

Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU

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Institutional services Community-based services	

Country codes

Country	
AT	Austria
BE	Belgium
BG	Bulgaria
CY	Cyprus
CZ	Czech Republic
DE	Germany
DK	Denmark
EE	Estonia
EL	Greece
ES	Spain
FI	Finland
FR	France
HU	Hungary
HR	Croatia
IE	Ireland
IT	Italy
LT	Lithuania
LU	Luxembourg
LV	Latvia
MT	Malta
NL	Netherlands
PL	Poland
PT	Portugal
RO	Romania
SE	Sweden
SI	Slovenia
SK	Slovakia
UK	United Kingdom

Introduction

In December 2006, the United Nations General Assembly adopted the Convention on the rights of persons with disabilities (CRPD). As of October 2017, the European Union (EU) and all its Member States, except Ireland, had ratified the convention. The CRPD is the first human rights treaty to expressly articulate a right for people with disabilities to live independently and be included in the community. This right is set out in Article 19 of the convention.

Article 19 lies at the heart of the CRPD. It "plays a distinct role as one of the widest ranging and most intersectional articles of the Convention and has to be considered as integral for the implementation of the Convention across all articles," as the Committee on the Rights of Persons with Disabilities (CRPD Committee) stressed in its General Comment on Article 19.¹ This article brings together the principles of equality, autonomy and inclusion, which underpin the human rights-based approach to disability anchored in the convention. While it does not define the scope of the term 'independently', the convention does link independence to choice and control over daily living arrangements.

Article 19 of the Convention on the Rights of Persons with Disabilities – Living independently and being included in the community

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- 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;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Giving life to Article 19 entails that persons with disabilities live in the community and not in institutionalised settings. A process of transition from institutional to community-based support therefore needs to be put in place for a significant number of persons with disabilities. Achieving this transition will necessitate the "eradicat[ion of] practical barriers to the full realization of the right to live independently and be included in the community", as highlighted in the general comment on Article 19.² These barriers include "inaccessible housing, limited access to disability support services, inaccessible facilities, goods and services in the community and prejudices against persons with disabilities".³

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CRPD Committee (2017), General Comment No. 5 - Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 6

² *Ibid.*, para. 54.

³ Ibid.

The Charter of Fundamental Rights of the EU also contains provisions relevant to the realisation of independent living and community participation of persons with disabilities.⁴ Its Article 21 prohibits any discrimination on the ground of disability, while Article 26 recognises the right of persons with disabilities "to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community."

The key European Union policy instrument in the area of disability is the *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*. The strategy follows the spirit of the CRPD and lists participation as one of its eight main areas of action. Participation includes the right to choose where and how to live, with one objective under this area being to "achieve full participation of people with disabilities in society by providing quality community-based services, including access to personal assistance." EU funds play a key role in ensuring the implementation of the disability strategy, also with regard to supporting the transition from institutional to community-based care. For more information on the financing of the transition, see FRA's report on funding of and budgeting for the process of deinstitutionalisation.

Little is known about which types of services are available for persons with disabilities in each EU Member State. This, in turn, impedes efforts made by the EU and its Member States to render the process of deinstitutionalisation effective. This information gap is compounded by a lack of data collection on types of services in some Member States.

The research conducted by FRA summarised here contributes to filling this knowledge gap by drawing on available data to provide baseline information on the availability and key characteristics of different types of institutional and community-based services in the 28 EU Member States. This overview report is complemented by background country reports, which present the data collected for this research in each EU Member State. Drawing on such evidence enables policymakers and practitioners in the field to identify where efforts should be focused to promote the transition from institutional to community-based support.

The present summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU forms part of FRA's broader work on the rights of persons with disabilities, particularly that on the right to independent living (see box). The objective of this body of work is to provide evidence-based assistance and expertise to EU institutions and Member States when they take measures or formulate courses of

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More information on the key legal instruments and policy documents in the area of disability in the EU are available on FRA's webpage on the topic.

⁵ European Commission (2010), European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe, COM (2010) 0636 final, Brussels, 15 November 2010, p. 3. See also, Council of Europe (2017), Human Rights: A reality for all. Council of Europe, Disability Strategy 2017-2023.

FRA (2017), <u>From institutions to community living: funding and budgeting</u>, Luxembourg, Publications Office of the European Union (Publications Office).

For more information on this work, see the <u>project page on FRA's website</u>.

action within their respective spheres of competence, to fulfil the right of persons with disabilities to live independently and to be included in the community.

From institutions to community living: FRA's reports on Article 19 of the CRPD

This summary overview report provides contextual information for a series of three reports looking at different aspects of deinstitutionalisation and independent living for persons with disabilities. The series complements FRA's https://www.human.rights.indicators.on-Article 19 of the CRPD, which also cover the how EU Member States monitor public and private services for persons with disabilities.

Taken together, the three papers highlight cross-cutting issues that emerge from data the agency collected and analysed in the context of its work on <a href="the three three

- Part I: commitments and structures: the <u>first report</u> in the series highlights the obligations the EU and its Member States have committed to fulfil.
- Part II: funding and budgeting: the <u>second report</u> looks at how funding and budgeting structures can work to turn these commitments into reality.
- Part III: outcomes for persons with disabilities: the third report
 completes the series by focusing on the impact these commitments and funds are having on the independence and inclusion of persons with disabilities experience in their daily lives.

Other relevant reports previously published by FRA include:

- <u>Choice and control: the right to independent living</u>: this report examines how persons with intellectual disabilities and persons with mental health problems experience autonomy, inclusion and participation in their lives across nine EU Member States.
- <u>Involuntary placement and involuntary treatment of persons with mental health problems</u>: this report, based on fieldwork in nine EU Member States, summarises the experiences of involuntary placement and involuntary treatment of persons with mental health problems.

Availability of data

This overview report summarises findings of research commissioned by FRA on types of institutions for people with disabilities and community-based services in place in the 28 EU Member States. The information presented in this summary overview report reflects the situation based on data available in June 2014 in the case of institutional services, and May 2015 in the case of community-based services. While changes might have occurred in relation to the availability of individual services in any given Member State, the focus of the present report rests on providing a global analysis of broader types of services available in the EU.

