 had been complied with, especially regarding informed consent, access to annual medical check-ups and certain specialized medical services, access to alternatives to psychotropic medications, and information SSPs are supposed to provide to beneficiaries on certain health topics.

# Standard 5: Privacy and confidentiality

#### Description

This standard includes requirements about PPAs' obligations to respect beneficiaries' privacy in all matters of personal life while living with the PPAs, including the right to a sexual life and intimate relationships, and to maintain contact with other persons.

Self-assessment	SSPs reported no complaints or irregularities identified during their monitoring visits in 2020 regarding compliance with the standard.
Comprehensive evaluation: external evaluation, interviews, document analysis	External evaluations showed that most beneficiaries had their own personal and personalized rooms and beds, as well as access to spaces where they could keep their belongings. The observed degree of privacy varied; one beneficiary shared a room with the PPA and had a few personal items decorating the room, while in the other cases PPAs seemed to have access to beneficiaries' rooms at any time. Regarding partnerships and intimate relationships, only one beneficiary had a boyfriend; generally, intimate and sexual relationships appeared to be a taboo topic for PPAs and beneficiaries.
Observations	Standards currently do not include specific issues related to intimate and sexual relationships, or respect for home and family life, such as choosing to live with a partner or decisions pertaining to intimate relationships, marriages, abortions, and childrearing.
Standard 6: Decision-	making and self-determination
Description	This standard covers requirements that relate to a PPA's obligation to offer decision-making support to beneficiaries with high needs for understanding, to respect the beneficiaries' decisions and opinions about their own lives, as well as their right to consult with family/friends in the decision-making process. SSPs may also involve other specialists who can offer beneficiaries decision-making support.
Self-assessment	Overall, both SSPs reported compliance with the standard. However, even though all beneficiaries have been reported as needing decision-making support, in the case of one SSP, none of the beneficiaries received specialized services.
Comprehensive evaluation: external evaluation, interviews, document analysis	While all PPAs reported that they had offered decision-making support to beneficiaries whenever necessary, it is unclear if this support is provided in a way that respects beneficiaries' wishes and preferences. For instance, one PPA explained that she made decisions about where the beneficiary should go, who to vote for, what haircut to get, etc., while the other PPAs offered support to beneficiaries to make their own decisions on matters such as personal appearance, daily schedules, and future plans. Two PPAs did not consider their beneficiaries able to make decisions, even with appropriate support.
Observations	Standards do not currently require PPAs to receive training or information on decision-making support so as to ensure that all decisions respect beneficiaries' wishes and preferences,

	regardless of their support needs, and to enable them to make their own decisions.
Standard 7: Activities	and participation
Description	This standard covers requirements related to a PPA's obligation to ensure the beneficiary is included in the PPA's family environment and in the community.
Self-assessment	No SSP reported complaints or registered irregularities regarding beneficiaries' (i) inclusion in the PPA's family; (ii) involvement in domestic tasks; (iii) relationships with family and friends; (iv) participation in leisure activities; and (v) right to practice religion.
Comprehensive evaluation: external evaluation, interviews, document analysis	External evaluations of PPA services and interviews with beneficiaries suggested that beneficiaries are generally not involved in domestic tasks such as cooking, laundry, etc., and only one beneficiary reported going shopping independently and knowing how to use money. Overall, PPAs expressed distrust in beneficiaries' ability to handle domestic tasks without getting hurt. Most beneficiaries receive support with hygiene and personal appearance. Regarding personal and social relationships, most beneficiaries knew their neighbors and interacted with at least some of them, while the majority of PPAs reported that they support and encourage beneficiaries to maintain and form new relationships in the community. However, while some beneficiaries socialize with neighbors and other PPA beneficiaries in the area, others do not have friends and rarely socialize outside the PPA's home. For instance, four out of five PPAs reported that beneficiaries met with family, relatives, or friends outside the PPA's home or received their visit at the PPA's home at least once a month (before the pandemic restrictions). In fact, the frequency of outings also varied—while most beneficiaries went shopping or to church at least weekly/monthly, one beneficiary had not gotten out of the PPA's home at least once a week. Beneficiaries participate in leisure activities that are usually organized by PPAs and involve family visits, religious excursions, or traveling in the country for tourism, and rarely
Chandard O. T	involve other persons or community events.
Standard 8: Training	
Description	This standard covers requirements that protect beneficiaries' ability to develop their knowledge, diversify their pursuits, and support their employment search.
Self-assessment	One SSP reported that no beneficiary had been provided with any such forms of support, while the other SSP reported some forms of support were provided—four beneficiaries received support to complete vocational courses, four actively searched

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	for a job with the PPA's support, and eight benefitted from vocational/employment services/opportunities.
Comprehensive evaluation: external evaluation, interviews, document analysis	External evaluations of five PPA services and interviews with beneficiaries showed that even though all beneficiaries had graduated from vocational schools or some form of special or social inclusion schools for youth with disabilities, only one had concrete plans to become employed in the near future and will also benefit from PPA support after the pandemic restrictions are lifted. In the other cases, PPAs evaluated the beneficiaries as being incapable of getting and maintaining employment on their own, while beneficiaries either distrust their own capacity to work or are undecided on whether they would like to pursue employment. One PPA specifically pointed out the lack of access to employment as a barrier for the beneficiary to opt out of the PPA service.
Observations	Data from all types of assessment suggested a lack of access to further employment services (pre- and post-employment) and to supported employment services at the local level, which could enable beneficiaries to develop their potential and the PPAs to ensure adequate assistance when necessary.

# Module 4. Management and interinstitutional relations

The fourth module is comprised of six standards with requirements related to: (i) the PPA service provision that respects beneficiaries' dignity and rights; (ii) monitoring the PPA activity by a case manager; (iii) management of risk situations; (iv) protection from exploitation, violence, and abuse; (v) protection from torture and cruel, inhuman, and degrading treatment; and (vi) beneficiaries' feedback on the quality of PPA service.

Standard 1: Respect for rights and dignity

Description	This standard covers the PPA's obligations to encourage and
	support the beneficiaries to achieve personal autonomy and
	independence, identify and denounce discriminatory
	attitudes, and exercise their rights and obligations as citizens
	(including the right to vote).
Self-assessment	Both SSPs reported that all requirements were complied with
	according to their assessment during the regular visits (either
	in person or by phone) at PPAs' homes.
Comprehensive	The external evaluations indicated that beneficiaries are
evaluation: external	dependent on their PPAs for the structure and activities of
evaluation,	daily life, as well as for social and personal relations and
interviews,	activities. All beneficiaries can leave the PPA's house only if
document analysis	accompanied by the PPA. In interviews, beneficiaries
	expressed rather minimal understanding of their rights, while
	some could point to instances of discrimination,
	marginalization, and violence they had experienced as persons
	with disabilities. PPAs cited the lack of civic groups or local
	with disabilities. IT As cited the tack of civic gloups of total

	activities for beneficiaries, or lack of accommodations, as barriers to their civic participation. Some PPAs suggested that they tell the beneficiaries who to vote for, or even voted on their behalf.
Observations	The standard needs clearer provisions to ensure that both PPAs and beneficiaries have specific knowledge about the autonomy, independence, and rights of persons with disabilities, as well as information about independent living (through mandatory training, information materials, etc.).
Standard 2: Case man	nager
Description	This standard obligates the assigned case manager to ensure that the PPA service is provided in accordance with the needs and rights of beneficiaries, including through mandatory monthly visits.
Self-assessment	Both SSPs reported compliance with minimum requirements. All beneficiaries are assigned a case manager who visits them monthly, and case managers have no more than five beneficiaries on their caseload.
Comprehensive evaluation: external evaluation, interviews, document analysis	The external evaluations showed that case managers carry out monthly visits to PPAs' homes and talk to beneficiaries about their wishes and preferences, living conditions, food, clothing, daily schedules, health status, relationship with their PPA, etc. Some beneficiaries knew the name of the case manager who visited them regularly, though not all of them understand the role of a case manager.
Observations	In general, case manager visits seem directed at evaluating the general living conditions of PPA beneficiaries, and sometimes their health status, and are less focused on disability-specific or mainstream activities and services that beneficiaries may need to be included in the community and live an active and independent life.
Standard 3: Risk man	agement
Description	This standard covers aspects related to risk management, such as the existence and content of a specific procedure that PPAs know and apply.
Self-assessment	Both SSPs reported full compliance with the standard, with the exception of one procedure that did not include aspects related to managing post-risk situations. No situations that required urgent interventions were registered in 2020.
Comprehensive evaluation: external evaluation, interviews, document analysis	Only one SSP submitted its risk management procedure for document analysis. The procedure briefly mentions types of risk situations (behavioral unrest and destructive behavior, runaways, aggression, etc.) and how PPAs are expected to respond (seeking counseling, making an emergency call to family doctors/specialists, providing home-based medical

	care, calling the police, etc.) and a further obligation to promptly notify the SSP.
Observations	Risk management requires specific knowledge about deescalating emergency situations, to avoid actions that might aggravate a beneficiary's state. The standard does not include any provision regarding training or other ways to provide such information to SSP staff, PPAs, or beneficiaries. In addition, the minimum requirements do not include any provisions on ensuring beneficiaries' informed consent in risk situations that may lead to a forced treatment or non-consensual interventions (for instance, advance planning regarding interventions that beneficiaries might want or not want, in the event they do not have legal capacity to express their informed consent).
Standard 4: Protection from exploitation, violence, and abuse	
Description	This standard covers minimum requirements that are needed to ensure beneficiaries' protection from exploitation, violence, and abuse, such as a specific procedure that is known and applied by PPAs, annual training for PPAs, PPAs' obligation to encourage and support beneficiaries to identify and report such situations, and SSPs' obligation to identify, register, and take prompt action should such situations occur.
Self-assessment	Both SSPs reported compliance with most requirements, but one SSP (Service 2) did not provide annual training to PPAs. No cases of exploitation, violence, and abuse were registered in 2020.
Comprehensive evaluation: external evaluation, interviews, document analysis	External evaluations indicate that PPAs were either not familiar with the specific procedure, or, when they reported they were, they could not indicate the content of the procedure. Some PPAs reported that it is not necessary to know the procedure, since they can rely on the SSPs whenever such situations (e.g., violence, abuse, etc.) arise. PPAs encourage and support beneficiaries to identify instances of violence and abuse by talking to them and teaching them how to "distinguish right from wrong," or by making sure they do not socialize in risky environments. However, in some cases, PPAs prefer to make decisions about situations that may appear dangerous, instead of informing beneficiaries and supporting them to make their own decisions. The majority of PPAs reported that they were unaware or had no access to information (for themselves or beneficiaries) on how to identify and report situations of violence and abuse, available legal services and psychological counseling services, shelters for victims of violence and abuse, or other relevant services.

Document analysis showed significant differences between the specific procedures used by the two SSPs to protect beneficiaries from exploitation, violence, and abuse. o In one case, the procedure stipulates that the beneficiaries are to be informed by PPAs on how to identify and notify such situations. However, there are no further provisions on how this should be done or whether PPAs are to be provided with relevant materials on the topic. In addition, beneficiaries can only report such situations via questionnaires administered by the case manager with unspecified frequency, while no further instructions exist on whether or how beneficiaries can address the SSP directly. o In the other case, the procedure is more detailed, and includes a timeline for registering and resolving complaints, a clearer description of the roles and responsibilities for SSP staff involved, and the psychological counseling services provided to beneficiaries. No specifications are made regarding ways in which the beneficiaries may directly address the SSPs, or other relevant services and support persons (legal services, advocates, etc.). o None of the procedures include any stipulations regarding the administration of medication to beneficiaries or how the beneficiaries' money or goods are to be managed, as required by the standard. None of the analyzed procedures specifically addressed Observations situations of exploitation, violence, and abuse from PPAs against beneficiaries. Both procedures make reference to annual training as a way to prevent such situations, but there is no provision for such formal training, or for informing beneficiaries. An independent, external mechanism for reporting and reviewing such cases should be made available to beneficiaries, along with access to legal and counseling services and advocates. Standard 5: Protection from torture and cruel, inhuman, or degrading treatment This standard covers similar requirements as Standard 17, but Description pertains to situations of torture and cruel, inhuman, and degrading treatment. One SSP did not provide the annual training to PPAs on Self-assessment protecting beneficiaries from torture or cruel, inhuman, and degrading treatment. No such cases were registered in 2020. See Standard 17. Comprehensive evaluation: external

evaluation,

interviews,	
document analysis	
Observations	See Standard 17.
Standard 6: Notificati	· · · · · · · · · · · · · · · · · · ·
Description	This standard covers requirements regarding the assurance of PPA service quality by facilitating the beneficiaries' ability to submit notifications and complaints according to a special procedure that is known and applied by the PPA. The procedure also includes information about how beneficiaries can submit notifications and complaints.
Self-assessment	Both SSPs reported compliance with most requirements. However, one SSP reported not complying with the requirement to potentially appeal to external mediators in cases of complaints. No notifications or complaints were registered in 2020.
Comprehensive evaluation: external evaluation, interviews, document analysis	The specific procedures that both SSPs submitted for document analysis are rather brief and general, and focus only on: (i) how beneficiaries can submit complaints, and (ii) the process for submitting, registering, and resolving the complaints. However, it does not detail aspects of service provision about which beneficiaries can submit complaints. One of the procedures does not specify the timeline for how the SSP should manage complaints, while the other procedure does not specify that complaints must specifically be about the quality of service provision.  Out of five PPAs that were externally evaluated, two in one county had not been informed by the SSP about the content of the procedure. The other three PPAs from the other county reported that they were familiar with the procedure but could not detail its content. Interviews with beneficiaries showed that they either give their feedback on the service quality directly to the PPAs, or to case managers during the monthly visits.
Observations	Unlike the minimum quality standards for other services evaluated in this report, the standards for PPA service do not specifically require the SSP to administer a questionnaire to beneficiaries to assess their views on the quality of service provision. In addition, the procedure on notifications and complaints should include more provisions on how to avoid any consequences that may occur in the event complaints are submitted by beneficiaries, verbally or in writing, given that, in many situations, the beneficiaries are in a close, dependent relationship with the PPAs.

