

**EQUALITY**



**From institutions to  
community living**

**Part III: outcomes for  
persons with disabilities**



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# **From institutions to community living**

## **Part III: outcomes for persons with disabilities**



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# Introduction

*“Recognizing the right to live in the community is about enabling people to live their lives to their fullest within society [...]. It is a foundational platform for all other rights: a precondition for anyone to enjoy all their human rights is that they are within and among the community.”*

*Council of Europe Commissioner for Human Rights (2012), The right of persons with disabilities to live independently and be included in the community, Issue Paper, p. 5*

Article 19 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) sets out the right to live independently and be included in the community. It lies at the heart of the CRPD. Article 19 represents “the sum of the various parts of the convention” and brings together the principles of equality, autonomy and inclusion.<sup>1</sup> These underpin the convention’s human rights-based approach to disability. This paper shortens the name of the right to the right to independent living.

Article 19 of the CRPD sets out a positive vision of “living in the community, with choices equal to others”. The convention, by contrasting this with “isolation or segregation from the community”, breaks down “full inclusion and participation in the community” of persons with disabilities into three elements:

- **choice:** having the opportunity to choose one’s place of residence and where and with whom to live, on an equal basis with others. This includes choice of the way any support is provided;
- **support:** having access to a range of services, including personal assistance, to support living and inclusion in the community. This support should respect the individual autonomy of persons with disabilities and promote their ability to effectively take part and be included in society;
- **availability of community services and facilities:** ensuring that existing public services are inclusive of persons with disabilities.<sup>2</sup>

These components are closely interrelated. Implementing Article 19 entails that “*general services* are constantly made more accessible to all, and *individualised support* bridges the gap to enable inclusion of each person, while providing maximum *choice* for the individual in the types of services provided and the manner in which they are provided” (original italics).<sup>3</sup>

## Why this report?

Both the European Union (EU) and its Member States have emphasised independent living in their legal and policy reforms to implement the CRPD.<sup>4</sup> However, comparatively little attention has focused on how to measure the impact of these changes on the lived experiences of persons with disabilities in the EU.<sup>5</sup> A lack of reliable and comparable information about independent living outcomes for persons with disabilities in the EU reflects this. Article 31 of the CRPD requires States Parties to collect data “to enable them to formulate and implement policies to give effect to” the convention.

This report responds to both the lack of attention to impact and the lack of data. It does so by presenting the findings of desk research and statistical analysis. These were conducted as part of the EU Agency for Fundamental Rights (FRA) human rights indicators on independent living for persons with disabilities.<sup>6</sup> Firstly, it assesses the extent to which EU Member States effectively implement the right to independent living, using eight indicators covering key aspects of Article 19 of the CRPD. Secondly, it provides concrete examples of how independent living outcomes can be reliably measured and compared across the EU. In particular, the report considers:

- how implementation of Article 19 can be measured, including by assessing:
  - how free persons with disabilities are to decide how to live life in the community, and
  - whether or not persons with disabilities feel left out of society;
- persons with disabilities’ choice and control over where and with whom they live, as per Article 19(a), by looking at:
  - how many persons with disabilities live in institutions in the EU Member States, and
  - how satisfied persons with disabilities are with their living arrangements in the community;
- the availability of support services for persons with disabilities in the community, in accordance with Article 19(b), by analysing data on:
  - how many persons with disabilities use support services to live independently, and
  - whether the help that persons with disabilities receive with daily living is sufficient;

## FROM INSTITUTIONS TO COMMUNITY LIVING: FRA REPORTS ON ARTICLE 19 OF THE CRPD

This report is one of a series of three reports looking at different aspects of deinstitutionalisation and independent living for persons with disabilities. They complement FRA's human rights indicators on Article 19 of the CRPD by highlighting cross-cutting issues emerging from the data that FRA collected and analysed:

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

- the access that persons with disabilities have to community services and facilities for the general population, in accordance with Article 19(c), by measuring:
  - the access that persons with disabilities have to some commonly available services and facilities;
- gaps in the data required to accurately assess the implementation of the right to independent living.

The first two reports in the FRA series focused on the transition from institutional to community-based support for persons with disabilities. This phrase is used interchangeably with the word 'deinstitutionalisation'. The analysis in this report also takes in broader elements of the right to independent living. Its findings are based on, and relevant to, the experiences of persons who may never have lived in institutions. Improved independent living outcomes are, however, the goal of the deinstitutionalisation processes.