The data were collected by FRA's multi-disciplinary research network (FRANET), through a combination of desk research and information requests to public authorities. More details on the method of data collection is available in the annex. No definition of an institution or of a community-based service was provided to the research network, so as not to restrict the scope of the data collection. The research network collected existing data on a number of characteristics of institutions and community-based services. The specific characteristics studied were based on those used in an EU-funded research project *Deinstitutionalisation and community living* – at *outcomes and costs* (DECLOC); the findings of this study were published in 2007.

The analysis of the evidence collected by FRANET shows much variation across the 28 EU Member States in the availability, comprehensiveness, breadth and depth of data, as well as in the sources of data. Some of the variation can be explained by differences in the competences of national and regional authorities in each EU Member State. These differences are likely, in turn, to reflect specific national administrative arrangements.

In some Member States, regularly updated databases provide detailed information about institutional and community-based services for persons with disabilities operating in the country, while in others data is not centrally collected or is not brought together at regular intervals.

There is also variation in the types of sources from which data on institutional and community-based services can be extracted. While relevant public authorities publish detailed annual reports in some Member States, much of the data in others was extracted from academic studies or reports from civil society organisations. The limited amount of comprehensive information available in many Member States meant that a significant proportion of the data stemmed from freedom of information requests to public authorities. In several of the smaller Member States, the research network also gathered information directly from service providers, often individual institutions.

A few examples highlight the diversity of information sources. While, for instance, all of the information collected in **Bulgaria**, **Denmark** and **Italy** came from data released by public authorities, data collection on disability services in **Austria** is done at the federal level. For Member States where information from social ministries or other public authorities was the main source of data, some services

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⁸ Information on FRA's network of in-country researchers can be found on <u>FRA's website</u>.

Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007), <u>Deinstitutionalisation and community living outcomes and costs: report of a European Study</u>. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent. More information on the project, including national reports is <u>available online</u>.

National background reports for each of the 28 Member States available on FRA's website.

provided by private entities and organisations may also not have been captured in the research.

The analysis of the collected data also reveals particular gaps in several Member States, with little to no information available on certain characteristics of institutional and community-based services. Concerning institutional services, no information was available at the time of data collection on the level of support provided or the length of admission in **Denmark**, for example, with little data on the length of time for which particular services have been operating available in **Germany**. Information in relation to the age group targeted by different types of community-based services was lacking in **Slovakia**.

Concerning community-based services, there was a general lack of data at the level of user control in most Member States. Furthermore, data was often not available in relation to the age group targeted by different community-based services in **Poland**, the **Czech Republic** and **Slovakia**, for example.

In some EU Member States, including **Croatia**, the **Czech Republic**, **Estonia**, **Hungary**, **Poland** or **Sweden**, certain characteristics of types of institutions are set out in the legislation that provides for their establishment. For example, the law may set out a maximum number of residents/users of a service type, the level of support that should be provided and the impairment group targeted by the service. Where relevant legal instruments provide such details, they often represented an important source of information. Conversely, some smaller-scale, informal community-based services may not be included in national-level data collection activities and might therefore not have been captured in this research.

Institutional services and community-based services

There are no commonly agreed definition of what constitute 'institutions' or 'community based services' for persons with disabilities.

The concept of 'institution' focuses on specific organisational features resulting, for example, in the separation of persons with disabilities from their families and local communities or on the lack of choice and control residents can exercise over their day-to-day lives.

Specialised services for persons with disabilities include a "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", as specified in Article 19 of the CRPD.

Summary overview of types of institutional services available across the EU

What is an institution?

There is no commonly agreed definition of what constitutes an 'institution' for persons with disabilities. The term is used across different countries and contexts to describe different types of settings, often in reference to forms of living arrangements in which persons with disabilities reside together. For more information on the impact of their living arrangements on persons with disabilities, see FRA's report <u>From institutions to community living – Part III: outcomes for persons with disabilities</u>.

The concept of 'institution' focuses on specific organisational features resulting, for example, in the separation of persons with disabilities from their families and local communities or on the lack of choice and control residents can exercise over their day-to-day lives. The World Health Organization defines an institution as "any place in which persons with disabilities, older people, or children live together away from their families. Implicitly, a place in which people do not exercise full control over their lives and their day-to-day activities. An institution is not defined merely by its size."

Similarly, the Common European Guidelines on the Transition from Institutional to Community-based Care define an 'institution' as any residential care in which: "residents are isolated from the broader community and/or compelled to live together; Residents do not have sufficient control over their lives and over decisions which affect them; The requirements of the organisation itself tend to take precedence over the residents' individualised needs." The Common European Guidelines also stress that:

"The small size of accommodation does not in itself guarantee elimination of institutional culture in the setting. There are a number of other factors, such as the level of choice exercised by the service users, the level and quality of support provided, participation in the community and quality assurance systems used which impact on the quality of the service." ¹³

Defining an institution merely on the basis of its size and location is therefore overly restrictive: in this sense, small-scale facilities and group homes can function as 'institutions', even if they are physically not removed from the community. Any understanding of the concept of 'institution' must therefore incorporate an analysis of both physical and social/cultural aspects. Such aspects were discussed at a meeting of experts held at FRA in November 2015, as part of the agency's

13 Ibid.

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World Health Organization (WHO) and World Bank (2011), World report on disability, Geneva, World Health Organization. p. 305.

European Expert Group on the Transition from Institutional to Family Based Care (2012), <u>Common European Guidelines on the Transition from Institutional to Community-based Care</u>, p. 25.

preparatory work for the project on the right to independent living of persons with disabilities.

There was a broad agreement among the experts present that physical features of institutions include isolated locations; segregation and compulsion; impossibility to live with families; and long length of admission. Social/cultural features include depersonalised services; lack of choice and control; lack of privacy and intimacy; lack of liberty and free expression of wishes; lack of accountability; strict schedules and regimes; requirements of the institution taking precedence over the needs of residents; residents are viewed as disabled; strict separation between staff and users; and the place of residence is contingent on the provision of care.