#### 2.6.4. Conclusions and recommendations

# Standards compliance and implementation

In general, SSPs report that most minimum requirements covered by the quality standards are respected. There are some exceptions regarding the lack of information about service provision in accessible formats, annual mandatory training for PPAs, and annual medical check-ups for beneficiaries. However, data from external evaluations of PPA services, interviews with beneficiaries, and analysis of service documents submitted by the two SSPs indicated some irregularities in the implementation of standards that lead to several suggestions for how to improve the quality of service to better ensure beneficiaries' choice, autonomy, and rights, as follows:

- Beneficiaries need more choice and control over the service delivery. All PPAs that were externally evaluated are former PMAs who initiated the procedure to become PPA. In effect, beneficiaries' applications for service were a mere formality. They received minimal (mostly verbal) information from SSPs about the PPA service, their rights and obligations, other services in the community, etc. In addition, the underdevelopment of the service locally adds to the list of factors that limit beneficiaries' ability to choose a service. According to data collected from PPAs, beneficiaries are generally considered incapable of understanding and making their own decisions even with adequate support, tailored to their level of disability. Currently, standards do not include provisions regarding mandatory training for PPAs, SSP staff, or beneficiaries on supported decision-making, informed consent, and on ensuring beneficiaries' choice and control over the services they receive.
- o Services provided by PPAs need to be more person-centered. Neither PPAs nor beneficiaries were familiar with the latter's activities and service plans, and in general, the PPA service is limited to providing housing and living conditions for beneficiaries, supporting daily activities, and facilitating access to medical services. Case managers largely monitor beneficiaries' living conditions and health status, and spend less time evaluating the extent to which beneficiaries live independently and whether they have access to community life. Consequently, this also informs beneficiaries' feedback on the quality-of-service provision, which in all cases is provided during case manager monitoring visits.
- o PPA services only provide beneficiaries with a residence option, and with fewer opportunities to fully participate in community life. Beneficiaries are rather isolated from the community, and their social and cultural lives unfold primarily according to that of their PPA's and their families. The near constant reliance on PPAs for daily activities (including those that take place outside the PPA's home), as well as the lack of opportunities for social, cultural, and leisure activities in the community, may undermine beneficiaries' autonomy and self-determination. The lack of disability-specific services—as well as mainstream services such as housing, training, and employment opportunities-may additionally limit beneficiaries'

potential to develop their full potential. SSPs should make sure that PPA beneficiaries are aware of other community-based services and activities, and plan to develop a wide range of services and opportunities where those do not exist.

#### Value and success of the service

Personal professional assistance is an underdeveloped service at the national level. Services evaluated in this report have a homogenous profile, since all beneficiaries previously benefitted from professional maternal assistance from their current PPAs. The comprehensive evaluations indicated that had PMAs not transitioned to PPAs, persons with disabilities would have ended up in a residential center for adults with disabilities. In this context, PPA appears to be a service that prevents institutionalization. However, preventing institutionalization is not equivalent to achieving independent living or community inclusion, since most beneficiaries remain socially isolated and have trouble accessing social and cultural opportunities, as well as disability-specific or mainstream services. PPA beneficiaries face similar barriers as other persons with disabilities who live in the community but remain marginalized, and cannot fully participate in society. PPA beneficiaries need access to a wide range of adapted community services—including housing, employment, education, and adequate social benefits tailored to their needs—if they are to enjoy all of their rights and have more control over their lives.

Personal assistance is a one-to-one relationship and a person-directed service that can offer tailored support to all persons with disabilities irrespective of their needs level. To comply with the requirements of independent living, personal assistance must be controlled by the person with disabilities, who: (i) receives and controls the funding for the service; 175 (ii) can contract the service or act as an employer and design the service to best suit their needs; (iii) can recruit, train, and supervise the persons providing personal assistance, and is not forced to share the service with other persons; and (iv) can decide on the length, intensity, and form of personal assistance. The PPA service complies with none of the latter: the PPAs are contracted directly by GDSACPs, beneficiaries have little control over the type of assistance they receive, as well as on the recruitment and training of PPAs, and they may be constrained to share the service with other beneficiaries.

<sup>&</sup>lt;sup>175</sup> For instance, by receiving a personalized budget for personal assistance services that the person can further contract independently.

# 3. Developing community-based services - challenges and future directions

This chapter offers an analysis of the current situation of community-based services for adults with disabilities in Romania, by considering the process that led to the development of these services as well as the aspects that may have to be considered in the future to develop a diversity of services that place persons with disabilities at the center of service delivery as equal partners. The process is analyzed in view of: (i) factors that determined the set-up of services as well as their specifics, and (ii) barriers that hampered either the development of services or the delivery of current services in a person-centered manner to ensure community inclusion and independent living.

# 3.1. Models of service development

Motives behind the development of community services are examined by delineating three models of change: (i) top-down; (ii) opportunity-based; and (iii) bottom-up.

# Top-down route to deinstitutionalization

The reason for establishing community services has been in many cases an external constraint derived from legal compliance, which has consequences in the way services are provided. Many of the SSP representatives and service coordinators have explained the development of community services (or lack thereof) in terms of the obligation to restructure large residential institutions to meet minimum quality standards or demands from local authorities. This type of development is a top-down model, which pays attention only secondarily and sometimes marginally to the assessment of community resources or beneficiaries' needs, as it focuses rather on the technicalities of service delivery. Empirically, the implications of legal compliance meant the evaluation and transfer of beneficiaries from one center to another, <sup>176</sup> the discontinuing of social services, and the ongoing reorganization of residential and community services, as well as the externalization of services.

The main consequence of top-down development is that principles of deinstitutionalization are rarely adopted or supported in a coherent philosophy of care. Deinstitutionalization marks a new paradigm of community services, putting forth principles such as normalization, community inclusion, person-centeredness, independent living, empowerment, and self-determination. Deinstitutionalization and person-centeredness are grounded in care management principles that define and understand disability less as an impairment and more in terms of barriers to community participation and lack or prioritization of "choices, preferences, shared power, rights, and inclusion." The research for this report shows that, although there are some

<sup>&</sup>lt;sup>176</sup> According to data from the World Bank survey of residential centers (2020), 61 percent of persons with disabilities from residential centers undergoing restructuring have been or will be transferred to other residential centers until 2021, as a result of the legal requirements of Decision no. 878/2018 whereby residential centers with a capacity above 50 places must be restructured.

<sup>&</sup>lt;sup>177</sup> Dempsey and Nanverkis (2006: 19-21); Mansell and Ericsson (2013); Braddock and Parish (2001).

<sup>&</sup>lt;sup>178</sup> Ratti et al. (2016: 64).

instances where similar principles are articulated in the development of local community services in Romania, they are still in their early stages of development. Services such as mobile teams and home-based care services are ways of preventing institutionalization, but their distribution at national level makes them an unfeasible alternative for the time being. 179

Downsizing large residential centers is the main reason behind the impetus to develop community-based services. The objective of decreasing the capacity of a residential center often means that transfer solutions for beneficiaries must be identified quickly. Usually this means transferring them either to other residential centers or to sheltered houses. Most GDSACP directors interviewed invoke the necessity to restructure large residential centers imposed by the Emergency Ordinance no. 69/2018 limiting the capacity of residential centers to a maximum of 50 beneficiaries. 180 Subsequently, the development of residential centers with less capacity is prioritized, while the development of community services is postponed to the future or delegated to other stakeholders, such as local authorities and private service providers. Coupled with the lack of financial and infrastructural resources as well as the low priority that social assistance for persons with disabilities has in local welfare policies, the development of community services lacks adequate planning to respond to specific needs of users.

<sup>&</sup>lt;sup>179</sup> As already described in chapters 2.3. and 2.4.

<sup>&</sup>lt;sup>180</sup> Emergency Ordinance no. 69/2018 for modifying Law no. 448/2006 regarding the protection and promotion of the rights of persons with disabilities.

# Box 18: Priorities and pressures in the process of developing community-based services

"The priority for GDSACP is the reorganization of existing residential centers and it depends on the county council funds. The plans for [name of centers] died somewhere along the way when the county council refused funding." - GDSACP director, South-Western region

"Our county is maybe not the poorest, but certainly among the most precarious counties in the country and the budget must be well administered, all demands must be solved. We are aware that we need roads, libraries, as well as [social] services." - GDSACP director, North-Eastern region

"We are bombarded daily with admission requests from the local community, saying that they do not have social services. If we go to Government Decision 430/2008, article 17 states the way system admissions work: the city hall must submit a form saying they lack community services, fill out case files and that's it. Automatically, the responsibility goes to GDSACP, on the one hand, but on the other, we have a deinstitutionalization strategy, where's the logic in that?" - GDSACP director, North-Eastern region

Source: World Bank interviews with GDSACP directors (March-April 2021).

There have been situations in which certain public and private service providers have responded to new quality standards by reorganizing social services, from sheltered houses into CAbRs or CIAs. 181 The new transformation was in some cases limited to names or addresses. 182

Legal requirements imposed by quality standards lead to the development of day centers. The minimum standards for sheltered housing require that their beneficiaries are provided with activities through a day care center, or other community services. 183 Consequently, as many complain about the lack of community services other than those supplied by GDSACP, the only alternative remains the establishment of new day centers. Where these services are absent, a partnership with another county may be created, or the sheltered housing service is discontinued or transformed into a different type of service. A consequence of this provision is that most day centers are located in urban areas, making access problematic for those who lack the means to travel.

The opportunity-based model of development is contingent on the resources available on the market, stakeholders that can be involved, and the way resources can be mobilized. Similar to the top-down model route to deinstitutionalization, this model does not prioritize community needs or those of persons with disabilities, but rather responds to funding requirements in terms of service provision (number of

<sup>&</sup>lt;sup>181</sup> Order no. 82/2019.

<sup>&</sup>lt;sup>182</sup> For instance, a private SSP from North-Western region needed to transform a sheltered housing service into a CAbR, since it could neither provide access to a day center to beneficiaries, nor access to employment opportunities, as required by quality standards.

<sup>&</sup>lt;sup>183</sup> Annex 2 of the Ordinance no. 82/2019 regarding the minimum quality standards for social services for persons with disabilities.

beneficiaries, type of service that can be developed, etc.) The following patterns of development have been noted: (i) financing opportunities for a type of service have been identified by GDSACP; (ii) Social Assistance units within the Mayoralty; or (iii) NGOs have applied and secured financing, and services have been established. It is more common for local authorities to enter a partnership than to set up a service on their own. A possible consequence is that, in the long-term, the established services may not prove their usefulness, particularly respite and crisis centers, which have been developed in the absence of an assessment of local needs and demands, and were discontinued or services integrated into another type of care facility.

# Box 19: Opportunities for developing community-based services

"Over the past few years, the political vision regarding social services for persons with disabilities has changed. We encountered more openness and availability from some mayors and reticence from others. We tried to conduct a sort of analysis or diagnosis and to analyze the situation of persons with disabilities from all over the county and see where services can be developed. We thought of these things considering external financing opportunities." - GDSACP director, North-Western region

"We identified the needs when we started the reform. We did one or another according to how we managed to secure financing. Normally, it would have been good to treat them according to a prioritization of needs. We cannot do this scientifically, according to theoretical principles of social assistance. We must do it depending on how we fund resources and opportunities." - GDSACP director, South-Western region "The idea for the project came from the NGO and the Mayoralty was a partner; they did not ask us, they thought of it and recommended we contribute to the project. The project included other marginal categories—Roma people, destitute children. For persons with disabilities, we offered activities and treatment at a sanatorium and this is how we established this service." - PSAS, South-Eastern region.

Source: World Bank interviews with GDSACP directors and PSAS representatives (March-April 2021).

#### Bottom-up development of community services

The bottom-up development of community services for persons with disabilities is the more sustainable route to deinstitutionalization. The model focuses on persons with disabilities—services available for them, their needs, prospects, and engagement with the community. At the same time, the model fits with a person-centered philosophy of care. Research participants mentioned development in the way services are provided, as most of them recount adapting services according to beneficiaries' needs. A few of the community-based services included in this research were established as centers for children and transformed into services for adults once beneficiaries came of age. Other services were developed as a response either to demand from the community or disability trends observed at the Service for Comprehensive Assessment of Adults with Disabilities (SCAAD). A common remark is the absence of community services for adults with disabilities, which leads, on the mediumand long-term to new admission in the public protection system. Social services such as mobile teams or home-based care services are considered among the best solutions for preventing institutionalization, as they also offer primary medical care within the community.

There is a significant need to diversify services at the community level. For persons with disabilities to live a full and meaningful life they need not only more services in the community, but also a diversification of the services provided, as the interviews have showed. In some cases, these needs become apparent once youth from the child protection system come of age and require further support to make the transition to a life in the community, sometimes to compensate for the lack of appropriate service provision in previous institutions, as interviewees pointed out. In other situations, services are being set up as a result of demands from persons with disabilities or their families, or according to the protection measures established by the SCAAD. For instance, mobile teams or home-based care services were established because SCAAD specialists noted the increase in afflictions such as cerebral vascular accidents or because GDSACP and Social Assistance units within the Mayoralty received inquiries about available social services for persons with disabilities. In addition to disabilityspecific needs, SSP representatives and service coordinators have indicated that persons with disabilities are economically vulnerable, cannot travel easily, and lack alternative services, leading to situations qualified by interviewees as discrimination by omission.

# Box 20: SSPs' perspective on the needs of persons with disabilities

"It's unrealistic to talk about reintegration when you have no community services. We should first set up services and then downshift, reorganize, and reintegrate. You see, the story of community inclusion is beautiful, as is taking into consideration the person's personality, desires, and life goals. Persons with disabilities, however, want a specific lifestyle, they want to be in a center. This is their home, their family, their friends. You want to take them into the community. Which community is that? His family does not want him back, otherwise, they would not have institutionalized him in the first place. What are we talking about? There are no alternative services, there is no community to welcome these people." - GDSACP director, Center region.

"It is not enough for institutionalized persons with disabilities to reside somewhere, they need to train, to be offered employment opportunities as well as entertainment options. This is how we developed. This is how we came to offer services in all life domains of institutionalized people." - NGO representative, North-Western region

"There was no day care center for persons with disabilities offered by the Mayoralty." It's not the quantity that imposes the licensing of a service." - Social Assistance unit, Centre region

"There are no alternatives in the area, no respite centers, no way for persons with disabilities to find a job. Many adults from the community end up institutionalized because they have no alternatives." - NGO representative, Western region

"Persons with disabilities must find their place in the world, not glue papers together or color. We must involve them to their maximum capacity, from arranging their clothes to cleaning, meal preparation. If they have the ability, we should assist them in finding jobs, or involve them in gainful activities, either a basket-weaving class or a tailoring workshop." - NGO representative, Centre region

"Sheltered housing is a gateway to community living. Our beneficiaries usually come from the protection system, mainly foster care, and they are people capable of integrating, even if they have disabilities. The sheltered housing fosters independent living skill acquisition." - Service coordinator, North-Easter region

"Our association was founded in the 1990s after a visit in an orphanage from a team of specialists from Germany. After seeing their living conditions, they decided to set up a permanent team in our county. We developed as a long-term need, they kept asking themselves: `what will happen with these children once they come of age?'" - NGO representative, North-Western region

Source: World Bank interviews with GDSACP, PSAS, and NGO representatives (March-April 2021).

# Box 21: Inventory of community services needed

Specialists from the field express the need to develop several types of disability community services. This articulation is prompted when discussing needs not satisfied by current services. The inventory includes recommendations from the field for improving current services and the most desired types of services, as well as what participants consider to be the riskiest investment.