The examples of how to measure implementation of Article 19 of the CRPD included in this report are therefore equally relevant to all persons with disabilities, whether they have spent time in institutions or not. For

a fuller picture of the current situation of independent living in the EU, you can read this report alongside the FRA human rights indicators on Article 19 of the CRPD. These broadly correspond to the three main elements of the OHCHR indicator framework, which is based on three clusters:

- (1) structural indicators focusing on the state's acceptance and commitment to specific human rights obligations;
- (2) process indicators on the state's efforts to transform commitments into desired results;
- (3) outcome indicators measuring the results of these commitments and efforts on individuals' human rights situation.

You can also read this report alongside the longer report that presents the findings of FRA's 12 statistical outcome indicators on independent living.<sup>7</sup>

For more information on other elements of FRA's project on the right to live independently and be included in the community, see [Annex 2](#).

## How to read the statistical data

This report draws on two strands of data collection and analysis by FRA. FRA's multidisciplinary research network, Franet, conducted desk research in the 28 EU Member States. Part of the analysis stems from this research. FRA, again with support from Franet, also analysed data from existing European social surveys, namely the European Statistics on Income and Living Conditions (EU-SILC), the European Quality of Life Survey (EQLS) and the European Health Interview Survey (EHIS). The statistical information is the result of this new analysis. You can find more information on the surveys used and the methodology supporting the analysis of statistical data in the annex.

This report's analysis focuses on differences in outcomes for persons with and without disabilities at the EU level. Where relevant and possible, other explanatory factors such as age, gender, and education or employment status are included in the analysis. The role of age is particularly important. This is because persons who the surveys identify as having disabilities are – on average – older than persons without disabilities participating in the surveys. 'Disability gaps' between outcomes for persons with and without disabilities sometimes occur because the persons with disabilities in the sample are older.

A number of issues call for caution with respect to some of the data and their interpretation. They mean there is little scope for comparison of findings between and across the surveys. This should be kept in mind when reading the statistical data:

- EU-SILC and EHIS identify respondents with 'activity limitations' through a question on whether or not respondents face 'limitations in daily activities people usually do' because of a health problem. The EQLS has an additional filter question before asking about daily activity limitations. For clarity, the graphs and text in this report refer to persons with disabilities (equivalent to persons with limitations) and persons without disabilities (equivalent to persons without limitations). EHIS and EU-SILC measure disability "through a concept of general activity limitation", Eurostat emphasises.
- The surveys cover different parts of the population. EHIS covers persons aged 15 and over, EU-SILC persons aged 16 and over, and the EQLS persons aged 18 and over.
- EU-SILC and the EQLS cover all 28 EU Member States, while EHIS covers 13 Member States.
- The surveys collected data at different times. EHIS data are from 2006 to 2009, while the most recent EU-SILC data are from 2014. Some surveys, notably EU-SILC and the EQLS, happen regularly. This creates the possibility to analyse changes over time.
- Some surveys are much larger than others. For example, the EU-SILC sample (114,868 respondents with disabilities in the 28 EU Member States in the 2014 round) is much larger than the EQLS sample (8,634 respondents with disabilities in the 28 EU Member States in the 2011-2012 round). This has certain advantages for analysing data.
- The Member States participating in EHIS conducted the survey in different ways and performed differently according to various quality-related issues. This affects the reliability of the data.

Finally, there is a major gap in the statistical data. There is no information about the experiences of persons with disabilities living in institutions. Any interpretation of the data must acknowledge this. Data from the European social surveys used in this report cover persons living in private households. They therefore do not include persons living in group settings such as institutions. Around 1.2 million persons with disabilities live in institutions in Europe, previous research has estimated. (This figure includes persons living in institutions in Turkey.) Leaving out their experiences is a significant weakness of the current data.