In August 2017, the Committee on the Rights of Persons with Disabilities offered further guidance on how to identify institutions, further emphasising the importance of 'cultural' elements.

"Although, institutionalized settings can differ in size, name and setup, there are certain defining elements, such as: obligatory sharing of assistants with others and no or limited influence over by whom one has to accept assistance, isolation and segregation from independent life within the community, lack of control over day-to-day decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment."

CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 16 (c).

A further issue is that different terms are used across the EU to describe similar types of institutions. For example, services identified as being of the 'sheltered housing' type are called, in the English translation, 'supervised housing' in **Belgium** and **Bulgaria**, 'serviced apartments' in **Latvia**, 'assisted housing' in **Austria**, or 'modulated placement centres' in **Romania**. For ease of reading, institutional services are referred to throughout by their name in the English translation; names in the national language are included in the respective <u>national background report</u>.

The lack of an accepted definition of an institution and varied understandings of commonly used terms pose a challenge to the collection of comprehensive and comparable data on common types and characteristics of institutions in place in the EU. The information presented here should be read in light of these twin constraints.

Types of institutional services available across the EU

The diversity and limited range of information on types of institutions available in EU Member States at the time of writing does not allow for direct cross-country comparisons. In addition, individual institutions of any given type are likely to have their own particularities. This overview provides a global picture of the types of institutions available in the EU, and does not include a detailed analysis of the set-up of individual institutions in any given EU Member State.

Certain types of institutional services can be found across the EU, with others only found in a limited number of Member States, as Table 1 shows. The analysis of the collected data indicates, for example, that psychiatric services are in place in many Member States, either as self-standing hospitals or as wards attached to general hospitals. This is also the case for sheltered housing, care homes, group homes or nursing homes. Some services are available only in very few Member States, such as supported housing, centres for occupational therapy, life-sharing communities, or training centres for independent living.

While the services identified in this research typically target adults with disabilities, in many cases similar services are also offered to children with disabilities and, less frequently, to older people with or without disabilities. Day centres and centres for vocational training in **Bulgaria**, for example, offer services to both children and adults with intellectual, psychosocial and sensory disabilities. Small group homes for people with mental health problems in **Luxembourg** cater to children, adults and older people, while residential institutions in **Hungary** cover a broad range of age categories.

Table 1: Types of institutional services for persons with disabilities available across the EU

Type of service	Number of EU Member States where available	EU Member States where available
Sheltered housing	23	AT, BE, BG, CZ, DK, EL, ES, FI, FR, HR, HU, IT, LT, LU, LV, MT, NL, PL, PT, RO, SE, SK, UK
Care home	22	AT, BG, CY, DE, EE, EL, ES, FI, FR, HR, HU, IE, IT, LT, LU, LV, NL, PL, PT, SI, SK, UK
Nursing home	20	AT, BE, BG, CY, CZ, DE, DK, EE, FI, FR, HR, HU, IE, IT, LT, MT, NL, PL, SK, UK
Group home	19	AT, CY, DE, DK, EE, ES, FI, HU, IE, IT, LT, LU, LV, MT, PL, PT, RO, SE, UK

Type of service	Number of EU Member States where available	EU Member States where available
Psychiatric hospital	17	BE, BG, CY, CZ, DE, DK, EL, FI, HR, IE, LT, NL, PT, RO, SE, SI, UK
Boarding school	15	AT, BE, BG, CZ, DE, DK, EE, FR, HR, IT, LT, PL, RO, SK, UK
Day centre	13	BE, BG, CY, EL, ES, HR, HU, IT, LU, LV, NL, RO, SK
Psychiatric ward in a general hospital	10	CY, DE, DK, EE, EL, IT, LT, MT, NL, RO
Children's home	9	BE, BG, CZ, EE, EL, LT, SE, SI, UK
Centre for family-type accommodation	7	BG, CY, EL, HR, NL, PL, RO
Foster care	7	BG, DK, EL, FR, HR, LU, PT
Supported housing	4	AT, FI, IE, SE
Centre for occupational therapy	3	HR, PT, RO
Life-sharing community	3	AT, DE, IE
Training centre for independent living	3	AT, PT, RO

Source: FRA, 2017

Common characteristics of institutional services in the EU

Common characteristics of institutional services available in EU Member States can be identified, despite the differences that exist between types of services across the 28 countries. The data collection focused on the following characteristics of institutions, which mirror those used as the basis of data analysis by the DECLOC project, 14 namely:

- the size of the institutions;
- the age groups they cater for;
- the types of impairments they offer support for;

Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007), <u>Deinstitutionalisation and community living outcomes and costs: report of a European Study</u>. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent. More information on the project, including national reports is <u>available online</u>.

- the level of support provided;
- the service providers;
- how services are funded;
- · the length of admission of persons with disabilities; and,
- how long different types of services have existed for.

Size of institutional services

The available data show considerable variation in the size of institutions, including those of the same type. Psychiatric hospitals in **Lithuania**, for example, can have anything between 11 to over 100 places, with nursing homes in **Malta** varying in size from six to 10 places, to over 100 places.

There is, however, a tendency for institutions in the EU to be large. In all Member States, except **Sweden**, the data indicate that there are institutions with at least 30 places. In more than two-thirds of Member States, some types of institutions typically have more than 100 places. These tend to include psychiatric hospitals or residential care homes for people with disabilities.

For instance, five out of the seven types of institutions identified in **Slovenia** typically have over 100 places, including psychiatric hospitals and so-called 'special social welfare institutions for adults'. In **Romania**, administrative data from the Ministry of Labour, Family, Social Protection and Older People records three types of residential institutions, including institutions with over 250 places.

Age groups catered for by institutional services

Institutional services can cater for distinct age groups or for different age groups at the same time. There are, for example, group homes for children, group homes for adults, as well as residential institutions where both adults and older people live together.

The way different age groups are defined varies. While services targeted at older people, generally address those over 65 years of age, others designated for adults tend to provide support to a wide range of age groups. In **Austria**, for example, some services for adults include children over 15 years. Psychiatric hospitals in **Belgium** provide services for children up to the age of 15, as well as for 'adults' over 15 years of age.