# Improving existing services

- (i) Diversifying services offered in terms of activities conducted in day care centers: interviewees express the need to provide legal counseling, rights, and benefits counseling, improving relationships with family, where it exists, leisure time facilities, as well as a diversification of occupation therapy activities to include creation and artistic expression.
- (ii) Improving infrastructure: repairing or replacing old equipment acquired through non-reimbursable funding; hiring more specialists to work in centers, especially kinotherapists, speech therapists and psychologists.
- (iii) Extending the network or community services in the county, replicating good practice models (especially mobile teams and home-based care services), reaching a wider range of beneficiaries. Interviewees remark the lack of access to services for persons residing in rural areas, usually more economically deprived than urban ones. Beneficiaries of mobile teams and home-based care services are bed-ridden and usually register setbacks due to lack of access to functional recovery services.

#### Most desire community services

- (i) Social protection units within the Mayoralty are more inclined to express the need of developing community services with an integrated medical component; that is, mobile teams, home-based care services, day care centers, and outpatient neuromotor recovery service center.
- (ii) GDSACPs tend to articulate needs for services with a residential component, particularly sheltered housing and respite centers. Some directors interviewed suggested the development of sheltered employment units.

### Riskiest community service

Respite centers are controversial services. Although many express the need for respire centers, the centers do not seem economically sustainable or efficient for the long term. Developing such centers, despite funding opportunities from the NARPDCA, is generally considered a risky investment. Risk is calculated based on several criteria. First, participants equal lack of demand for a short-term residential service with economic unsustainability. Second, quality standards for respite centers (one beneficiary per room and trained personnel) are considered too restricting. Third, interviewees claim that persons with disabilities usually reach out when it is already too late and can only qualify for care and assistance in a residential center. Social protection units within the Mayoralty consider respite centers as the more attractive solution for offering mandatory annual leave or sick leave for personal assistants. However, since most personal assistants come from beneficiaries' families, they are considered reluctant to leave beneficiaries in a center, even for a short period of time. "Most parents," explains an NGO representative, "are not emotionally prepared." The research showed that counties where respite centers were established were forced to discontinue services and integrate solutions for crisis situations within existent services.

Source: World Bank qualitative research (March-April 2021).

# 3.2. Service development - relevant aspects and barriers

### Responsibilities and resources

According to the GDSACP, the responsibility for developing community services lies with the social assistance units within the Mayoralty. One of the most evident findings of the study is the denial of responsibility for the development of community services. GDSACPs see the responsibility as pertaining to social assistance units within the Mayoralties. They feel that social assistance units have better knowledge of the community and more competence in assessing needs. However, when the latter try to develop community services, they find it difficult to work within the norms imposed by quality standards and social services nomenclature. 184 Interviews with DGASPC directors showed that some of them would like to have more legal leverage in exercising its function and demanding coercive power over local authorities.

## Box 22: Responsibilities for developing community-based services

"We asked public local authorities to develop day care centers. Nobody wanted. They said that they barely have money to pay wages, let alone develop new services. There are no coercive measures, no way to make Mayoralties responsible." - GDSACP Director, Southern region

"By law, public local authorities are supposed to open community services, but they are stubborn. They could intervene better than GDSACPs, especially in cases when people do not necessarily need institutionalization. The only proposal from public local authorities to GDSACP is to admit people into residential centers." - GDSACP Director

"There is a need to establish psychiatric hospitals, I am sorry for saying that, but persons with paranoid schizophrenia have no place in the community; they represent a danger to others. And the [name of county] Mayoralty prioritizes social over medical needs. GDSACP is social assistance service, not a psych ward." - GDSACP Director, South-Western region

Source: World Bank qualitative interviews with GDSACP directors (March-April 2021).

The costs associated with developing community services for persons with disabilities are deemed too high. The high costs associated with opening community services are often invoked as a barrier to service development. In general, obtaining funding poses a series of problems. 185 First, not all GDSACPs have technical capacity for writing projects. They articulate the process as being too complex and cumbersome to even be started. Second, most interviewees who invoke non-reimbursable funding reference the Program of National Interest (PNI) initiated by NARPDCA. The program, they argue, stipulates a costly contribution from County Councils, which consequently

<sup>&</sup>lt;sup>184</sup> More specifically, participants reference Ordinance no. 82/2019 regarding the minimum quality standards for social services for persons with disabilities, and Decision no. 857/2015 regarding the classification of social services. <sup>185</sup> This argument is not supported by community-based disability literature which argues that the costs associated with the transition to community services are lower than those of operating large residential institutions (Castellani, 1996; Dempsey and Nanverkis, 2006; Axelsson, Granier, and Adams, 2014). This does not account for the costeffectiveness of providing services that might prevent institutionalization altogether.

leads to reticence and even downright refusal of plans for developing services. Other issues mentioned in relation to the PNI are related to the vague and complicated methodology, as well as the partial coverage of costs, which in some cases led to prolonged institutionalization for persons with disabilities with higher support level needs for whom no solutions could be funded in the community.

The real costs of running the services also hamper service maintenance and further development. Current legislation stipulates a standard cost for each type of social service (both residential and community-based) for adults with disabilities. 186 Currently, the standard cost is defined as the minimum amount related to the annual expenses necessary for the provision of social services, calculated per beneficiary of a certain type of social service, taking into account the minimum quality standards and/or other criteria provided by law. The standard cost is further used to determine the amounts allocated to local budgets from certain state budget revenues in order to provide social services. As mentioned in Chapter 1, quality standards are considered too rigid by SSPs to be covered by available funding, which sometimes hinders the process of developing disability community services from inception or based on an approach that thwarts innovation and creativity in developing services. Interviewees struggle with the obligation of having a maximum of two residents hosted in one room or ensuring adequate clothing.

<sup>&</sup>lt;sup>186</sup> Government Decision nr. 426/2020 regarding the approval of standard costs for social services. Annex 2. Residential centers and maximum sheltered houses have higher standard costs than community-based services, as follows: Care and Assistance Centers for Adults with Disabilities (66.853 RON/year/beneficiary); Recovery and Rehabilitation Center for Adults with Disabilities (67.920 RON); Center for Independent Living for Adults with Disabilities (64.700 RON); Maximum Sheltered House (60.932 RON); Minimum Sheltered House (33.282 RON); Day Center (25.439 and 29.851 RON); Outpatient Neuromotor Recovery Center (16.284 RON); Respite/Crisis Center (52.000 RON); Mobile Team (36.669 RON); Home-based care services (14.728 RON).

# Box 23: Funding as a barrier for service development

"Legislation did not help much either. When the PNI was launched, our opinion was that the methodologies should be as clear and simple as possible, and it was not the case. When it comes to public spending, the situation changes. We had all these questions related to PNI: how to conduct a public procurement process, what is the selection criteria. In our county there are thousands of properties listed, how should we draw up the tender book? They might seem unimportant details, but they can lead to unpleasant situations for public workers. The County Council just said no." -GDSACP director, Western region

"All available funding is for community centers. After evaluating our beneficiaries, we concluded that only 30 can be transferred to a sheltered house. The rest of them are bed-ridden, have complex medical issues, they have no chance of being integrated as specifies the quality standard for sheltered housing." - GDSACP director, North-Eastern region

"Evers since GDSACP was established in 2005, there was a lot of talk and debate about closing residential centers and the importance of being as close as possible to persons with disabilities, to where they live. We heard the message and got straight to business. However, there is little chance for us to be pioneers now. When the legislation was laxer, we could develop more services. Now, we must go to the nomenclature of social services and see what we can develop." - GDSACP director, South-Western region

Source: World Bank qualitative interviews with GDSACP directors (March-April 2021).

GDSACP directors complain about the lack of infrastructure; that is, land, buildings, service staff, and private partners within the community. Establishing community services is contingent on good collaboration between interested parties. There are counties where partnerships between GDSACPs and public local authorities cannot be established, making access to land and buildings difficult, if not impossible. At the same time, community services are dependent on the existence and availability of specialists (social workers, psychologists, speech therapists, etc.) to work in future centers. GDSACP complains about the lack of expertise at the county level. And lastly, there are only a few private service providers, which makes it difficult to establish services.

# Partners in the process of developing disability community services

This section discusses the process of developing disability community services with reference to challenges encountered as well as ideal models of partnerships. Three categories of actors will be taken into consideration for the analysis: social protection units within the Mayoralty, GDSACPs (both management and service coordinators), and NGO representatives. Central authorities are usually referred to mainly as NARPDCA and in some instances the Ministry of Labor, while local authorities are considered social protection units within the Mayoralty, GDSACPs, and County Councils. Generally, developing community services is an isolated process, as institutions and organizations rarely collaborate with each other unless they are legally bound. There are two levels of collaboration. The first level is one where institutions collaborate with the institutions they are accountable to. In the process of developing community services, social protection units within the Mayoralty engage local councils, while GDSACPs communicate routinely with County Councils, which are their credit principals. Private SSPs are in contact with GDSACPs and social protection units when services are contracted. This type of engagement is further reproduced in collaboration with central authorities, as participants describe interaction with NARPDCA as merely formal. The second level of collaboration is more personalized and materializes through solving specific issues. An ideal model of collaboration is, according to all actors interviewed, built on mutual dialogue that takes into consideration both public and private entities.

#### Collaboration with central authorities

Collaboration with central authorities is dependent on the type of actor and the objectives pursued. Social Protection Units within the Mayoralty describe their collaboration with NARPDCA as purely formal, meaning that is mostly limited to administrative issues. The units interact with central authorities for service licensing or for clarifications on specific legislative issues. Other than that, there is little to no interaction between local and central levels involved in the management of disability. Whenever social protection units asked for NARPDCA's help in explaining specific licensing details, they describe the assistance received as diligent and timely, which suggests there is room for constructing a more meaningful partnership for all parties involved. In contrast, private SSPs describe their collaboration with NARPDCA as problematic and argue that NARPDCA has no role in developing community services. Many NGO representatives interviewed describe central authorities as inflexible and authoritarian, which in their view hampers the process of developing services.

Social Protection Units within the Mayoralty and private SSPs feel voiceless when plans and strategies for services are being developed. Social Protection Units argue that only GDSACPs are consulted on disability issues and feel that community services cannot be developed without their expertise. This issue echoes in the way financing opportunities are launched, as some feel that funding programs are not well-grounded in identified needs at a local level. For instance, social protection units consider that downsizing and reorganizing large residential centers is unjustifiably prioritized. The opinion is voiced by GDSACPs, who demand more active involvement of social protection units when development strategies are formulated. Strategies at the local level would increase social protection units' accountability for developing disability community services and encourage participation. At the same time, private SSPs complain that they are not consulted when the national disability strategy is devised and that the selection of NGOs who participate is arbitrary. They claim that the number of days allocated for public debate and transparency is insufficient, that feedback mechanisms are scarce, and that there are no measurement indicators and objective procedures in the selection of participant NGOs.

Centralized decisions regarding the process of developing community services pose problems to both private and public SSPs. Private SSPs complain about the lengthy

process of developing community services, especially those financed through non-reimbursable programs. They signal issues related to public procurement, collaboration with central authorities, and the formal path of documentation. At the same time, public SSPs suggest decentralization as a solution for facilitating a more time-efficient process of developing services.

#### Box 24: SSPs collaboration with central authorities

"We received no support from central authorities in developing services, our collaboration culminated with the response received from the Ministry of Labor that "if we do not agree, [we should] shut down services, persons with disabilities have no place in the community." Our relationship with NARPDCA is one of control, threats, and termination of services." - NGO representative, Centre region

"The role of GDSACP cannot be greater than that of social protection units, which are closer to persons with disabilities; you cannot develop community services if you do not know the beneficiary. GDSACPs cannot know all beneficiaries, giving that they manage the entire population of persons with disabilities in the county." - PSAS representative, Southern region

"For persons with autism, for instance, we need a national plan, a strategy. We started the process 10 years ago, but we did not make it very far. Institutions should work together and come up with person-centered procedures, not service-centered ones; they should raise awareness on the needs of persons with disabilities. The autism spectrum is difficult to categorize as a mental disability." - NGO representative, Southern region

"We approached the Ministry of Labor with specific legislation amendments, and they said that changing the legislation is their job, not mine, mine is to apply legislation as is." - NGO representative, Center region

"A part of our problems comes from the way central authorities use the word maybe. Maybe is interpretable and is contingent on the existent vision within a community and not on beneficiaries' needs. If the lawmaker says that social protection units are obliged to do something, you can be sure that that thing will be done. If you leave it to the whims of one or another, it is clear that there will always be more important things than social services." - GDSAPC director, Southern region

"Coming from the private sector, I feel that you can solve a lot of problems with a phone call: you plead your case and your situation may be solved. Looking at it from an institutional perspective, we realized that even if there is a will, things cannot be done in a day, like it happens in the private sector. It took us two years to realize that even if a representative says the standard cost, for instance, will be actualized, there are still many phases to the process and more actors involved. We understood this, but we do not agree." - NGO representative, North Western region

"In 2015 we devised the first plan for shutting down a residential center. This year we will inaugurate the service. It has been six years. The children we evaluated in 2015 are no longer in the protection system. All the beautiful plans we set up are no longer valid. Public procurement processes delayed development. Constructors came, contested each other, and then contested again. We had another project for persons with disabilities started in 2006 and finalized in 2015. That's how long it took to develop a residential service." - NGO representative, Western region

*Source*: World Bank interviews with GDSACP, PSAS, and NGO representatives (March-April 2021).

Collaboration with local authorities and other SSPs

The development of community services for persons with disabilities is an isolated process. Institutions and organizations that develop services rarely collaborate. The only form of collaboration between local and county authorities is when social protection units and GDSAPCs support each other's objectives and promote the service among their beneficiaries. Other than that, each provider claims that services are established without the assistance, partnership, or collaboration of another institution or organization. Without collaboration mechanisms in place, providers communicate routinely with the institutions to which they are accountable. In this sense, social protection units rely on local councils and GDSAPCs on county councils for infrastructural support, as councils are responsible for the allocation of buildings and land, approving budgets, plans, eligibility criteria and functioning regulations. Private SSPs engage social protection units and GDSAPCs when social services are contracted.

GDSAPCs are contested both in their role as service providers as well as regarding their approach to disability. While there is a general agreement that GDSAPCs play a pivotal role in the development of community services, there is also discontent with their multiple roles simultaneously filled. Private SSPs argue that GDSAPCs should conduct more comprehensive assessments of needs, instead of being overwhelmed by the obligation of evaluating needs, delivering, coordinating, and monitoring services. In addition, when services are contracted, private SSPs complain about GDSACPs' approach to disability, which they consider raising three types of issues. First, GDSAPCs are said to have a transactional policy toward contracting social services that focus on costs for setting up services, rather than on the extent to which services respond to beneficiaries' needs. Second, GDSAPC is considered to have no interest in persons with disability once they transition to the community and no longer access services. And third, GDSAPCs are thought to deny persons with disabilities the chance of making choices, having preferences, and being actively involved in how their lives should be lived.