*For more information, see EU-SILC 2012 module on housing conditions, and 2013 module well-being; the European Foundation for the Improvement of Living and Working Conditions (Eurofound), EQLS 2011-2012; the first wave of the European Health Interview Survey between 2006 and 2009; Eurostat, Glossary: disability; the Commission's webpage; and Mansell, J., Knapp, M., Beadle-Brown, J., Beecham, J. (2007), Deinstitutionalisation and community living – outcomes and costs: report of a European study. Volume 2: Main report, Canterbury, Tizard Centre, University of Kent.*



# Key findings and FRA opinions

The opinions outlined below build on the following key findings:

- Persons with disabilities living in the community experience worse independent living outcomes than persons without disabilities, across all the areas analysed in this report. This is particularly apparent among persons with more severe impairments and among those with a lower economic status.
- Persons with disabilities are less likely than persons without disabilities to feel that they are free to decide how to live their lives. They are also more likely to feel left out of society.
- Large numbers of persons with disabilities continue to live in institutions in EU Member States.
- Persons with disabilities are, on average, less likely to be satisfied with their accommodation in the community than persons without disabilities.
- A variety of community-based services are available to persons with disabilities in EU Member States. This includes some form of personal assistance in 22 Member States. Nevertheless, for many persons with disabilities living in the community, the help they receive with everyday tasks is not sufficient to meet their needs.
- Nearly half of persons with disabilities face difficulties in using common everyday services, such as grocery shopping, banking, postal services, primary healthcare services and public transport.
- There is a lack of robust, comparable and timely data on independent living outcomes for persons with disabilities within individual Member States and across the EU. In particular, very little information is available about how many persons with disabilities live in institutions and their experiences. This impedes evidence-based policy making and undermines efforts to realise the right to independent living.

Article 19 requires that all persons with disabilities be able to choose where and with whom to live, on an equal basis with others. A range of appropriate living arrangements must be available in the community to realise this choice. However, persons with disabilities are less satisfied than other persons with their

household accommodation, this report shows. This suggests a need to assess the suitability of housing stock and planning policies to better meet the accommodation requirements of persons with disabilities – for example, in terms of location, accessibility or disability-related adaptations.

Institutionalised settings inhibit persons with disabilities from exercising choice and control over their daily lives. To that degree, they are therefore incompatible with Article 19. This includes not having to resort to living in institutionalised settings because of a lack of viable alternatives. The FRA report *Choice and control: the right to independent living* highlights this.<sup>8</sup>

## FRA opinion 1

*EU Member States should ensure that a range of community-based living arrangements are available that give persons with disabilities, regardless of type and degree of impairment, a meaningful choice over where to live. Particular attention should be paid to persons with disabilities who are at risk of poverty.*

## FRA opinion 2

*EU Member States should implement measures to end the institutionalisation of persons with disabilities. These include closing down existing institutionalised settings and stopping new admissions to them. These measures should be guided by evidence-based national deinstitutionalisation strategies and should draw on a comprehensive mapping of the status of deinstitutionalisation in the Member States.*

Individualised, user-controlled support is essential to achieve independent living. It empowers persons with disabilities to be included in the community. This requires both that appropriate services be in place and that they respect the dignity and individual autonomy of persons with disabilities. There are gaps in the provision of community-based services in EU Member States and, where available, they are often not sufficient to meet users' needs, this report suggests.

Personal assistance services are particularly well placed to offer persons with disabilities choice and control over their support. However, such services are not available in all Member States, FRA evidence shows.

#### FRA opinion 3

*EU Member States should ensure that adequate, good-quality and freely chosen personalised support for independent living is available for all persons with disabilities, irrespective of their impairment. This support should be available regardless of an individual's living arrangements. It should also be under the user's control.*

*EU Member States should pay particular attention to developing personal assistance services.*

Being able to access services and facilities for the general population, such as education, transport and housing, on an equal basis with others enables persons with disabilities to participate actively and meaningfully in the lives of their communities. Persons with disabilities are more likely than other persons to face barriers in accessing services that are commonly available to the public, this report shows. Making services responsive to the needs of persons with disabilities has major implications for the way services across different sectors are provided. This is particularly the case in terms of ensuring accessibility, equal treatment and non-discrimination.

One way to improve accessibility is to develop minimum standards and guidelines on accessibility, according to FRA's human rights indicators on the right to political participation of persons with disabilities.