In other Member States, services primarily designed for children are sometimes used by young adults with disabilities. This may reflect the possibility in some countries for the status of 'minor' to be extended beyond the age of 18 years for persons with disabilities. Boarding schools for children with autism in **Croatia** cater for children and young adults up to the age of 21, for instance; young people with disabilities can remain at boarding schools in **Poland** until the age of 23.

Older age can also play a role in determining what services are available. For example, in **Sweden**, some services target older adults with physical disabilities from the age of 65. On the other hand, sheltered housing in **Finland** caters for adults under the age of 65.

Type of impairments catered for by institutional services

Institutional services available in EU Member States predominantly cater for persons with mental health problems (that is, psychosocial disabilities) and persons with intellectual disabilities. This reflects findings of previous research by FRA¹⁵ and other organisations.¹⁶

Many types of institutions, however, provide services for people with different types of impairment. This is the case in **Germany**, for example, where residential homes offer services for people with intellectual disabilities, people with mental health problems, people with physical disabilities, as well as people with speech, hearing and visual impairments. Other types of institutional services are organised so that people with different types of impairments live together.

Some institutional services cater specifically for people with severe disabilities, irrespective of the type of impairment, as is the case for nursing and occupational homes in **Belgium**. Similarly, sheltered housing for people under 65 with severe impairments are available in **Finland**.

Institutional services for persons with sensory impairments often take the form of boarding schools for children with visual or hearing impairments, as is the case in **Austria**, the **Czech Republic**, **Germany** or **Italy**. Institutional services catering specifically for adults with sensory impairments also exist in **Austria**, **Cyprus** and **Bulgaria**.

Information available in some Member States indicates that institutional services for older people sometimes involve those with and without disabilities living together, as is the case in **Cyprus** or **Bulgaria**. In other countries, services cater specifically for older people with disabilities, such as in **Austria**.

Level of support provided to persons with disabilities

More than half of the service types identified provide 24-hour support to residents, although this was sometimes limited to certain time periods, such as during term-time for boarding schools or during weekdays only. In **Ireland**, for instance, residents of some community group homes and residential centres return to their family homes during holiday periods or on weekends. Similarly, 'Week-stay social

¹⁵ See the reports stemming from the project <u>The fundamental rights of persons with mental health problems and persons with intellectual disabilities</u>.

See, for example, Mental Health Europe (2012), <u>Mapping exclusion: institutional and community-based services</u> in the mental health field in Europe.

welfare institutions' in the **Czech Republic** provide 24-hour support during the week, with users spending weekends with their families.

Types of providers of institutional services

The available data show a wide range of types of providers of institutional services, also within countries. This reflects the different administrative and welfare systems in place across the EU. This variety also underlines the number of different stakeholders involved in providing services for persons with disabilities. For more information on national bodies and organisations responsible for implementing structural reforms inherent to deinstitutionalisation processes, see FRA's report *From institutions to community living – Part I: commitments and structures*.

In some EU Member States, services are provided almost exclusively by public authorities, at either the national or regional levels. In **Ireland**, for example, almost all institutional services are provided by national authorities. In contrast, in **Romania** it is local and regional authorities who provide the vast majority of service types. In the case of psychiatric hospitals, national authorities tend to be the service providers across the different EU Member States.

Private foundations operating as non-profit, professional organisations typically provide institutional services in the **Netherlands**. In **France** and **Luxembourg**, services tend to be predominantly provided by civil society organisations. In other Member States, religious organisations play a significant role in providing services, including in **Austria**, **Croatia**, **Cyprus**, **Malta**, **Poland** or **Portugal**.

In other countries, a combination of bodies and organisations provide institutional services. This is the case in **Spain**, for example, where providers include regional or local public authorities; fully private institutions; and private institutions with a number of places subsidised by the state.

Funding of institutional services

As with service providers, there is a range of funding sources for institutional services, although the role of government – both national and regional – is greater. Again, the split between national and regional authorities is likely to reflect the different administrative histories of the EU Member States, with regional authorities playing a greater role in federal states. National governments remain the predominant source of funding in less decentralised countries. For more information on funding and budgeting, see FRA's report <u>From institutions to community living.</u> <u>Part II: funding and budgeting</u>.

Concerning funding at the regional level, the **Italian** constitution includes health protection among the competences transferred to the country's 20 regions. Similarly, in **Finland**, municipalities are responsible for organising health care and social services for their residents. They are therefore the main funders of these

services, through the taxes they collect from their residents. This local funding is, however, complemented by discretionary government transfers from the state to cover the expenses of health care and social services. Furthermore, many services are subject to customer charges. In several Member States, including **Poland**, **Romania**, **Sweden** and **Slovakia**, a number of services are jointly funded by national governments and regional authorities.

The source of funding is often linked to the typical provider. In line with the tendency for institutional services in the **Netherlands** to be provided by private foundations, they are typically funded by patients or through insurance premiums. Services in **France** are primarily funded through benefits or the social security system. In **Cyprus**, the Church funds some older people's homes and shelters, while in **Malta**, sheltered houses for adults over 18 can be funded by the Church, as well as the State.

For many Member States EU structural and investment funds (ESIF) are a key source of additional funding to achieve the transition from institutional to community-based support for persons with disabilities. In at least 12 EU Member States – **Bulgaria, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Portugal, Romania, Slovakia** and **Slovenia** – ESIF funded projects related to living arrangements for persons with disabilities during the 2007-2013 funding period, according to evidence that FRA collected. In a number of cases, this included reconstructing or renovating existing institutions.

Length of admission of persons with disabilities

The typical length of admission to the different service types is for the majority of services over two years. Most Member States, however, did not have data on the typical duration of these services. In **Portugal**, for example, the length of admission is determined by the needs of the user, but there is no information on how long people typically use services. Similarly, in the case of **Greece**, **Hungary**, **Poland** and **Romania**, the research could not identify any data on the typical length of time for which persons with disabilities actually use these services, although legislation prescribes that admission can be for either defined or undefined periods of time.