#### Box 25: Private SSPs' discontent with GDSACPs

"GDSAPC should evaluate needs and then contract services. They should not deliver services." - NGO representative, Western region

"In relation with persons with disabilities, GDSAPC, especially its commissions for assessing persons with disabilities, has a bureaucratic approach towards persons with disabilities. They have no interest in their problems, their situation, they want the documents and goodbye. They barely have time or intention of knowing your problems." - NGO representative, Centre region

"If the commission for assessing persons with disabilities would function beyond its bureaucratic duties and dig a little deeper into discovering people's needs and set up a database with these needs [it would be great]. Consequently, if needs were discussed with NGOs or other competent authorities as well as persons with disabilities and their representatives, a strategy would be elaborated and GDSAPC would see who can cover these needs." - NGO representative, Centre region

"GDSAPC did not help us with anything; their response has always been straightforward, saying that it is not their area of interest, and that after a person has left the institution, GDSAPC cannot do anything else." - NGO representative, North Western region

"We receive all these emails from GDSAPC: "schizophrenia, stroke, liver, send us the costs if you have available places." They are only interested in costs, not in people's history of present illness, if they want to live in the community, what's their story, where they used to live, if they are supported by their families. [Our last email] from GDSAPC asked if we can receive 25 beneficiaries, with no data about them. [...] They are not objects, it is not your average bag you use at the market that you can move as you see fit." - NGO representative, Centre region

Source: World Bank interviews with NGO representatives (March-April 2021).

Outsourcing of service provision is considered to hold great promise for service development in the future. This applies particularly to contexts where services are not already externalized, due to either the absence of private service providers in the area or the lack of partnerships between public and private institutions. There are few avenues of interpretation. On the one hand, the public protection system is seen as overloaded and in drastic need of change. All GDSACPs directors interviewed complain about local authorities' lack of initiative regarding community disability services, in particular, and the role of social assistance, in general. This translates as GDSACPs' obligation to institutionalize persons with disabilities who would otherwise not be able to remain in their houses.

# Box 26: Outsourcing as an option for service development

"GDSACP cannot force the mayor or any local authority to hire a social worker or develop a social service." - GDSACP director, North-Eastern region

"It was difficult to make local authorities understand what social assistance is. We are not done yet, not everyone understood. But over time, with each new electoral cycle, we conducted these talks with all mayors to explain the use of social assistance and the necessity to hire social workers." - GDSACP director, South-Western region "The externalization represents the future of service provision. The state protection system is overwhelmed and needs change. We need a diversification of private service providers according to people's needs, there are not enough social services." -GDSACP director, Southern region

"We need another vision; community services and partnerships are indispensable." State institutions are alone in the process. Civil society must be made aware, there are resources, and we just do not know how to access them. There is this reluctance, we lack motivation, we seem to be floating in this inertia." - GDSACP director, Southern region

Source: World Bank qualitative interviews with GDSACP directors (March-April 2021).

In some cases, outsourcing leads to discontent and animosity between public and private service providers. Few GDSACPs are currently undergoing reorganization due to outsourcing of services, which leads to unexpected tensions between service providers. In counties where GDSACPs services are subcontracted, the process has not been as successful as expected, especially due to discrepancies in the philosophy of care. Private SSPs are considered by GDASCP representatives to have a different vision of persons with disabilities and to engage them in activities below their capacity, and in some situations to choose the beneficiaries with the highest levels of personal autonomy and best chances of independent living. Lastly, a double standard in licensing social services for private and public sectors has been pointed out, as GDSACP representatives believe that it is easier for an NGO to set up a service and to have access to external funding. Significantly, the experience of NGO representatives interviewed points out a rather reverse situation.

# Box 27: Challenges related to the outsourcing of services

#### Vision on disability

"The activities that NGO engages persons with disabilities in are not for them. They do mostly children's games, well below their capacity. We [public service suppliers] try to offer the very services that persons with disabilities need, we focus on job market insertion, socialization, rehabilitation, practical stuff. It is not okay to only play with them or give them coloring supplies."

## Collaboration between private and public community services

"I observed that many NGOs who carry out European funded projects have a shortterm perspective, they do some activities with beneficiaries, they do their projects, and tomorrow they leave, and everybody is happy because they cashed in. They do not care what happens with persons with disabilities. And the burden falls on our shoulders; we must work daily with beneficiaries, accompany them to work, and we do it on our time and dime, with our personal cars. Employers call us when a beneficiary is in crisis, they are never going to call an NGO."

# Overlapping of services provided

"There are some projects that overlap the services public service providers supply: the beneficiaries from sheltered housing go to a day care center developed through a project by an NGO. We overlap. We try to provide a service and they another. But it is very difficult to coordinate and our biggest dissatisfaction is that it is supposed to be us who provide these services, NGOs should supply services for persons with disabilities living in the community."

Source: World Bank qualitative interviews with GDSACP directors (March-April 2021).

Although fraught with difficulties and discontent, collaboration in the process of developing community-based services remains an objective of most SSPs. While offering a broad description of obstacles in collaborating with relevant actors in the community for effectively planning the development of community services, SSPs remain committed nevertheless to conjugating their efforts with other local stakeholders in the process. A portrait of ideal collaborations often comprises references to aspects related to: (i) dialogue and transparency; (ii) needs assessment; (iii) funding opportunities; (iv) community involvement; and (v) person-centered service delivery (see Box 28 for a more detailed description of each aspect).

Box 28: Elements for ideal collaborations in developing community services

# Dialogue and transparency

Interview data indicated the following groups of actors involved in the process of establishing community services: NARPDCA, GDSACP, public social assistance units, local councils, county councils, NGOs or other private service providers, community, persons with disabilities. While their priorities might be different, they all express their desire to be more actively involved in the process of community transition. Stakeholders argue that NARPDCA should set up consultation and feedback mechanisms and be more transparent in its communication process. This is as much a critique as an opportunity, showing that the management of social services in the field of the protection of persons with disabilities is a matter of concern for all actors involved and that they would be willing to share their time, energy, and resources for meaningful services to be established. Furthermore, NARPDCA should be more involved with local and city councils in persuading them to prioritize the transition to community services, which might bridge the gaps between political parties, and mitigate political involvement in the way community services are developed. Dialogue has been one of the keywords invoked repeatedly when discussing ideal partnerships and public commitment to disability services. Active involvement of all interested parties would lead to more satisfaction with services, increased quality of care, and long-term sustainability of services.

# Assessment of needs

Developing a community service departs from a comprehensive assessment of beneficiaries' needs. GDSACPs and social protection units, authorities more involved in the management of disability at a local and county level, are the ones with the highest expertise in evaluating needs. Ideally, research participants argue, the two institutions should work together in assessing needs and correlate needs with community resources. NGOs, either service providers, self-advocacy groups or disabled persons organizations, should be involved as active partners in the process. The results should be made available to all interested parties.

## Financing opportunities

A comprehensive assessment of needs leads to identifying or creating relevant funding opportunities. The Program of National Interest initiated by NARPDCA raised the interest of 27 projects, and the current opportunity to develop respite centers is still considered a risky investment. Research participants demand financing opportunities in line with their needs. This recommendation has the potential of increasing the appeal of submitting financing proposals, creating more sustainable disability community services in the long term. Furthermore, interviewees require that methodologies should be more explicit, simple, and accessible. This might originate in public workers' lack of know-how or proficiency in writing and submitting funding proposals. One possible solution could be more training in accessing grants.

# Community participation

When developing a community service, providers should engage local communities in the process. Nolens volens, communities do not fully understand what disability means and are still skeptical toward welcoming persons with disabilities. Evidence shows countless examples of how services managed to foster the engagement of persons within the community. It is indeed a time-consuming process, built on awareness campaigns, forms of mutual aid, exchange, and reciprocity. In cases of successful community involvement, organizations such as the church and religious organizations were engaged.

# Person-centered approach to services

Disability community services should aspire and work toward principles of personcenteredness. Research shows that there are still advances to be made in the training of staff and the adoption of person-centered planning at a policy level, as well as a definition of intellectual disability according to current standards.

Source: World Bank qualitative research (March-April 2021).

#### Person-centered service delivery

Person-centeredness is an essential aspect of service development and delivery that prioritizes the needs and preferences of persons with disabilities. Person-centered planning is an approach rooted in the effort to "understand the experience of persons with developmental disabilities and work with them and their allies to change the experience for the better."187 The shift from service-centered approaches to person-

<sup>&</sup>lt;sup>187</sup> O'Brien, O'Brien, and Mount (1997).

centeredness is predicated on the tension between impairment and capacity. In other words, providers should focus on a person's capacities and gifts, instead of deficits, and determine the best supports that would help people express their gifts, as well as the people to enlist in helping persons with disabilities discover and achieve their visions and dreams of the future. 188 This involves a power transfer from staff and health professionals to the person, their family, friends, and community, 189 grounded on principles of participation, self-determination, choice-making, empowerment, and respect. 190

# Box 29: Principles of a person-centered approach

- 1. The person is at the center.
- 2. Family and friends are partners in planning.
- 3. The plan reflects what is important to the person, their capacities, and what support they require.
- 4. The plan results in actions that are about life, not just services, and reflect what is possible, not just what is available.
- 5. The plan results in ongoing listening, learning, and further action.

Source: Sanderson (2000).

Within community services, the SSP focuses on medical issues, which leads to a fragmented understanding of the person. The person is seen as a patient, as a sick person, and is not encouraged to develop skills and abilities for independent living at all.

The activities that persons with disabilities are provided in the community are contingent on the available services, infrastructure, and staff. Essentially, in the service-centered approach persons are fitted into program slots. Literature directs attention to the fact that "persons with disabilities should live in homes, not in programs, and they should work in jobs, not in workshops." 191 Beneficiaries are sometimes admitted to a particular sheltered house or a day care center because these are the only services available in the area. Should there be services in a different city or commune, eligibility criteria often bind them to services located in the town where they have their residence. However, that is rarely the case since there are often no services from which persons with disabilities can choose. The choice is limited to what is available. The most unfortunate cases interviewees recount are those where a person makes the transition from the child to the adult protection system. Once people come of age and no longer qualify for services in the child protection system, they have little knowledge of the services available for adults, leading to situations where they register setbacks in their treatment or physical therapy. On the other hand, activities delivered are as varied as is the personnel employed in a service. There are numerous instances where beneficiaries engage in kinesiotherapy, for instance, even though they might not

<sup>188</sup> Idem.

<sup>&</sup>lt;sup>189</sup> Sanderson (2000).

<sup>&</sup>lt;sup>190</sup> O'Brien and O'Brien (2000).

<sup>&</sup>lt;sup>191</sup> Mansell and Ericcson (1996: xii).

need or want this type of intervention, or the other way around, should the center not employ a specialist.

In determining support for persons with disabilities, service staff tend to decide on behalf of beneficiaries. This means that persons with disabilities are not in control of what supports and services they receive and decision making is relegated to staff. The process of evaluating beneficiaries and determining support is described as one where usually the multidisciplinary team meets and talks about the person. A person-centered approach suggests a change in perspective, from talking about the person to talking to the person. 192 Service staff sometimes have difficulties in accepting beneficiaries' autonomy and, as service coordinators and SSPs remark, the main predicament staff must overcome is treating persons with disabilities as children, rather than as adults. The problem is rooted in the attitude of the staff toward persons with disabilities and when staff acts as gatekeepers has consequences in restricting access to services.

Families, especially parents, are considered to be overprotective, which hampers person's transition toward autonomous or independent living. Families are described by SSPs not only as overprotective, but also as hesitant in allowing persons to pursue employment opportunities, travel outside the community center, or engage with the community. This attitude, however, is detrimental when implementing personcentered principles of support. Family members should be taken as equal partners in determining a person's vision of the future and in planning support. Dismissing family involvement as overprotectiveness diminishes their chances of active participation and overlooks the enormous knowledge that they might have about the person.

Procedurally, service providers ensure that services are person-centered and that persons with disabilities are involved in the organization and functioning of services by applying satisfaction surveys. Current quality standards require all service providers to administer satisfaction questionnaires to their beneficiaries. Surveys, however, measure satisfaction after the service was provided, usually one year after beneficiaries were admitted, making them an inefficient choice-enabling tool in contrast to feedback provided more regularly that may affect the quality of service delivery more effectively. Data is not always centralized<sup>193</sup> and it is not always clear if changes occur departing from the data collected. Furthermore, questionnaires are sometimes dated and signed and beneficiaries rarely express dissatisfaction with services. Since, on many occasions, service employees assist beneficiaries in filling out questionnaires, there is a considerable bias regarding the quality of data collected. Qualitative data pointed to only one service provider where the questionnaires were anonymous and filled out by beneficiaries together with volunteers or students. In the same service employees were dismissed because of negative reviews from beneficiaries, but this is a rather isolated occurrence of measures taken in the

<sup>192</sup> See Smull et al. (2005) for the Essential Lifestyle Plan, a widely used formalized person-centered tool. The instrument explains the difference between talking about and talking to the person in planning individualized

<sup>&</sup>lt;sup>193</sup> Aspects related to collecting and analyzing data on beneficiaries' satisfaction with service provision are treated in each of the previous chapters in community-based services.

aftermath of beneficiaries' feedback. In general, satisfaction surveys appear to be tools used to give persons with disabilities rather the satisfaction and illusion of choice.