#### FRA opinion 4

*EU Member States should extend the prohibition of discrimination on the grounds of disability to cover the provision of goods and services available to the general public. They should also ensure that failure to provide reasonable accommodation is recognised as a form of discrimination. Reasonable accommodation includes modifications and adjustments that ensure that persons with disabilities can exercise rights on an equal basis.*

*The EU should urgently adopt the proposed European Accessibility Act to set minimum standards for the accessibility of key products and services in the EU. The EU legislator should also consider all avenues to ensure that the proposed Equal Treatment Directive is adopted swiftly. This will guarantee equal protection against discrimination on the grounds of disability in access to goods and services.*

#### FRA opinion 5

*The EU and its Member States should develop, spread awareness of and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services that are open or provided to the public. These criteria should encompass the accessibility needs for all persons with disabilities.*

Article 31 of the CRPD requires States Parties to "collect appropriate information, including statistical and research data" to enable policymakers "to formulate and implement policies to give effect to the [convention]". In practice, there is a lack of robust, comparable and timely data on independent living outcomes for persons with disabilities, as this report shows. This restricts the ability of Member States to implement Article 19, because it impedes evidence-based policymaking. Moreover, data gaps prevent Member States from demonstrating meaningful progress in achieving independent living.

#### FRA opinion 6

*The EU and its Member States should collect and collate reliable, comparable and timely data on independent living outcomes for persons with disabilities. This data collection should incorporate persons with disabilities living in institutions. This could include collecting and publishing qualitative and quantitative data for applying human rights-based indicators, such as those that FRA developed on Article 19 of the CRPD. To improve accountability and transparency, these data should be publicly available.*

#### FRA opinion 7

*Eurostat and national statistical offices in the EU Member States should continue to work with international bodies such as the Washington Group on Disability Statistics to develop inclusive methodologies for collecting statistical data on the right to independent living. These methodologies should allow for disaggregation of data by the type and severity of impairment. Statistical data collection should facilitate the participation of all persons with disabilities, including those with severe impairments and those living in institutions.*



# 1

## Measuring the achievement of independent living



The CRPD Committee’s General Comment on Article 19 breaks down the core elements of the right to independent living into practical steps. States Parties should take these steps to ensure the full implementation of Article 19.<sup>9</sup> FRA’s human rights indicators on Article 19 reflect many of these actions; for example:

- repealing all laws that prevent persons with disabilities from choosing where and with whom to live;
- replacing institutionalised settings with independent living and community-based services;
- developing user-led support services, including personal assistance;
- providing assistive devices.

Translating this guidance into workable and meaningful indicators poses a challenge, however. Three particularly pressing conceptual questions emerge from the FRA indicator development: (1) how to measure the intersection between barriers and impairment; (2) the difference between living arrangements or services being available and having access to them in practice; and (3) capturing the subjective and objective aspects of the right to independent living. For a detailed discussion of issues regarding data availability, see ‘The need for more and better data’.

Article 1 of the CRPD defines disability as the “interaction” of impairments with “various barriers” to participation. This implies that any effort to measure implementation of convention rights needs to consider both individuals’ specific impairments – that is, to identify persons with disabilities among the general population – and disabling barriers.<sup>10</sup> The first is difficult given the lack of a commonly agreed definition of disability and the significant differences in levels of

‘self-reporting’ of disability in surveys. Individuals may be more or less likely to indicate that they have an impairment. This is because there are different concepts of what constitutes disability or there is a stigma associated with being seen as ‘disabled’. Measuring barriers is also challenging, as they may affect persons with disabilities in different ways and to different extents. For example, measuring the barriers associated with inaccessible transport would be especially relevant to persons with physical impairments. On the other hand, stigma could be a particular barrier for persons with psychosocial impairments.

Statisticians have sought to bring these two elements together – for example, through the ‘disability identification’ questions. These were developed by the Washington Group on Disability Statistics established by the UN.<sup>11</sup> However, difficult questions remain about how best to incorporate both impairment and barriers into measuring implementation of rights. Many surveys currently use questions such as ‘do you have difficulty walking or climbing steps?’ and ‘to what extent are you limited because of a health problem in activities people usually do?’ to identify persons with disabilities, for instance. However, these questions do not differentiate between the impairment and the barriers created by inadequate support or accessibility. Individuals may also attribute difficulties to factors other than disability – for example, to older age.

Caution is needed when it comes to the relationship between availability on the one hand and inclusion outcomes on the other. In theory, persons with disabilities may be able to choose from a variety of available arrangements in the community, for instance. However, in practice, their access to these arrangements could be impeded because appropriate housing is scarce or expensive in their local area. For some measures, indicators of expenditure may be closely linked to outcomes

for recipients. For example, additional cash benefits can raise standards of living. For in-kind services, in contrast, there is a less consistent association between expenditure, service usage and inclusive outcomes. This will depend on service quality. Measures of satisfaction and unmet needs are also relevant. Moreover, newly available, high-quality services may not be usable if the public transport that a person requires to reach them is inaccessible.