History of institutional services

The final characteristic on which data was collected was the typical age of institutional service types to give an insight into the development of new services for people with disabilities. The collected data indicate a link between the type of service and its typical duration: services such as group homes or sheltered housing tend to be more recent. This is the case, for instance, for small group homes in **Hungary**, which were introduced in the last few years. Conversely, most psychiatric hospitals and residential homes have been in operation for over

50 years. Some exceptions were noted, such as in **Cyprus**, where an institutional unit for minors with mental health problems was set up within the last few years.

Summary overview of types of community-based services available across the EU

What is a community-based service?

This section looks at specialised services for persons with disabilities that operate in the context of Article 19(b) of the CRPD: "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." As such, it does not touch on wider community-based services available to the general public.

The Common European Guidelines on the Transition from Institutional to Community-based Care define community-based services for persons with disabilities as a "spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution". The CRPD committee further specifies that individualised services "are not restricted to services inside the home, but must also be able to extend to the spheres of employment, education or political and cultural participation, support services empowering parenthood and the ability to attend family relatives and others, participation in political and cultural life, once leisure interests and activities, and travel as well as recreation." Despite access to specialised services being a precondition for persons with disabilities to live independently, the availability of such services remains marginal, according to the United Nations Special Rapporteur on the rights of persons with disabilities.

Yet, as is the case for institutional services, there is no common understanding in EU Member States as to what constitutes a community-based service. The analysis of the collected data shows that a range of different services are categorised as community-based services in Member States. In addition, similar terms are used across EU Member States to describe services with widely different characteristics, particularly in relation to the amount of control exercised by users. For ease of reading, community-based services are referred to throughout by their name in the English translation; names in the national language are included in the respective national background report.

The information presented in this overview of community-based services available in EU Member States must therefore be read against a backdrop of a lack of agreed

European Expert Group on the Transition from Institutional to Community-based Care (2012), <u>Common European Guidelines on the Transition from Institutional to Community-based Care</u>. p. 27.

¹⁸ CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 29.

United Nations, Human Rights Council (2016), Report of the Special Rapporteur on the rights of persons with disabilities, p. 5.

definitions and differing interpretations of what constitutes a community-based service. The inclusion of any type of service described below in the section on community-based services does not signify endorsement of this categorisation by FRA. Rather, it is a reflection of the information available in Member States at the time of data collection.

Types of community-based services available in the EU

Similarly to institutional services, the diversity and limited range of information on community-based services currently available in many EU Member States does not allow for direct cross-country comparisons. This also reflects the variety of definitions employed in EU Member States to refer to community-based services.

Certain types of community-based services can, however, be found across the EU, with others only found in a limited number of Member States, as Table 2 shows. For example, in-home services, residential care and day-care centres are available in all 28 EU Member States, with foster care available in 26 of them. Less common types of services include peer support and counselling (16), informal support (16), befriending (15) or circles of support (12). For more information on what these services entail, see the Annex.

That more informal types of services are found in fewer Member States could reflect an on-going bias towards more traditional and larger-scale types of services. This also suggests that there is a lack of recognition of informal services by the State, which leads to information about such services not being captured in official data. The information available at the time of data collection further indicates that informal types of services are more likely to be provided by civil society organisations rather than by public authorities.

Table 2: Types of community-based services for persons with disabilities available across the EU

Type of community- based service	Number of EU Member States where available	EU Member States where available
In-home	28	AT, BE, BG, CY, CZ, DE, DK, EE, EL, ES, FI, FR, HR, HU, IE, IT, LT, LU, LV, MT, NL, PL, PT, RO, SE, SI, SK, UK
Day care centres	28	AT, BE, BG, CY, CZ, DE, DK, EE, EL, ES, FI, FR, HR, HU, IE, IT, LT, LU, LV, MT, NL, PL, PT, RO, SE, SI, SK, UK
Residential	28	AT, BE, BG, CY, CZ, DE, DK, EE, EL, ES, FI, FR, HR, HU, IE, IT, LT, LU, LV, MT, NL, PL, PT, RO, SE, SI, SK, UK

Type of community- based service	Number of EU Member States where available	EU Member States where available
Foster care	26	AT, BE, BG, CY, CZ, DE, DK, EE, EL, ES, FI, FR, HR, HU, IE, IT, LT, LU, LV, NL, PT, RO, SE, SK, UK
Family support/respite care	23	AT, BE, CY, CZ, DE, DK, EE, ES, FI, FR, HR, HU, IE, IT, LT, LU, LV, NL, PL, RO, SE, SK, UK
Personal assistance	22	AT, BE, BG, CZ, DE, DK, EE, ES, FI, FR, HR, IE, LV, MT, NL, PL, PT, RO, SE, SI, SK, UK
Direct payments/personal budget/individual budget	20	AT, BE, CY, CZ, DE, DK, EE, EL, ES, FR, IE, IT, LT, LU, LV, NL, RO, SE, SI, UK
Crisis intervention and emergency services	19	AT, BE, BG, CY, CZ, DE, EE, EL, FI, FR, HR, LT, LU, LV, NL, PL, RO, SK, UK
Peer support/counselling	16	AT, BE, CZ, DE, DK, ES, FI, FR, HU, IE, IT, LU, LV, NL, SE, UK
Informal support	16	AT, BE, BG, CZ, DE, EL, FI, FR, HU, IE, IT, LU, LV, NL, PT, UK
Befriending	15	AT, DE, BE, CZ, ES, HR, HU, IE, IT, LT, LU, LV, NL, SE, UK
Circles of support	12	AT, BE, CZ, EE, HU, IE, IT, LU, LV, NL, PT, UK

Source: FRA (2017)

The analysis of the collected data reveals differences in the availability of individual types of services within and between EU Member States. A look at the situation concerning personal assistance, the only form of support explicitly identified in Article 19 of the CRPD, illustrates these divergences.²⁰

Data collected by both FRA and the European Network on Independent Living show that some form of personal assistance is available in most EU Member States. However, the nature of this service varies considerably:

• At the time of data collection, personal assistance was available as a pilot service in some Member States, as was the case in **Portugal**, for example.

²⁰ See European Network on Independent Living (2015), <u>Personal assistance services in Europe 2015</u>. <u>Personal assistance tables</u> are available online for 14 EU Member States.