The notion of independent living has a variety of definitions from one service to another, making it inadequate in setting goals, planning provision of support, and measuring outcomes for persons with disabilities. SSPs and service coordinators define independent living as: the interaction between staff and person; meeting new people; going to church, or other community services; acquiring a wheelchair or assistive technology; managing time; managing money; accommodation; finding and securing employment. Definitions may take into consideration disabilities, residence, family involvement, and existing services. For the concept to have a meaningful impact, it should be quantified, allowing progress to be measured according to person-driven criteria, as well as current standards of understanding and defining disability. Only 36 percent of sheltered houses have offered training to their staff in 2020 on "Independent living" but in the absence of available certified materials and trainers, it is not clear how the content of training aligns with the independent living principles and to what extent service delivery is guided by these principles in practice. 194

Box 30: SSPs' understanding of person-centeredness

## Focus on impairments

"Personnel should learn to provide these services according to the specificities of disease, be it neuromotor, mental or otherwise. We need a plan of development grounded on the nature of the disability and instruct families as well." - PSAS representative, Center region

"Community inclusion is out of the question, 98% of them have serious medical problems; you cannot do social assistance with them, nor can you do habilitation and rehabilitation." - GDSACP director, South Western region

"We evaluated our beneficiaries a couple of years ago and resulted in discovering their needs, that is where they can be amended." - GDSACP director, North-Western region

#### Choice limitations

"Our beneficiaries have diverse mental problems. Some of them want things we cannot deliver. They keep hearing about community reintegration, they want to go there, but having no services to access and a lot of medical problems on top, we prefer to keep them in our center, rather than setting them free in the community. God forbid, they might end up homeless or exploited." - Service coordinator, Southern region

"The problem is not whether persons with disabilities are discriminated against or not, I would rethink the entire issue. Are there service offers for persons with disabilities? If there are and they do not have access, then yes, I would say they are discriminated. If there are not, I find it difficult to understand how a person would

<sup>&</sup>lt;sup>194</sup> Data from the survey on 100 sheltered houses carried out by the World Bank between April-May 2021.

feel discriminated if s/he does not even know what services they can access." - NGO representative, North Western region

"We cannot talk about community integration when there is no network of services, these are just ideals we, the people who know how things should be, aspire to." -PSAS representative, Center region

"If the day center would be built, it would be better. I do not know any services in our town, so everything extra is welcomed. It is not enough for persons with disabilities, though. The day center we have now is over 40 kilometers away, specialists commute. The psychologist comes three times a week, the ergo-therapist two times a week." - GDSACP director, South Eastern region

"Our service fights for our beneficiaries, but we are somehow limited. Ideally, there would be ways for us to assist people to integrate into the community. There are no services to help us help them and have some control at the same time to see how they manage." - Service coordinator, North Eastern region

#### Substituted decisions

"The multidisciplinary team is solid, and the first step was for specialists to see what they can offer. They managed to know each other better in order to talk about beneficiaries, and they do their best to give supports according to beneficiaries' needs." - Service coordinator, Centre region

"We insist on practical abilities and what people can do. If one person has practical abilities, we emphasize handiwork. We have to figure out their strengths and work with them, otherwise, they lose themselves in painting and drawing. We try to treat them as adults." - Service coordinators, North-Western region

"Even if they are 25, they are guided to read Little Red Riding Hood, without considering that maybe they would like to know more about girls or music or whatnot. That is the main problem of the education system, it does not instruct you about these things, and when you find work in a center you work as you see fit, even if there's a team supporting you." - NGO representative, Center region

"We meet colleagues who do not believe that working with beneficiaries toward independent living is important. Let me give you an example. We struggled immensely to teach personnel how to work with beneficiaries. We suggested opening a bank account for them and to give them the responsibility of paying 5 RON a month for account maintenance. [Staff opposed, saying] "Why should they do that? Let the poor person be, I know better" [...] We must counsel both employee and beneficiary and it takes time. Why should I repeat 100 times? Repeat as many times as it takes for them to understand and improve that behavior." - GDSACP director, North-Western region

Source: World Bank interviews with GDSACP and NGO representatives and service coordinators (March-April 2021).

Integration and complementarity of services

There is emerging international evidence that integrated services can result in improved outcomes for beneficiaries, particularly those with complex needs. Although there are several approaches to service integration (see Box 31), when the term "integration" is used, it usually refers to the merging of two or more public services, such as social, health, education, employment, and cash benefits to avoid gaps as well as duplications or overlaps in service provision. 195 Other benefits of service integration pertain to cost effectiveness, accessibility, and quality of services for both service users and providers. 196 On a broad level, the term "integrated services" refers to a set of operations designed to improve service coordination and user outcomes. In a more specific way, integration is a set of approaches and models for creating connectedness, alignment, and collaboration within and between sectors at the funding, administrative, organizational, service delivery, and clinical levels. 197 Persons with disabilities may need to choose from a variety of integrated services as an effective strategy to overcome complex life situations through collaborative solutions, greater resource use, and improved user outcomes. 198 The integration of services may be achieved in various ways including but not limited to: case-management (assessing, planning, and coordinating service delivery for each individual), one-stop shops (a single point of contact for all services), and various forms of partnership arrangements as multi-professional teams or where two or more organizations collaborate. 199

# Box 31: Approaches to service integration

**Vertical integration** of services is possible by bringing together different levels of the care hierarchy (hospital, clinical and community-based health services for instance). Vertical integration can refer to organization, finance, or management.

**Horizontal integration**, on the other hand, combines previously disjointed services, professions, and organizations from several sectors to better serve service customers with diverse disadvantages and complex requirements. Horizontal integration can occur at national, regional, or local or delivery levels and may be achieved through:

- o collocation (having all agencies in one location and thus reducing the travel and time costs for service users)
- o collaboration (an essential step in decreasing service gaps for service users, it means that service providers are working together through information sharing and training, and creating a network of providers to boost the service quality)

<sup>&</sup>lt;sup>195</sup> Individual services, such as social services and employment services, may be effective in their own right and provide effective services to their clients, however there may be gaps or duplications in services. Particular services provide an imperfect picture of each person's or family's requirements as a whole, which can lead to inefficient responses to individual problems. Rather than working jointly, agencies and their services frequently overlap. Taylor (2009).

<sup>&</sup>lt;sup>196</sup> OECD (2015: 20-24).

<sup>&</sup>lt;sup>197</sup> Richardson & Patana (2012).

<sup>&</sup>lt;sup>198</sup> Lara Montero et al. (2016).

<sup>&</sup>lt;sup>199</sup> Idem.

 cooperation (the most complete integration defined as experts communicating and working on the case of a service user, for example, within small clinical teams or from multiple services).

Source: Richardson and Patana (2012); OECD (2015).

Integration and complementarity of service provision for persons with disabilities are not considered a priority by many service providers. Several GDSACP representatives emphasized that they are currently focusing on restructuring residential services but not on integrating or improving the complementarity of service provision. This is concerning, since it indicates that restructuring of and developing new services that respond to the support needs of persons with disabilities outside of residential institutions are not seen as mutually constitutive processes. The most referenced barrier to ensuring complementarity and integration is the lack of diverse services in the community. Thus, integration and complementarity appear as secondary to service development, whereas actually they should be seen as going hand in hand. Nevertheless, integration and complementarity, as well as the quality of life of persons with disabilities, are hampered by the lack of access to social housing, low number of licensed home-based care services, and insufficient numbers of social workers and case managers.

In order to facilitate integration and complementarity of social services, regularly updated information on social services should be made available to persons with disabilities and their caretakers, as well as to other service providers and public authorities. Several social service providers pointed to the necessity of setting up online databases of relevant services (both medical and social), where all service providers could clearly outline their service offers, responsibilities, and funding structures. Other NGO representatives pointed to the need to establish a public office funded by public funds on the local level that would collect all necessary information related to the different service providers and that persons with disabilities and caretakers could turn to for advice.

Box 32: Recommendation for a national/local database of services

Lack of knowledge regarding available services is seen by research participants as a type of discrimination. A solution proposed by a few specialists from the field is to set up a national or local database with all services listed. The simplest thing to do, the director of a social assistance unit argues, "would be to for persons with disabilities to see all services available for them once they receive their disability certificate. Things would be very clear. They would ponder: ` need education or training, where can I go? There's this Inclusion Center, or I can go to my local Social Assistance unit because they pay my benefits and give me transportation vouchers, I can go to that or that service for ABA therapy.' They get lost in the sea of community needs and remain alone and with problems" (Social Assistance unit, Centre region). An NGO representative echoes a similar idea: "there is not enough information on the offers available. You cannot open a website like www.dizabilitati.ro, click on your type of disability and find public and private service providers. Or at least to direct you to a phone number you could call. There is none. There is no written campaign on the life of persons with disabilities in our city. Not a newspaper per se, but a monthly magazine where each NGO could write an article, present their services, praise their success or failures" (NGO representative, North-Western region).

This idea is not novel. The UK implemented a national registry of services where persons with disabilities can, for instance, find day care centers based on their postcode. 200 Services Australia aims at proving information on all services under the motto "We're making government services simple so you can get on with your lives,"201 and National Disability Services202 offers a similar registry for over 1,200 nongovernmental service providers.

Source: World Bank qualitative research (March-April 2021).

Integration of services responding to the diverse needs of persons with disabilities should be organized in a way that does not constitute a violation of the right to live in the community, 203 by providing services in an isolated environment. A part of GDSACP service providers emphasized that integrated service provision is offered in residential institutions, considering that various activities (recovery and rehabilitation, medical, vocational, etc., are offered to beneficiaries in the same location). While residential institutions can cater to certain needs of persons with disabilities while they still live there, institutionalization cannot secure community inclusion and infringes on the right of independent living. Similarly, other examples of integrated service delivery that are incompatible with community inclusion and participation mentioned by our interview partners included offering day-care activities, sheltered housing, and recovery activities as part of the same complex of services where persons with

<sup>&</sup>lt;sup>200</sup> See https://www.gov.uk/day-care-centres

<sup>&</sup>lt;sup>201</sup> See https://www.servicesaustralia.gov.au

<sup>&</sup>lt;sup>202</sup> See https://www.nds.org.au

<sup>&</sup>lt;sup>203</sup> Council of Europe Commissioner for Human Rights (2012).

disabilities are kept in the same location with little connection with the outside world or with services for the general population.

The Individual Service Plan (ISP) constitutes a good but underused opportunity to plan an integrated approach to service delivery for persons with disabilities. The Individual Service Plan is a document that sets out short, medium-, and long-term objectives and ways in which support and intervention, and activities and services outlined in the Individual Program for Rehabilitation and Social Integration (PRSI) will be realized.<sup>204</sup> Interviewees have pointed out that the ISP should be used as an opportunity for planning an integrated service plan for persons with disabilities.

NGOs have been more successful in using an individualized and integrated approach to the services needed by persons with disabilities. On the one hand, this has involved planning for several months and weeks in advance together with the client and outlining the service needs and aspirations of the person. In concrete terms, this has allowed persons to choose to transfer from residential institutions or services to communitybased ones, as well as to be assisted in seeking and maintaining employment and a place of residence. The integration has involved identifying both relevant social services, as well as relevant market offers or opportunities (on the housing market for rent, on OLX, job posts, etc.) and supporting the person in dealing with the ensuing situations (meeting with landlords, preparing for job interviews, etc.).

# Case management

Ensuring service integration is one of the tasks of case managers. Law no. 292/2011 of social assistance defines case management as the method of integrating and coordinating all social activities aimed at vulnerable groups. 205 In particular, the case manager must coordinate, monitor, and evaluate the implementation of individual service plans (ISPs). Case managers and social workers were referenced by SSPs as the most important actors in facilitating the integration and complementarity of services for persons with disabilities. It is worrisome that this is the professional group that is considered overburdened and affected by low staffing levels, as well as by difficulties in recruiting suitable professionals for available positions.

Case managers are responsible for assessing the situation of beneficiaries and facilitating their access to available community-based services. According to the current quality standards, 206 the case manager has the task to coordinate the assessment of educational, social, medical, housing, employment and other services in

<sup>&</sup>lt;sup>204</sup> Law no. 448/2006. A detailed analysis of the use of ISP can be found in the "Analysis report of the implementation of the individual plans for adult persons with disabilities," corresponding to Output no. 7 under the Reimbursable Advisory Services Agreement on Support for Speeding up the Transition of People with Disabilities from Residential Institutions to Community-based Services (P168518).

<sup>&</sup>lt;sup>205</sup> Art. 6 letter u).

<sup>&</sup>lt;sup>206</sup> Order no. 1218/2019, Standard 2, Minimum requirement 8.

the community where beneficiaries live, with the support of local social workers or members of the multidisciplinary committee. Case managers' activities also involve an assessment of the degree to which services are accessible to beneficiaries. 207

Case management is central also for ensuring the person-centered aspect of service **delivery.** Case management involves the coordination and integration of social services directed at persons with disabilities. Case management activities have to be carried out by respecting individual autonomy and the inalienable dignity of persons with disabilities and their rights to live independently and make their own decisions. <sup>208</sup> Case managers thus work with persons with disabilities in the development of their individual plans and should be key actors in transitioning to community-based services. Currently, case managers are widespread in services run by the GDSACP, in local-level social services run by public authorities (DSA/PSAS), and are generally social workers. Only one NGO of those interviewed mentioned working with case managers.

Appointing case managers remains a challenge for most service providers. In some cases, GDSACPs are unable to appoint case managers to work with persons with disabilities either from residential centers or from the community, due to a lack of financial resources. This has led to difficulties in obtaining accreditation for their social services. The funding mechanisms for case management positions presently depend on targeted funding from county councils and the lack thereof jeopardizes the hiring process, since institutions have to "convince" the county council to fund these positions and in some cases, they fail.

Case management activities are carried out ineffectively due to the insufficient number of professionals with an adequate profile and the consequent unrealistically high workload. Despite the current legislation stipulates a ratio of 1 case manager to 50 beneficiaries who live in residential centers or in the community, <sup>209</sup> legal provisions are not always clear to some public service providers. Even when local public authorities (Directorates for Public Assistance) try to follow the mandatory ratio, efforts are hampered by lack of resources to hire specialists that in some cases leads to the assignment of the only employed social worker as a case manager. Likewise, in certain counties the lack of available qualified staff for case management led to appointing as case managers social workers and psychologists already working in residential institutions or to case managers relying on information from social workers and psychologists in residential institutions without establishing direct contact with the clients. As pointed out by interviewees, the overburdening of case managers and the apparent lack of managers working with persons with disabilities working in the

<sup>&</sup>lt;sup>207</sup> Order no. 1218/2019, Standard 2, Minimum requirement 11.

<sup>&</sup>lt;sup>208</sup> See Minimum Quality Standards for applying the case management method in the protection of adults with disabilities from 9.08.2019.

<sup>&</sup>lt;sup>209</sup> Decision no. 797/2017 of November 8, 2017 for the approval of the framework regulations for the organization and functioning of public social assistance services and the indicative staff structure.

community leads to a lack of knowledge about individual situations and further hampers the effective coordination, monitoring, and assessment of the fulfilment of the individual service plans.

# Availability of trained staff for developing community-based services

The vast majority of public service providers, as well as some of the private service providers pointed to difficulties in ensuring satisfactory staffing levels of their services. The main reason quoted was the lack of available qualified candidates to fill vacant positions that are publicly advertised. The problem of attracting qualified employees is especially more acute in certain geographic regions/counties, as well as in relation to positions requiring certain university qualifications. At least one GDSACP considered setting up a partnership with a university to offer internships and hire recent graduates from their programs, while others considered establishing partnerships with professional bodies (college of psychologists and college of social workers) to ensure professional training of specialists. The problem of attracting sufficient staff was even more severe for NGOs that could not offer the same level of salaries for the same level of expertise and qualifications as public SSPs. Even when NGOs would succeed in attracting sufficient staff, they strongly felt that their employees were underpaid. As a response to the problem of ensuring qualified staff, an NGO set up an accredited training program for certain relevant qualifications: social worker/"lucrător social", personal assistant/"asistent personal" and nurse/"infirmieră".

SSPs considered the legislation related to the development of community services to be ambiguous and in need of change. Issues of unfeasibility and vagueness of quality standards have been raised by SSPs who argue that even when they demand clarifications from central authorities, the clarifications received are unclear. The most insuperable obstacle is articulated in relation to the personnel to be hired in community centers. Firstly, specialists are said to be difficult to find and contract in small towns and communes, and some service providers have been forced to discontinue services. Secondly, there is a difference of interpretation regarding the personnel needed for the functioning of day centers. Several interviewees remark the disappearance of psychopedagogues from organizational charts plans and the relegation of beneficiary evaluation to public social authorities instead of social assistants working the centers. Furthermore, private SSPs who operate in multiple counties say that the law is interpreted differently from one county to another.