- Personal assistance is also not necessarily available in the entirety of a Member State – such as in **Poland**, where it was only available in Warsaw, or in **Belgium**.
- Access to personal assistance in **Bulgaria** was limited to children with severe degrees of impairment; children or adults leaving institutions; and adults with a low socio-economic status and a minimum of 90 % of reduced work capacity.
- There also are large differences in the amount of time for which personal assistance is provided. In **Denmark**, personal assistance can be provided for up to 24 hours a day, compared to up to 40 hours a week in **Latvia** or up to 20 hours a week in **Sweden** in some cases, for example.

Common characteristics of community-based services in the EU

Common characteristics of community-based services available in EU Member States can be identified, despite differences that exist between types of services across the 28 countries. The analysis of the collected data shows commonalities with regard to eligibility criteria; types of impairment; the level of support provided; the level of user control of services; service providers; and the funding of community-based services.

Eligibility criteria

In a majority of EU Member States, legal provisions stipulate restrictions on eligibility based on certain criteria at least for some community support services, FRA's https://example.com/human rights indictors on Article 19 show. Eligibility criteria vary, depending on the type of service, but most frequently include one or more based on age, degree and type of impairment; these criteria often intersect.

The analysis of data collected for this overview further shows that eligibility criteria for similar types of services vary between Member States. For example, eligibility criteria for personal budgets include the status of residence and citizenship of persons with disabilities or their family members (Austria, Czech Republic); minimum income thresholds (Belgium, Cyprus, Italy, Poland); the degree of impairment (Austria, Belgium, Italy, Latvia, Luxembourg); or the ability to work (Poland).

Member States apply different criteria to assess the eligibility for day care, including the degree of impairment (**Portugal**); being unemployed or studying (**Sweden**); living independently but needing support (**Hungary**); receiving allowances on the basis of having a severe impairment (**Finland**); or, having an intellectual disability and not being able to live independently (**Austria**).

The same holds for in-home support, where eligibility can be determined on the basis of income thresholds (**Cyprus, Greece**) or the severity of impairment

(**Latvia, Slovakia, Slovenia**). Concerning residential care, eligibility criteria include being an adult (**Austria**), income thresholds (**Cyprus**), not being in need of intensive care (**Germany**), or having an intellectual disability and returning from long-term social care or social rehabilitation institutions (**Latvia**).

Types of impairment

Taken together, community-based services in the EU cover different types and degrees of impairment. The analysis of the collected data suggests that services are only available to persons with severe impairments in some countries, as is the case for personal budgets (**Czech Republic, Slovakia**); day care (**Portugal**); in-home care (**Belgium, Estonia**); personal assistance (**Denmark, Finland, Romania**); residential care (**Estonia**); or respite care (**Estonia**).

Certain types of community-based services appear only to be available for persons with specific impairments. In **Finland**, for example, informal support is only available to persons with intellectual disabilities, as are residential and in-home services in **Estonia**; peer support and counselling in **France**; or residential services in **Latvia**. Circles of support and crisis intervention are specifically available for persons with intellectual disabilities in the **Netherlands**, as is the case for day care centres in **Bulgaria**. In-home services in **Belgium**, as well as personal assistance in **Slovenia** are only available to persons with physical disabilities.

Type and level of support provided

The level of support provided to persons with disabilities varies greatly from service to service, and from country to country. The following common practices were identified, with services typically funded by municipalities, as outlined in the section on funding, below:

- personal budgets or cash payments in Austria, Belgium, Czech Republic,
 Denmark, France, Luxembourg, Netherlands, Romania and Slovakia;
- assistance with performing daily tasks in **Bulgaria**, **Finland**, **France**, **Greece**, **Luxembourg**, **Netherlands**, **Poland**, **Portugal**, **Romania** and **Slovakia**;
- psychological support or counselling in Austria, Cyprus, Czech Republic,
 Greece, Latvia, Poland, Romania, and the United Kingdom;
- medical assistance in France and Greece;
- career advice in **France**, **Ireland** and **Spain**;
- leisure and recreational activities in **Finland, Ireland, Malta, Slovakia** and **Spain**.

Some types of support are provided on a 24/7 basis – but not in all Member States. 24/7 care includes crisis intervention (**Finland**); residential care (**Austria, Finland, Sweden, United Kingdom**); or in-home care (**Belgium**).

Other types of support are provided during the day-time only, such as befriending in **Belgium**, crisis intervention and in-home care in **Estonia**, or in-home care in **Bulgaria**. Other services are only available during working hours, such as day care in most Member States where available, or, for a defined number of hours in any given time period. This is the case for in-home support in **France**, **Germany**, **Italy**, **Lithuania**, **Luxembourg**, **Slovenia**; peer support in **Austria** or **France**; and respite care in **Austria** or **Hungary**.

Level of user control of services

Community-based services available to persons with disabilities tend to give greater control to users than institutional services. Nevertheless, a great deal of variation between Member States and types of services can been identified.

Low levels of autonomy were found in relation to foster care in **Greece, Spain** and the **United Kingdom**, where children seem to have little control over decisions relating to the family in which they will be placed. In **Denmark**, decisions on foster care are generally taken with the custodial parent. In other Member States, children are consulted when it comes to selecting a foster family (**Austria, Croatia, Cyprus, Estonia, Poland, Sweden, Slovakia**).

While users generally do not have a say in staff recruitment in residential care settings, their wills and preferences can nevertheless be taken into consideration in the provision of such services in **Austria**, **Croatia**, **Finland**, **Germany**, **Greece** or **Malta**. The size of residential care facilities may affect the level of control a person can exert over their service provision. For example, in the **United Kingdom**, residents in larger care homes often cannot determine the support provided, whereas those who live in smaller homes can exercise greater control in this respect.

Where in-home care is available, users tend to have some choice of service provider. However, this may be restricted to pre-defined lists of service providers drawn up by local authorities, as is the case in **Belgium**, **Estonia**, **Germany**, **Hungary**, or the **Netherlands**. In some Member States, including **Finland** and **Greece**, persons with disabilities can be consulted, with regards to their needs and wishes, when choosing service providers.

Persons with disabilities who receive personal budgets and cash payments typically have a significant degree of autonomy in how they want to use these services. This is the case in the **Austrian** province of **Styria**, and Member States such as **Belgium**, **Cyprus**, **Czech Republic**, **France**, **Germany**, **Ireland**, **Latvia**, **Lithuania**, **Luxembourg**, **Romania** and the **United Kingdom**. In other cases, these monies are earmarked for particular types of services, such as for personal assistance in the **Austrian** province of Carinthia, or for services authorised by the government, as in the autonomous communities in **Spain**. In **Bulgaria**, the user's will and preferences are established in advance and included in a personal plan, which the provider of financial support should take into consideration.

Personal assistance is where persons with disabilities seem to have the highest level of user control. This service is mainly self-directed in **Austria, Belgium, Czech Republic, Denmark, France, Germany, Ireland, Latvia, Luxembourg, Malta, Romania, Sweden** and the **United Kingdom**. In the **Netherlands**, personal assistants must be chosen from a list provided by local authorities, whereas in **Portugal**, personal assistants must have undergone prior training.

Typical provider of services

The main providers of community-based services in Member States are national authorities (**Croatia, France, Hungary**); regional/provincial authorities (**Austria, Belgium, France**); and local authorities. Among local authorities, service providers include municipalities (**Austria, Belgium, Bulgaria, Cyprus, Denmark, Estonia, Finland, Greece, Hungary**); social services (**Croatia, Cyprus, Greece**); and health services (**Greece, Ireland**).

Civil society organisations play an important role in the provision and facilitation of community-based services in several Member States. This is particularly the case as regards befriending (Belgium, Germany, France); circles of support (Belgium, Estonia); crisis intervention (Austria, Germany, Estonia); day care centres (Austria, Germany, France); peer support (Germany, Hungary); personal assistance (Croatia, Czech Republic); and family support/respite care (Austria, Germany, France).

Typical funder of services

Community-based services are typically funded by municipalities, drawing on funds they receive from the State. In some Member States, health insurance contributions are also used to fund community-based services, such as personal budgets (**Germany, Italy, Luxembourg**); crisis intervention (**Austria, Netherlands**); day care (**Portugal**); in-home care (**Germany, Luxembourg**); personal assistance (**Luxembourg**); and family support/respite care (**Czech Republic**).

In some cases, users are asked to contribute directly to funding services, including day care centres (**Austria**, **Belgium**, **France**, **Hungary**, **Spain**); in-home support (**Belgium**, **Hungary**, **Portugal**, **Spain**, **United Kingdom**); residential care (**Austria**, **United Kingdom**); personal assistance (**Austria**); and family support/respite care (**Austria**).

Conclusion

There are significant differences in how services for persons with disabilities are defined, set up, and run both within and between Member States. The lack of accepted and shared definitions of what constitutes institutions or community-based services poses a challenge for the collection of comprehensive, comparable and reliable data on the nature and characteristics of these services.

The great diversity and limited depth of information available in many Member States on institutions and community-based services does not allow for direct comparisons across countries about how these services are set up, how they function or how they are funded. The absence of systematic data collection contributes to a lack of evidence-based knowledge about the extent and nature of institutionalisation and community living across the EU.

This restricts the possibility for policymakers and other stakeholders in the EU and its Member States to take measures to implement the transition from institutions to community-based support, as well as to review the effectiveness of existing policies. This, in turn, brings to light the complexity of the task the EU and its Member States face in reforming services available to persons with disabilities so that they are compliant with Article 19 of the CRPD.

Annex: Scope and methodology of the research

The aim of the research was to identify and map the main types of institutional and community-based services in place in each Member State. Accordingly, the research did not seek to collect comprehensive data on all of the institutions or community-based services for persons with disabilities existing in the 28 EU Member States, nor does it attempt to provide an analysis of the quality of the service provided.

The research reflects the situation based on data available in June 2014, in the case of institutional services, and May 2015 in the case of community-based services. The data collection was largely conducted through desk research, using available secondary sources, supplemented by some requests to public authorities and service providers for specific information that was not publically available. The data were collected by FRA's multi-disciplinary research network (FRANET), covering all 28 EU Member States.²¹

The summary overview reflects discussions held during an expert workshop organised by FRA in November 2014, at which the preliminary results of the data collection were presented. FRA expresses its gratitude for these valuable contributions.

Institutional services

Drawing on the EU-funded study 'Deinstitutionalisation and community living – outcomes and costs' (DECLOC), published in 2007,²² information was collected on a number of different characteristics of institutions. For each of these characteristics, the contractors from FRA's research network were provided with a number of different categories and asked to select that which best applied to the particular service type.

In order not to restrict the scope of the data collection, and to reflect the different understandings of institutions and institutionalisation across the EU, no definition of an institution was provided. The characteristics and corresponding categories provided to the research network were as follows:

Size: The number of available places in a typical institution of certain type. The categories were: 1-5 places; 6-10 places; 11-30 places; 30-100 places; over 100 places.

Age group: The typical age of residents/users of the type of service, either: children (0-18 years); adults (aged over 18); and older adults (aged over 60).

²¹ Information on FRA's network of in-country researchers can be found on FRA's website.

Information on the DECLOC project, including the main report and country reports, is available on the University of Kent's webpage on the study.

Type of impairment: The available categories were:

CATEGORISATION	DESCRIPTION/EXPLANATION
Mental health problem	Service provided for people with mental health problems/ psychosocial disabilities
Intellectual disability	Service provided for people with intellectual disabilities
Physical disability	Service provided for people with physical disabilities
Sensory disability	Service provided for people with sensory disabilities e.g. blind/partially sighted, deaf/hard of hearing
Mixed	Service provided for people with different types of disability
Older adults	Older adults who did not have a pre-existing disability, but including people with dementia
Impairment group	Data does not indicate the impairment group targeted by
not specified	the service

Level of support provided: The extent of the support typically provided by institutions of this type. The categories are: '24-hour support provided'; 'only night and weekend support provided'; 'less than 10 hours a week provided'; 'daytime support provided; no night time staffing' and 'variable support provided; depending on the residents' needs'.