Staff shortage may continue to pose problems for the development of community services in the future. Even when staffing levels were considered satisfactory, service providers complained of having difficulties in securing staff for service development to extend community-based services. Specific areas of professional expertise were strongly affected by staff shortages, most prominently social workers and psychologists (at the local level), speech therapist (in certain counties), occupational therapists (due

to lack of formal training structures), and specialists in working with persons with autism (at the national level, with the exception of Bucharest).

Staff working in residential institutions for persons with disabilities should receive adequate training to avoid reproducing institutionalized forms of service provision.<sup>210</sup> A considerable number of public and private providers emphasize the need to re-train staff to ensure the right to independent living of persons with disabilities that use their services. Staff currently working in services for persons with disabilities (residential and community-based) or other social services (e.g., for children) will need to develop new and different competencies in order to successfully support persons with disabilities in the realization of their right to independent living. The purpose of re-training was described as the changing of mindsets, mentalities, and established ways of working in residential and other social protection institutions. New competencies were considered to involve: (i) understanding the principles of independent living and more broadly the rights of persons with disabilities; (ii) overcoming the tendency to create relationships of subordination with persons with disabilities using their services; and (iii) accepting and encouraging the autonomy of persons with disabilities and their right to decide in all matters concerning their lives. In practical terms this also involves doing everyday routine tasks (such as feeding/eating, choosing clothing, etc.) together and in coordination with the clients, as opposed to for them.

Proper resources for staff training are currently lacking. Most service providers emphasized the importance of lifelong learning and continuous professional development of all staff (with and without higher education) in the process of transitioning to community-based services, as well as staff's willingness to participate in training programs. However, service providers also reported a lack of available training resources. In addition, several SSPs complained about the quality of available programs, emphasizing their lack of relevance for practical everyday activities. In order for training programs to become more relevant to work with persons with disabilities, SSPs consider that these should be more firmly grounded on experience and build on more practical approaches to teaching and learning (e.g., case study analysis).

Staff training can be ensured either through national programs or by promoting regional, national, and international cooperation between service providers. The best way to address the learning needs of staff, as suggested by SSPs representatives, would be through a national program targeting all staff who work directly with persons with disabilities, while special provisions should be made for offering this training to anyone who works directly with persons with disabilities on a daily basis irrespective of their formal training (e.g., targeting carers). Many SSPs consider experience exchanges with other service providers on regional, national, and international levels to be very

<sup>&</sup>lt;sup>210</sup> European Union for Fundamental Rights (2018: 56).

valuable contexts for learning and professional development in the context of deinstitutionalization. GDSACP staff have established informal channels for exchange learning with other GDSACP staff from the same region, while some NGOs have set up regular annual international visits to SSPs abroad or work exchange programs (emphasizing benefits both in terms of increased income and competences acquired). Such initiatives should be encouraged and formalized, since they appear to create fruitful learning and professional development opportunities.

#### Personal assistance

Personal assistance is one of the key services for independent living, but there are difficulties with ensuring access to this service. According to current legislation, <sup>211</sup> persons with severe disabilities can benefit from personal assistance or may choose a monthly allowance. In March 2020, only 32 percent of persons eligible for personal assistance or an allowance were benefitting from the service (74.186 persons), with large disparities between counties and localities. <sup>212</sup> Employing personal assistants is considerably more expensive than offering allowances and represents a financial burden for local authorities, according to DSA representatives interviewed. As a consequence, mayoralties tend to make monthly allowances rather than employment contracts more widely available to persons with disabilities, or pressure the personal assistants to end their employment contract, which leads to an increased burden on the families of persons with disabilities, since most personal assistants are, in fact, family members. <sup>213</sup>

The quality of care and support provided by personal assistants varies greatly. Interviewed SSPs emphasized the essential role of personal assistants for supporting persons with disabilities to live in the community. However, SSPs working directly with beneficiaries who have personal assistants point to difficulties in maintaining efficient communication and recovery-oriented dialogue with the latter. Moreover, SSPs that offer mobile team services and home-based care services have pointed to the lack of appropriate care and hygiene that persons with disabilities sometimes receive from their personal assistants. These issues should receive priority in the training of personal assistants. However, in 2019, only 10 counties offered training to less than 2 percent of personal assistants in those counties.<sup>214</sup> In some situations, private SSPs compensate this lack by providing training themselves to the personal assistants of their beneficiaries on how to provide health assistance and personal care.

Access to services for the general population (education, employment, housing, health)

<sup>&</sup>lt;sup>211</sup> Law no. 448/2006. Personal assistants are employed by Mayoralties on a minimum net wage at the level of caretaker allowance (currently 1.348 RON) plus additional benefits.

<sup>&</sup>lt;sup>212</sup> World Bank (2021: 222).

<sup>&</sup>lt;sup>213</sup> According to World Bank interviews with GDSACP directors for the "Complex diagnosis report on the situation of public residential centers for adult persons with disabilities," corresponding to Output no. 3.1 under the Reimbursable Advisory Services Agreement on Support for Speeding up the Transition of People with Disabilities from Residential Institutions to Community-based Services (P168518) (2020: 45)

<sup>&</sup>lt;sup>214</sup> World Bank (2021: 224).

Ensuring access to inclusive community services is essential for independent living and may decrease the need for disability-specific services. Access to community services is essential for living fully included in the society and is as an obligation stipulated by Article 19 of the CRPD. In addition, the more inclusive are mainstream services such as education, health, employment, and transportation, the less the need to develop services that respond only to the needs of persons with disabilities. <sup>215</sup> For instance, training personnel working in health services on how to communicate and work with persons with disabilities can reduce the need for specialized rehabilitation day services for persons with disabilities, and is more "cost-effective and avoids the risk of segregation and sub-standardization of a specialized service."216 Many of the local service providers interviewed pointed to the fact that persons with disabilities continue to be discriminated against at the local level when accessing health and education services, as well as when seeking employment. Measures directed at increasing the level of accessibility and inclusiveness that general services provided to persons with disabilities must be prioritized as an important step in the process of developing disability-specific services.

Service providers mostly rely on social workers to facilitate access of persons with disabilities to services for the general population. Some services rely on nurses to facilitate access to medical services. Many of the interviewed SSPs had established networks of family doctors and specialists, as well as long-lasting partnerships with County Employment Agencies (CEAs) in view of ensuring professional training and access to the labor market for persons with disabilities. Some providers are also involved in supporting persons with disabilities applying for social housing and returning to education through programs such as Second chance (A doua ṣansă), a program carried out by the Ministry of Education directed at persons who have not completed their primary or secondary education, or partnerships with county-level school monitoring bodies (county school inspectorates).

The lack of social housing available for persons with disabilities continues to pose significant difficulties. Access to social housing within a reasonable amount of time is paramount to ensuring independent living for persons with disabilities who do not wish to live in sheltered houses but cannot afford to rent housing on the open housing market. Persons with disabilities is an eligible category for social housing alongside other marginalized groups to which local authorities can grant priority in allocating available housing. Nevertheless, many SSPs noted that although they support persons with disabilities in putting together the documents necessary for gaining access to social

<sup>&</sup>lt;sup>215</sup> CRPD Committee (2017: 32). Council of Europe Commissioner for Human Rights (2012).

<sup>&</sup>lt;sup>216</sup> CRPD Committee (2017: 33).

<sup>&</sup>lt;sup>217</sup> World Bank, Ministry of Regional Development and Public Administration (2015).

housing, this is often unrealistic as sufficient social housing is not available<sup>218</sup> and waiting lists are very long. Developing social housing and ensuring priority to persons with disabilities should be a priority of service development on a local level, as well as an integrative part of the social housing national policy.

National educational programs should be inclusive and address the needs of persons with disabilities. Facilitating access to education for persons with disabilities is another major challenge experienced by SSPs as well as NGO representatives. Several SSPs and service coordinators mentioned attempting to facilitate access of persons with disabilities to the Second chance program but are not able to enroll any longer due to age restrictions. <sup>219</sup> However, the lack of accommodations for the needs of persons with disabilities and a generally negative experience that persons with disabilities had with this program were some of the issues mentioned regarding the inclusiveness of the program. Similar experiences were reported when trying to facilitate access of persons with disabilities to training courses organized by CEAs that required certain education levels that had not been attained by the persons with disabilities that had only attended special education institutions.

<sup>&</sup>lt;sup>218</sup> This is especially true for urban areas. See World Bank, Ministry of Regional Development and Public Administration (2015: 23).

<sup>&</sup>lt;sup>219</sup> Ministry of Education (n.d).

# Supporting families

Despite recent efforts to restructure large residential institutions, one of the main routes through which persons with disabilities come from residential institutions to live in the community is family reintegration. This process, according to SSPs, is in practice largely centered on the material conditions of the family and the financial benefits that they may be able to access after a successful reintegration, but not on the person with disabilities' aspirations to be included in the community. Moreover, this route to living in the community is only available to those persons with disabilities living in institutions that have family with sufficient material resources who are willing to take them in and de facto discriminates against those persons with disabilities who have no such support.

Beneficiaries and their families are thought to be reticent about transferring from a residential to a community center. History and frequency of family visits in residential centers and increasing demand from local authorities to institutionalize persons with disabilities leads to an uncertainty regarding families' level of commitment to community inclusion of their family members with disabilities. This represents a major source of concern for those developing or planning to develop community services and who consider families as partners in the planning of individualized support. Furthermore, beneficiaries are also thought to be no more inclined to transfer to a different service, perhaps located in another town or commune. To ensure transitions to community living there is need to both support caregivers by evaluating and addressing the full spectrum of their needs, <sup>220</sup> as well as persons with disabilities themselves to enable them to make autonomous decisions, and identify the support they need. <sup>221</sup>

#### Working with communities

Communities do not appear as relevant actors in the process of developing community services. Rather, the community where a service is planned or developed is mentioned as an important actor only when it opposes development. Establishing a service is an opportunity-based process that takes into consideration available resources—buildings, land, funds, the approval of local and county councils—rather than one that accounts for community needs or that plans beneficiaries' active engagement within the community. This rupture is evident when service coordinators remark on the community's reticence and hostility toward persons with disability or the difficulty of finding and securing employment for beneficiaries.

The community where services can be developed is seen to be hesitant to welcome persons with disabilities. Local communities are considered reluctant to live near

<sup>&</sup>lt;sup>220</sup> European Expert Group on the Transition from Institutional to Community-based care (2012: 131-132).

<sup>&</sup>lt;sup>221</sup> The EEG suggests that building confidence and enhancing decision-making skills with regard to the living environment of persons with disabilities in the community can also be addressed by ensuring access to information, advice, and support on the benefits and challenges of independent living, especially from other persons with disabilities who already live independently and who may have experienced institutionalization themselves (2012: 122).

persons with disabilities but are more tolerant regarding community services for children. There are several instances where the community opposes the construction of community services for adults with disabilities, either by staging a protest or coalizing with local authorities. Generally, interviewees argue that developing a community service should take into account that services will be delivered within the community and staff should be prepared in mitigating public opinion, unlike residential centers which are in more isolated places farther away from residential buildings in the community.

#### Box 33: Communities' reticence

"We have to start changing our perception of people in need, that these people have to be isolated, away from the community, or that they all should be lumped together in a place away from normal people. These is still prejudice we face." - GDSACP director, Southern region

"We like it not to admit, when it comes to persons with disabilities in the community, most of the times we deal with reticence from both the community and local authorities. If, for children, local authorities were always open in giving us a kindergarten, an after-school, a building for us to transform into a family house, when it comes to adults with disabilities, the situation changes dramatically. I am not saying that they are intolerant, but children and adults are treated differently." -GDSACP director, Western region

Source: World Bank interviews with GDSACP representatives (March-April 2021).

Working with communities is thus particularly important in overcoming resistance to community-based services and ensuring community inclusion of persons with disabilities. Especially in the process of deinstitutionalization, community-based services should be developed by also taking into account the characteristics and needs of destination communities, as well as anticipated risks.<sup>222</sup> Community inclusion work should be focused on creating inclusive local communities which, "with strong social networks ('social capital'), bring rewards for the whole community: strong political institutions, improved economic development, improved health, and more effective public services."223 This, however, has not so far been a systematic and planned effort on the part of public service providers as part of the process of developing communityservices, and contact with communities has been rather accidental and sporadic. In addition, efforts should also be made to facilitate contacts between members of local communities in which existing services operate and persons with disabilities using these services in order to avoid isolation and segregation within the community and facilitate community participation and inclusion.<sup>224</sup>

<sup>&</sup>lt;sup>222</sup> People First of Canada/Canadian Association on for Community Living (2010: 134).

<sup>&</sup>lt;sup>223</sup> Pye Marie and Sayce Liz (2014).

<sup>&</sup>lt;sup>224</sup> Council of Europe Commissioner for Human Rights (2012: 39).

Public SSPs have seldom engaged in awareness-raising campaigns regarding the rights of persons with disabilities. When they have engaged in such campaigns, this has been a minor activity (leaflet-based information campaign, local radio shows, etc.) or has been carried out in partnership with NGOs and economic actors. More successful campaigns have been carried out in a number of cities and smaller towns to increase the public visibility of persons with disabilities by organizing balls, basketball championships, etc. Moreover, public SSPs have often engaged with promotion of their services (including residential services) alongside campaigns promoting the rights of persons with disabilities, likely creating confusion between the two. However, stereotypes regarding persons with disabilities appear to have been transformed after local community members got to know persons with disabilities living in the same community and using community-based services in that community.

#### 3.3. Conclusion and recommendations

So far, service development has been driven by external factors. Most services have been developed as a result of obligations to downsize large residential institutions, as well as in response to opportunities of specific available funds. In some cases, services were also developed to meet quality standards requirements—such as day centers for beneficiaries living in sheltered houses. Very few services were set up in response to needs of persons with disabilities at the community level, such as mobile teams and home-based services. These development models have led to service underdevelopment as well as to a lack of service variety: sheltered houses and day centers are still the most numerous types of services.

Service underdevelopment has a number of causes: (i) unclear roles and responsibilities as well as passing responsibilities between main stakeholders regarding service development; (ii) an overly centralized process of service development; (iii) a lack of adequately trained service staff, as well as material and financial resources; (iv) lack of technical expertise at the local level; (v) a dearth of partnerships with private SSPs; and (vi) resistance of communities to service development and to welcoming persons with disabilities.

Person-centeredness is rarely a principle of service development and delivery. Most community services adopt a medical-based understanding of disability, which means focusing on individual impairments, instead of capacities and needs. In addition, access to services and activities is limited to available services, infrastructure, and staff, rather than responding to the needs of persons with disabilities. In fact, support needs are evaluated and determined by service staff generally by excluding the service user; by talking *about*, rather than *to* the person. Families also tend to be dismissed as overprotective and not involved as partners in service planning.

Service integration is currently not a priority for SSPs. The exclusive focus on downsizing residential centers coupled with limited availability of disability-services as well as inaccessible mainstream services at the local level makes service integration an impossible task. This situation is further compounded by a lack of databases or offices that could provide information about available services, as well as by an insufficient number of case managers responsible for ensuring service integration and the personcentered aspect of service delivery.

Access to community services is limited. Persons with disabilities continue to be discriminated against at the local level when accessing health and education services, as well as when seeking employment. At the same time, lack of social housing available for persons with disabilities continue to pose significant difficulties. Inaccessible mainstream services further maintain or increase the demand for disability services and is a barrier to inclusion and active participation in the community for persons with disabilities.

The analysis in the current report led to a series of recommendations:

- More community services need to be developed, more options for persons with disabilities to choose from (including those in residential services). Lack of options makes beneficiaries vulnerable—they are more likely to accept poor services and less likely to complain or report problems/abuses;
- Services must be developed to respond to the needs of persons with disabilities to prevent institutionalization and ensure community inclusion, rather than to funding programs or legal requirements; they should be developed through a proper assessment of community needs and through real and transparent consultations with all stakeholders, including persons with disabilities, their families and NGOs;
- o Person-centeredness should ground all service delivery at all stages—needs assessment, planning, monitoring, and feedback.
- Local authorities and GDSACPs should implement a coordinated system for collecting data on the needs for services at the local level (via evaluations carried out by SECPAH, case managers, etc.), that must be regularly updated and that can inform the development of county strategies for service development.
- Service development should be designed in a tailored manner, considering the needs of persons who are or will be deinstitutionalized as well as for preventing the institutionalization of those in the community. A systemic approach of service design and service delivery must consider both vertical and horizontal service integration.
- o Invest in staff: proper training, better pay, better working conditions;
- Measures directed at increasing the level of accessibility and inclusiveness that general services provide to persons with disabilities must be prioritized as an important step of the process of developing disability-specific services; any planning of service development should be based on a comprehensive analysis of mainstream services accessibility.
- More awareness-raising campaigns on the rights of persons with disabilities are needed to mitigate communities' resistance to service development and to the inclusion and full participation of persons with disabilities in society on an equal basis. In addition to awareness-raising, more targeted community inclusion work should be planned and carried out to identify community needs and further benefits of deinstitutionalization.

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# Legislation

- Law no. 272/2004 regarding the protection and promotion of the rights of the child.
- Law no. 448/2006 regarding the protection and promotion of the rights of persons with disabilities.
- Law no. 292/2011 of social assistance.
- Law no. 197/November 1, 2012, regarding quality assurance in the field of social services, published in Official Journal no. 754/November 9, 2012, amended and supplemented.
- o Law no. 177/October 10, 2019, for the modification of Law no. 197/2012.
- Decision no. 797/2017 of November 8, 2017, for the approval of the framework regulations for the organization and functioning of public social assistance services.
- Decision no. 601 from July 16, 2020, regarding the exception of unconstitutionality of the provisions. Available at: https://www.ccr.ro/wpcontent/uploads/2021/01/Decizie\_601\_2020.pdf
- Emergency Ordinance no. 69/2018 for modifying Law no. 448/2006 regarding the protection and promotion of the rights of persons with disabilities.
- o Government Decision no. 118/February 19, 2014, which adopts the Methodological norms for the application of Law no. 197/2012.
- Government Decision no. 548/July 27, 2017, regarding the approval of conditions for obtaining the certificate, certification procedures, and the statute of the personal professional assistant.
- o Government Decision no. 50/2015 on the organization, functioning, and attributions of the National Authority for Persons with Disabilities.
- Government Decision no. 867/2015, which adopts the official classification list for all social services in Romania.
- Government Decision no. 1002/2019, which regulates the functioning of the National Authority for the Rights of Persons with Disabilities, Children and Adoptions.
- o Government Emergency Ordinance no. 113/2011 on the organization and functioning of the National Agency for Payments and Social Inspection.
- Government Emergency Ordinance no. 82/November 16, 2016, for the approval
  of the Special Statute of the specific public position of social inspector and for
  the amendment and completion of some normative acts.
- Government Emergency Ordinance no. 102/June 29, 1999, regarding the special protection and employment of persons with disabilities.
- Order of the Minister of Health and Family no. 22/January 29, 2003, regarding the approval of quality standards for services provided in special protection institutions for handicapped persons.

- Order no. 205/June 17, 2005, regarding the approval of minimum quality standards for residential centers for adults with disabilities, day centers for adults with disabilities, and protected houses for adults with disabilities.
- o Order no. 383/2005 for approving general quality standards regarding social services and the procedure for evaluating their fulfilment.
- Order no. 559/2008 regarding the approval of specific quality standards for residential centers, day centers, and sheltered houses for adults with disabilities.
- o Order no. 2126/2014 regarding the approval of minimum quality standards for the accreditation of services for elderly.
- o Order no. 67/January 21, 2015, regarding the approval of minimum quality standards for the accreditation of social services for adults with disabilities.
- Government Order no. 1887/2016 from September 15, 2016, establishes the conditions and the algorithms for these payments, which apply to all social services, depending on type and amount of income of beneficiaries or their families.
- o Order no. 1069/February 13, 2018, regarding the approval of minimum mandatory standards for ensuring the care and protection of adults with accentuated or high degrees of disability by a personal professional assistant.
- o Order no. 1690/May 21, 2018, for approval of the procedure for monitoring and controlling the activity of a personal professional assistant.
- Order no. 814/2019 regarding the amendment of Annex no. 1 to the Order of the Minister of Health no. 1468/2018.
- Order no. 82/2019 regarding the approval of mandatory minimum quality standards for social services for persons with disabilities.

# Annexes Summary tables of minimum quality standards for disability social services

TABLE A1. Minimum quality standards for sheltered housing services

	Modules	Standards for sneltered not	Number of minimum requirements	Number of criteria used in evaluation
Sheltered housing	I. Social service	1. Organization and functioning	18	10
	management	2. Housing	27	8
		3. Food	15	1
		4. Health assistance	16	5
	II. Accessing	1. Information	10	2
	the social	2. Admittance	11	2
	service	3. The beneficiary's personal file	8	2
		4. Service suspension/termination	12	3
	III. Evaluation and planning	1. Evaluation	11	2
		2. The personal future plan	10	1
		3. Monitoring	6	2
	IV. Services and activities	1. Information and social counseling/social assistance	8	1
		2. Psychological counseling	10	1
		3. Recovery and rehabilitation	11	1
		4. Care and assistance	11	1
		5. Independent life skills (cognitive skills)	9	0
		6. Independent life skills (everyday life skills)	7	0
		7. Independent life skills (communication skills)	8	0
		8. Independent life skills (mobility skills)	8	0
		9. Independent life skills (self-care skills)	9	0

	10. Independent life skills (self-health care skills)	9	0
	11. Independent life skills (self-management skills)	9	0
	12. Independent life skills (social interaction skills)	11	0
	13. Independent life skills (economic independence skills)	8	0
	14. Education/preparation for work	13	0
	15. Involvement and civic and social participation	13	0
V. Protection	<ol> <li>Respecting beneficiaries' rights</li> </ol>	2	1
and rights	2. Risk management	5	1
	3. Code of ethics	5	1
	4. Protection from negligence, exploitation, violence, and abuse	9	3
	5. Protection from torture and cruel, inhuman, or degrading treatment	7	3
	6. Assistance in case of death	6	1
	7. Complaints	5	1
	8. Beneficiary satisfaction	4	1
	Total	331	54

Source: Annex 2 to Order no. 82/2019.

TABLE A2. Minimum quality standards for crisis center and respite center services

Type of service	Modules	Standards	Number of minimum requirements	Number of criteria used in evaluation	
Respite centers/Crisis	service	1. Organization and functioning	18	10	
centers	management	2. Housing	23	8	
		3. Food	7	1	
		4. Health assistance	13	5	
		1. Information	10	2	

	II. Accessing	2. Admittance	7	2
	the social service			2
		4. Service suspension/termination	9	3
	III. Evaluation and planning	1. Evaluation (prior to being admitted in RC/after being admitted in the CC)	9	2
	•	2. Personalized plan	4	1
		3. Monitoring	6	2
-	IV. Services and activities	1. Information and social counseling/social assistance	7	1
		2. Psychological counseling	10	1
		3. Care and assistance	12	1
		4. Everyday life	10	1
	V. Protection and rights	1. Respecting beneficiaries' rights	2	1
		2. Risk management	5	1
		3. Code of ethics	5	1
		4. Protection from negligence, exploitation, violence, and abuse	9	3
		5. Protection from torture and cruel, inhuman, or degrading treatment	7	3
		6. Assistance in case of death	6	1
		7. Complaints	5	1
		8. Beneficiary satisfaction	4	1
		Total	196	54

Source: Annex 3 to Order no. 82/2019.

TABLE A3. Minimum quality standards for home care services

Type of service	Modules	Standards	Number of minimum requirements	Number of criteria used in evaluation
for persons	I. Social service management	1. Organization and functioning	19	8
with disabilities	II. Accessing		8	2
disabilities	the social	2. Admittance	9	3
	service	3. The beneficiary's personal file	7	2
		4. Service termination	3	1
	III.	1. Evaluation	12	3
	Evaluation	2. Personalized plan	7	1
	and planning	3. Monitoring	4	2
	IV. Services and activities	<ol> <li>Information and social counseling/social assistance</li> </ol>	9	1
		2. Personal care	10	2
		3. Feeding and hydration	10	1
		4. Involvement and civic and social participation	11	1
	V. Protection and rights	1. Respecting beneficiaries' rights	2	1
		2. Risk management	5	1
		3. Code of ethics	5	1
		4. Protection from negligence, exploitation, violence, and abuse	9	3
		5. Protection from torture and cruel, inhuman, or degrading treatment	8	3
		6. Complaints	5	1
		7. Beneficiary satisfaction	3	1
		Total	146	38

Source: Annex 4 to Order no. 82/2019.

TABLE A4. Minimum quality standards for mobile team services

Type of service	Modules	Standards	Number of minimum requirements	Number of criteria used in evaluation
Mobile team	I. Social service management	1. Organization and functioning	19	9
	_	2. Information	8	2
	the social	1. Admittance	9	3
	service	2. The beneficiary's personal file	7	2
		3. Service termination	3	1
	III.	1. Evaluation	12	3
	Evaluation	2. Personalized plan	7	1
	and planning	3. Monitoring	4	2
	IV. Services and	1. Information and social counseling/social assistance	8	1
	activities	2. Psychological counseling	10	1
		3. Facilitating the beneficiary's independence	8	1
		4. Developing personal mobility	9	1
	V. Protection	<ol> <li>Respecting beneficiaries' rights</li> </ol>	2	1
	and rights	2. Risk management	5	1
		3. Code of ethics	5	1
		4. Protection from negligence, exploitation, violence, and abuse	8	3
		5. Protection from torture and cruel, inhuman, or degrading treatment	7	3
		6. Complaints	5	1
		7. Beneficiary satisfaction	3	1
		Total	139	38

Source: Annex 5 to Order no. 82/2019.

TABLE A5. Minimum quality standards for day center services

Type of service	Modules	Standards	Number of minimum requirements	Number of criteria used in evaluation
Day centers/Outpatient	I. Social service	1. Organization and functioning	19	11
neuromotor recovery service centers	management	2. Safety and comfort for beneficiaries	16	7
		3. Food, care, and assistance	12	0
		4. Health assistance	3	1
	II. Accessing	1. Information	10	2
	the social	2. Admittance	8	2
	service	3. The beneficiary's personal file	8	2
		4. Service termination	8	1
	III. Evaluation and planning	1. Evaluation	10	3
		2. Personalized plan	10	3
		3. Monitoring	6	2
	IV. Services and activities	1. Information and social counseling/social assistance	8	1
		2. Psychological counseling	11	1
		3. Recovery and rehabilitation	13	2
		4. Independent life skills	11	2
		5. Work skills development, preparation for employment, employment maintenance assistance	17	1

	6. Integration and social and civic participation	10	1
	7. Outpatient neuromotor recovery	10	1
V. Protecti and righ		2	1
	2. Risk management	5	1
	3. Code of ethics	5	1
	4. Protection from negligence, exploitation,	9	3
	violence, and abuse		
	5. Protection from torture and cruel, inhuman, or degrading treatment	7	3
	6. Complaints	5	1
	7. Beneficiary satisfaction	4	1
	Total	227	54

Source: Annex 6 to Order no. 82/2019.

TABLE A6. Minimum quality standards for professional personal assistant services

Type o service	of Modules		Standards	Number of minimum requirements	Number of maximum points awarded in evaluation
Personal Professiona Assistant	al	service through which the	1. The service through which the person with serious or severe disabilities receives care and protection from the PPA	12	4

	care and protection			
	II. Accessing		6	1
		3. Admittance	3	1
•	service	4. The beneficiary's personal file	8	1
		5. Service suspension/termination	10	1
; !	III. The care and protection of the	3	3	1
:	serious or	7. Housing, accessibility, and hygiene	13	1
	severe disability	8. Food and feeding	6	1
	from the	9. Health and mobility	13	1
	PPA	10. Privacy and confidentiality	3	1
		11. Decision making and autonomy	4	1
		12. Activities and participation	13	1
		13. Work skills development and employment	6	1
	IV. Management and inter-	14. Respect for rights and dignity	3	1
		15. Case manager	5	1
	institutional relations	16. Risk management	5	1
!	retations	17. Protection from exploitation, violence, and abuse	7	1
		18. Protection from torture and cruel, inhuman, or degrading treatment	7	1
		19. Complaints	5	1
		Total	120	1 point per standard = 22 points

Source: Order no. 1069/2018.

**Annex-Tables** 

Annex-Table 1: Profile of sheltered housing services included in the evaluation

Alliex-Table 1			o. of serv		Total number of beneficiaries in 2020*		
		Total	MSH	mSH	Total	MSH	mSH
Total no.	Total	100	89	11	703	641	62
Capacity (the	2-4	7	4	3	28	19	9
requirement	5-9	70	67	3	458	443	15
is between 2 and 10	10	21	16	5	192	154	38
beneficiaries)	10+	2	2	0	25	25	0
Area type	Urban	58	51	7	408	373	35
	Rural	42	38	4	295	268	27
County	Alba	9	9		70	70	
	Argeș	7	7		41	41	
	Bacău	8	8		57	57	
	Bihor	5	4	1	29	27	2
	Botoșani	1	1		7	7	
	Brașov	4	3	1	30	24	6
	Brăila	3	3		28	28	
	Bucharest	6	5	1	32	30	2
	Cluj	2		2	18		18
	Constanța	21	20	1	146	140	6
	Dâmbovița	11	11		75	75	
	Dolj	4	4		41	41	
	Harghita	3	1	2	15	9	6
	Hunedoara	2	2		12	12	
	lași	4	4		22	22	
	Mureș	1	1		10	10	
	Sălaj	2	2		16	16	
	Suceava	1	1		10	10	
	Vaslui	2	2		14	14	
	Vrancea	4	1	3	30	8	22

Source: World Bank survey of sheltered housing (2021).