Typical provider: Corresponds to the body/entity that typically provides the type of service. The categories were:

CATEGORISATION	DESCRIPTION/EXPLANATION
National	Services are provided by national authorities
Local authority/ municipality/county	Services are provided by local authorities (e.g. region, municipality, state)
Private	Services are provided by private/for profit companies
Voluntary/ not-for-	Services are provided by civil society
profit	organisations/voluntary sector
Mainly independent	Most services are provided by civil society organisations or private companies (some services are provided by national or local authorities)
Mixed	Services are provided by a mix of providers e.g. state, local authority and private sector
National and local	Services are provided by a mixture of national and local
authority/municipality	authorities

Typical funder: The body/entity that typically funds the type of service, from the following categories:

CATEGORISATION	DESCRIPTION/EXPLANATION
EU funding	Services benefit from EU funding through, e.g. the European Social Fund
National government	Services are funded by national authorities. This could be through national insurance schemes or tax schemes
Regional/local/municipal/ county authority	Services are funded by local governments/agencies such as local authorities
Mixed government and private	Services are partly funded by national or local authorities, but users also pay some costs themselves either through insurance or direct payments
All private/insurance	Services are paid for by users themselves
Mixed	Services are funded by a mixture of funders, including civil society organisations and voluntary organisations
Benefits/social security	Services are entirely funded through the benefits or social security system

Length of admission: The typical length of time for which people use the type of service, either: 'up to 6 months'; '6 months to 2 years'; 'over 2 years'; or, 'mixed lengths of admission'.

Age of institution/service: The length of time for which institutions of each type have been operating, either: 'less than 5 years'; '5-10 years'; '10-50 years'; or, 'over 50 years'.

Community-based services

FRA's research network was asked to identify the types of community-based service in place in each of the 28 EU Member States. In order not to restrict the scope of the data collection, and to reflect the different understandings of community-based services across the EU, no definition of a community-based service was provided.

FRA provided the network with a list of common types of community service, drawn from the Common European Guidelines on the Transition from Institutional to Community-based Care:²³

• **In home:** home help consists of assistance with household tasks, such as shopping, cleaning, cooking, etc. Home-care services include assistance with daily routine tasks such as getting up, dressing, bathing and washing or taking medicines.

²³ European Expert Group on the Transition from Institutional to Family Based Care (2012), <u>Common European Guidelines on the Transition from Institutional to Community-based Care</u>, Chapter 5.

- Day care centres: service provided during set periods of the day; includes support, meals and some aspects of personal care, as well as social and cultural activities.
- **Residential:** usually small scale residential services in the community such as group homes, protected homes, family type arrangements, etc.
- **Foster care:** where children are placed in the domestic environment of a family that is not their own.
- **Family support/respite care:** provides support to carers in their caring role and allows them to have a break, may be formal or informal, and may be provided in the home or out of the home.
- **Personal assistance:** typically purchased through earmarked cash allocations, the purpose of which is to pay for any assistance needed.
- **Direct payments/personal budget/individual budget:** cash payment enabling service users to employ personal assistants or freely choose using various service providers.
- Crisis intervention and emergency services: various activities aimed at supporting an individual or a family to overcome a difficult situation, for example: individual and family counselling, crisis resolution teams (usually rapid support for people living in the community who are experiencing a mental health crisis) and emergency foster care for children at risk of neglect or abuse.
- **Peer support/counselling:** provided by non-professionals with the counsellor and the client having equal status, and sharing experience and assistance in gaining independence and self-confidence.
- **Informal support:** help provided by another person close to the user family members, relatives and friends without any official forms of support.
- **Befriending:** service provided by trained volunteers to help overcome isolation and enable full involvement in the community and social life.
- **Circles of support:** informal group of people close to the user to whom she/he can turn for support.

Mirroring the approach taken for the mapping of institutional services, the characteristics and corresponding categories provided to the research network were as follows:

Age group: The typical age of residents/users of the type of service

CATEGORISATION	DESCRIPTION/EXPLANATION
Children	Persons aged 0-18
Adults	Persons aged 19-60
Older Adults	Persons over the age of 60

Type of impairment: The available categories were:

CATEGORISATION	DESCRIPTION/EXPLANATION
Mental health problem	Service provided for people with mental health problems/ psychosocial disabilities
Intellectual disability	Service provided for people with intellectual disabilities
Physical disability	Service provided for people with physical disabilities
Sensory disability	Service provided for people with sensory disabilities e.g. blind/partially sighted, deaf/hard of hearing
Mixed	Service provided for people with different types of disability
Older adults	Older adults who did not have a pre-existing disability, but including people with dementia

Typical provider: Corresponds to the body/entity that typically provides the type of service. The categories were:

CATEGORISATION	DESCRIPTION/EXPLANATION
National	Services are provided by national authorities
Local authority/ municipality/county	Services are provided by local authorities (e.g. region, municipality, state)
Private	Services are provided by private persons
Voluntary/ not-for- profit	Services are provided by civil society organisations/voluntary sector
Mixed	Services are provided by a mix of providers e.g. state, local authority and private sector

Typical funder: The body/entity that typically funds the type of service, from the following categories:

CATEGORISATION	DESCRIPTION/EXPLANATION
EU funding	Services benefit from EU funding through, e.g. the European Social Fund
National government	Services are funded by national authorities. This could be through national insurance schemes or tax schemes
Regional/local/municipal/ county authority	Services are funded by local governments/agencies such as local authorities
Mixed government and private	Services are partly funded by national or local authorities, but users also pay some costs themselves either through insurance or direct payments
All private/insurance	Services are paid for by users themselves
Mixed	Services are funded by a mixture of funders, including civil society organizations and voluntary organisations

User control: The level to which the users could direct/influence the services

CATEGORISATION	DESCRIPTION/EXPLANATION
Full	Users are fully involved in the decision making and can choose between different services and service providers
Partial	Users are partially consulted in the decision making, either in relation to the type of service, service provider or in drawing up the individual care plan
Limited	Users have very limited influence in decision making

Level of support provided: The variation in the extent of the support provided means it is not possible to create general categories.