Note: \*Data on the number of beneficiaries were reported by service providers.

Annex-Table 2: Profile of beneficiaries of sheltered houses included in the evaluation, in 2020

Distribution by sex		heltered uses		Sheltered uses		Sheltered uses
	N	%	N	%	N	%
Men	317	44.9	294	45.9	23	37.1
Women	386	55.1	347	54.1	39	62.9
TOTAL	. 703	100	641	100	62	100
Distribution by		heltered		Sheltered	Minimum	Sheltered
age groups	Но	uses	Но	uses	Ho	uses
	N	%	N	%	N	%
18-19 years	11	1.6	11	1.7	0	0.0
20-24 years	95	13.5	86	13.4	9	14.5
25-29 years	123	17.5	114	17.8	9	14.5
30-34 years	124	17.6	119	18.6	5	8.1
35-39 years	96	13.7	88	13.7	8	12.9
40-44 years	82	11.7	81	12.6	1	1.6
45-49 years	66	9.4	57	8.9	9	14.5
50-54 years	38	5.4	32	5.0	6	9.7
55-59 years	5 19	2.7	12	1.9	7	11.3
60-64 years	s 13	1.8	11	1.7	2	3.2
65-69 years	15	2.1	14	2.2	1	1.6
70-74 years	8	1.1	7	1.1	1	1.6
75-79 years	6	0.9	4	0.6	2	3.2
80-84 years	5 5	0.7	3	0.5	2	3.2
85 years and over	2	0.3	2	0.3	0	0.0
TOTAL	703	100	641	100	1,555	100
Distribution by degree of		heltered uses		Sheltered uses		Sheltered uses
disability	N	%	N	%	N	%
Low	, 11	1.6	8	1.2	3	4.8
Milo	l 151	21.5	123	19.2	28	45.2
High	397	56.5	371	57.9	26	41.9
Severe	144	20.5	139	21.7	5	8.1
No certified disability	()	0	0	0.0	0	0.0

Distribution by legal capacity	_	neltered uses		Sheltered		Sheltered uses
TOTAL	703	100	641	100	62	100
Rural	295	42%	268	41.81%	27	43.55%
Urban	408	58%	373	58.19%	35	56.45%
_	N	%	N	%	N	%
residence	Ho	uses	Но	uses	Но	uses
Distribution by	Total SI	neltered	Maximum	Sheltered	Minimum	Sheltered
TOTAL	703	100	641	100	62	100
Over 10 years	156	22.2	138	21.5	18	29.0
5-10 years	218	31.0	207	32.3	11	17.7
2-5 years	156	22.2	137	21.4	19	30.6
0-2 years	173	24.6	159	24.8	14	22.6
residence in the – current (SH)	N	%	N	%	N	%
length of	Ho	uses	Но	uses	Но	uses
Distribution by	Total SI	neltered	tered Maximum Sheltered		Minimum Sheltered	
TOTAL	703	100	641	100	62	100
Deafblindness	0	0.0	0	0.0	0	0.0
Rare diseases	0	0.0	0	0.0	0	0.0
HIV/AIDS	4	0.6	4	0.6	0	0.0
Associated	88	12.5	79	12.3	9	14.5
Psycho-social	101	14.4	98	15.3	3	4.8
Intellectual	484	68.8	439	68.5	45	72.6
Visual	3	0.4	2	0.3	1	1.6
Auditory	1	0.1	1	0.2	0	0.0
Somatic	0	0.0	0	0.0	0	0.0
Physical	22	3.1	18	2.8	4	6.5
_	N	%	N	%	N	%
Distribution by type of disability	Total Sheltered Houses		Maximum Sheltered Houses		Minimum Sheltered Houses	

N

645

Legal capacity

%

91.8

N

588

%

91.7

%

91.9

N

57

No legal capacity	58	8.2	53	8.3	5	8.1
TOTAL	703	100	641	100	62	100

Source: World Bank survey of sheltered housing (2021).

Annex-Table 3: Profile of beneficiaries of crisis and respite centers included in the evaluation, in 2020

	Service 1	Service 2
Distribution by sex		
Men	6	13
Women	3	5
Distribution by age groups		
18-19 years	0	3
20-24 years	1	4
25-29 years	0	0
30-34 years	0	1
35-39 years	2	1
40-44 years	0	1
45-49 years	2	5
50-54 years	0	0
55-59 years	3	2
60-64 years	0	0
65-69 years	1	1
Distribution by degree of disability		
Mild	1	4
Accentuated	5	13
Severe	3	1
Distribution by type of disability		
Intellectual (Mental)	7	5
Psychosocial (Psychic)	0	6
Associated	2	7
Distribution by family situation		
No known family	4	4

Known assistant		5	14
Distribution residence	by		
	Urban	6	0
	Rural	3	18
Total numb beneficiaries	er of	9	18

Source: World Bank survey of crisis and respite centers (2021).

Annex-Table 4: Profile of beneficiaries of the mobile team services included in the evaluation, in 2020

evaluation, in 2020		
	Service 1	Service 2
Distribution by sex		
Men	19	8
Women	14	15
Distribution by age groups		
18-19 years	0	0
20-24 years	3	3
25-29 years	1	2
30-34 years	1	0
35-39 years	2	0
40-44 years	5	0
45-49 years	2	0
50-54 years	2	5
55-59 years	2	2
60-64 years	4	2
65-69 years	1	0
70-74 years	4	6
75-79 years	5	0
80-84 years	1	1
85 years and over	0	2
Distribution by degree of disability		
Mild	1	1
Accentuated	6	5
High	26	17
Distribution by type of disability		
Physical	28	21
Somatic	1	1
Intellectual	1	0
Associated	3	1

Distribution by living		
situation		
Cared for by family	32	9
With personal assistant	1	10
With Professional Personal	0	4
Assistant		
Distribution by residence		
Urban	17	18
Rural	16	5
Total number of	33	23
beneficiaries		
C 11/ 11/ 1 C 1		3.4.\

Source: World Bank survey of mobile team services (2021).

Annex-Table 5: Profile of beneficiaries of home-care services included in the evaluation, in 2020

evaluation, in 2020		
	Service 1	Service 2
Distribution by sex		
Men	26	1
Women	60	13
Distribution by age groups		
18-19 years	0	0
20-24 years	1	0
25-29 years	0	0
30-34 years	0	0
35-39 years	0	0
40-44 years	1	0
45-49 years	0	0
50-54 years	3	0
55-59 years	2	0
60-64 years	6	0
65-69 years	13	2
70-74 years	16	0
75-79 years	15	1
80-84 years	16	3
85 years and over	13	8
Distribution by degree of		
disability		
Low	0	1
Mild	10	1
Accentuated	46	1
High	30	3
No certified disability	0	8

Distribution by type of disability		
Physical	48	2
Somatic	14	0
Visual	6	2
Intellectual	12	0
Associated	0	1
Psycho-social	6	1
Distribution by living situation		
Cared for by family	85	0
With personal assistant	0	0
With Professional Personal Assistant	0	0
Living independently	1	14
Distribution by residence		
Urban	86	14
Rural	0	0
Total number of beneficiaries	86	14

Source: World Bank survey of home-care type services (2021).

Annex-Table 6: Profile of PPA beneficiaries in the two GDSACPs

	Service 1	Service 2
Distribution by sex	6	8
Men	3	1
Women		
Distribution by age group		
18-19 years	1	0
20-24 years	8	4
25-29 years	0	5
Distribution by degree of disability		
Accentuated	3	0
High	6	9
Distribution by type of disability		
Mental	4	7
Psychiatric	1	0
Associated	4	1
Rare illnesses		1
Distribution by family situation		

Known family	8	0
No known family	1	9
Distribution by residence		
Urban	2	8
Rural	7	1
Total number of	9	9
beneficiaries		

Source: World Bank survey of home-care type services (2021).

Annex-Table 7: Profile of day centers and outpatient neuromotor recovery service centers included in the evaluation

		Number of day centers			Total benefi	nun iciaries in	nber of 2020*
		Total	Day Centers	Outpatient Neuromotor Recovery Service Centers	Total	Day Centers	Outpatient Neuromotor Recovery Service Centers
		34	22	12	2,700	1,145	1,555
Capacity	Under 8	1	1	0	16	16	0
(minimum number	8	12	8	4	797	404	393
of beneficiaries/day)	10-19	6	2	4	304	72	232
belieficial les/day)	20-29	7	6	1	530	221	309
	30+	8	5	3	1,053	432	621
Area type	Urban	33	21	12	2,694	1,139	1,555
	Rural	1	1	0	6	6	0
County	Alba	1	1	0	11	11	0
	Argeș	2	0	2	96	0	96
	Bihor	1	1	0	16	16	0
	Botoșani	1	0	1	74	0	74
	Bucharest	7	6	1	478	169	309
	Cluj	2	1	1	88	24	64
	Constanța	1	1	0	138	138	0
	Covasna	1	0	1	60	0	60
	Dâmbovița	2	1	1	228	73	155
	Dolj	2	2	0	406	406	0
	Galați	3	3	0	107	107	0
	Harghita	2	1	1	78	6	72
	Hunedoara	2	2	0	118	118	0
	Ialomița	1	0	1	416	0	416

Maramureș	1	0	1	168	0	168
Olt	2	1	1	124	20	104
Suceava	2	1	1	65	28	37
Timis	1	1	0	29	29	0

Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).

Note: \*Data on the number of beneficiaries were reported by service providers.

Annex-Table 8: Profile of beneficiaries of the day centers and outpatient neuromotor recovery service centers included in the evaluation, in 2020

	Day Centers		Outpatient	Neuromotor		
	\ 1	0/	Recovery Service Centers			
Distribution by sex		%	N	<u></u> %		
Men	563	49.2	821	52.8		
Women	582	50.8	734	47.2		
TOTAL	1,145	100	1,555	100		
Distribution by	age					
groups						
	N	%	N	%		
18-19 years	38	3.3	21	1.4		
20-24 years	101	8.8	64	4.1		
25-29 years	128	11.2	92	5.9		
30-34 years	132	11.5	85	5.5		
35-39 years	117	10.2	117	7.5		
40-44 years	117	10.2	79	5.1		
45-49 years	88	7.7	105	6.8		
50-54 years	89	7.8	238	15.3		
55-59 years	63	5.5	161	10.4		
60-64 years	87	7.6	207	13.3		
65-69 years	71	6.2	196	12.6		
70-74 years	71	6.2	93	6.0		
75-79 years	24	2.1	49	3.2		
80-84 years	12	1.0	26	1.7		
85 years and over	7	0.6	22	1.4		
TOTAL	1,145	100	1,555	100		

# Distribution by degree of disability

	N	%	N	%
Low	22	1.9	80	5.1
Mild	122	10.7	223	14.3
Accentuated	652	56.9	793	51.0

High	346	30.2	419	26.9
No certified disability	3	0.3	40	2.6
TOTAL	1,145	100	1,555	100
Distribution by type of	<u> </u>		,	
disability				
	N	%	N	%
Physical	318	27.8	897	57.7
Somatic	113	9.9	103	6.6
Auditory	8	0.7	1	0.1
Visual	7	0.6	34	2.2
Intellectual	355	31.0	177	11.4
Psycho-social	177	15.5	60	3.9
Associated	156	13.6	235	15.1
HIV/AIDS	2	0.2	3	0.2
Rare diseases	6	0.5	3	0.2
Deafness or blindness	0	0.0	2	0.1
TOTAL	1,145	100	1,555	100
Distribution by livin	g			
situation				
	N	%	N	%
Live with the family	761	66.5	1,096	70.5
Living independently	72	6.3	145	9.3
With personal assistant	t 61	5.3	84	5.4
With Professiona	al	0.5	0	0.0
Personal Assistant				
Sheltered housing	183	16.0	0	0.0
Residential Center	61	5.3	230	14.8
Other living situation	1	0.1	0	0.0
TOTAL	1,145	100	1,555	100
Distribution b	у			
residence				
	N	%	N	%
Urban	937	81.8	1,327	85.3
Rural	208	18.2	228	14.7
TOTAL	1,145	100	1,555	100
Distribution by lega	al			
capacity				
	N	%	N	%
Legal capacity	946	82.6	1,444	92.9
No legal capacity	199	17.4	111	7.1
TOTAL	1,145	100	1,555	100
Source: World Bank su	rvey of day	centers and c	utpatient neuro	motor recovery serv

centers (2021).

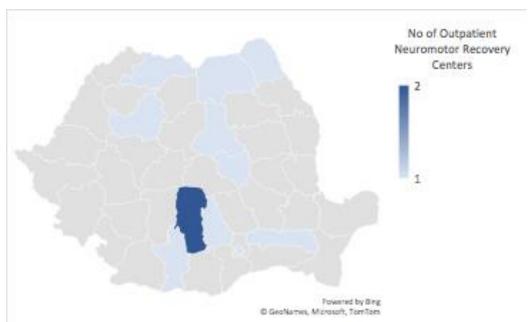
Annex-Table 9: Frequency of meetings between beneficiaries of day centers and of outpatient neuromotor recovery service centers included in the evaluation and their case managers

	N			% of total nr of beneficiaries		
Number of beneficiaries that meet their case managers with the following frequency	Tot al	DC	ONR SC	Tot al	DC	ONR SC
Weekly	306	187	119	38. 2	40. 5	35. 1
Once every two weeks	115	61	54	14. 4	13. 2	15. 9
Monthly	215	182	33	26. 8	39. 4	9.7
Once every few months	93	17	76	11. 6	3.7	22. 4
Other frequency, which one?	72	15	57	9	3.2	16. 8
Total	801	462	339	100	100	100

Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).

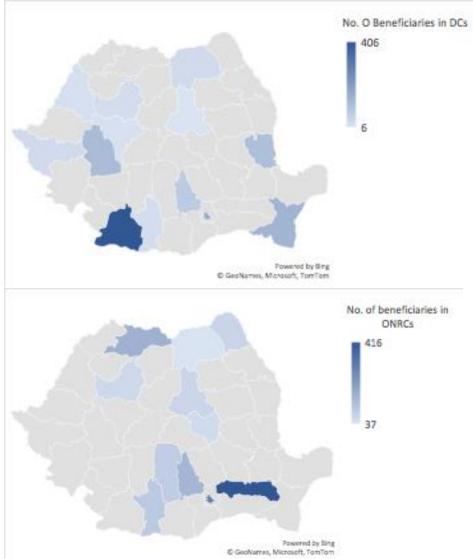
Annex-Figure 1: Geographic distribution of day centers and outpatient neuromotor recovery service centers included in the evaluation





Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).

Annex-Figure 2: Geographic distribution of beneficiaries of day centers and outpatient neuromotor recovery service centers included in the evaluation



Source: World Bank survey of day centers and outpatient neuromotor recovery service centers (2021).









"Persoane cu dizabilități - tranziția de la servicii rezidențiale la servicii în comunitate", Cod SIPOCA/SMIS2014+: 618/127529

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