The implementation of some aspects of choice, support and availability of community-based services and facilities can be measured against objective criteria. For example, measuring the number of persons using personal assistance services or the number of available personal assistants would give a sense of whether or not the aspect of support is being adequately fulfilled. However, if an assessment of the implementation of independent living limits itself to such indicators, it risks neglecting the real power of Article 19: its call for meaningful inclusion and participation. To get a holistic picture of the implementation of Article 19, it is essential to understand whether or not persons with disabilities feel part of the community that they live in. Both objective and subjective elements are involved in measuring whether or not the promise of independent living in the community is being fulfilled in practice.

## Freedom to decide how to live life in the community

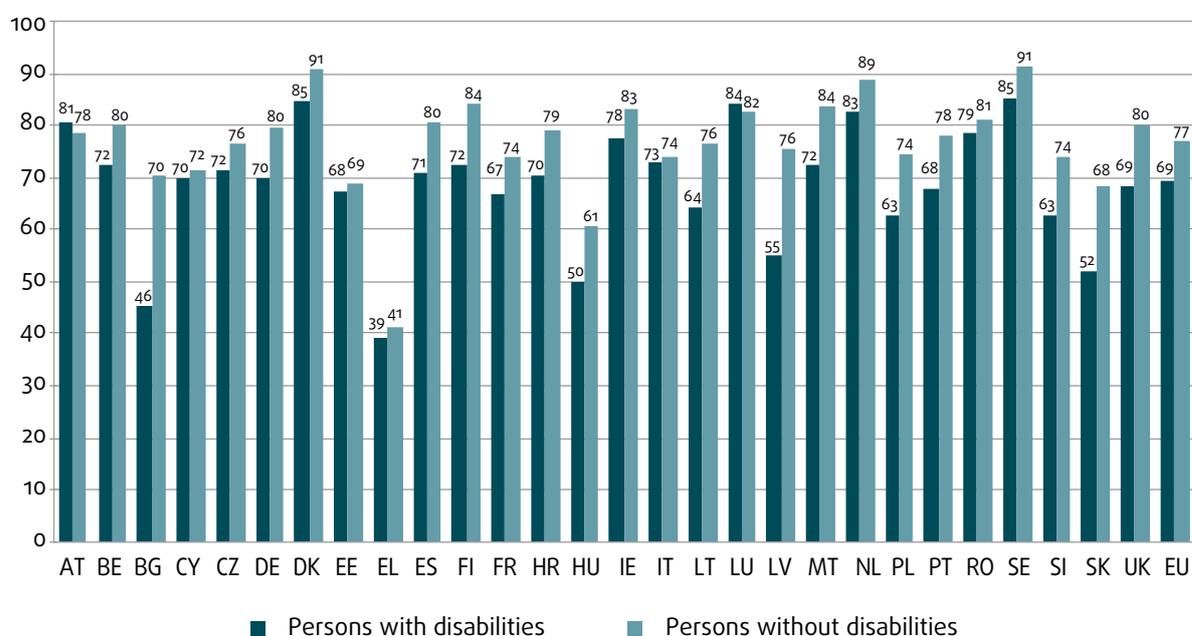
Two of FRA’s statistical outcome indicators focus specifically on the ‘spirit’ of Article 19 as a whole. They look at perceived freedom to decide how to live life in the community and, in contrast, the extent to which persons feel left out of society.

*“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others.”*

*United Nations Convention on the Rights of Persons with Disabilities, Article 19*

Fulfilling the right to independent living means that persons with disabilities should feel that they have life choices on an equal basis with other persons. However, in nearly all Member States, persons with disabilities are less likely to feel that they have such a choice than persons without disabilities, FRA analysis of data from the European Quality of Life Survey (EQLS) reveals. At the EU level, 69 % of persons with disabilities agree or strongly agree with the statement ‘I feel I am free to decide how to live my life’. This is in comparison with 76 % of persons without disabilities: a difference of nearly eight percentage points.

Figure 1: Persons who agree or strongly agree with the statement: ‘I feel I am free to decide how to live my life’ (%)



Notes: Question 29: ‘Please tell me whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with each Statement: c) I feel I am free to decide how to live my life.’ Possible answers are: 1. Strongly agree, 2. Agree, 3. Neither agree nor disagree, 4. Disagree, 5. Strongly disagree, 6. Don’t know, and 7. Refusal.

Source: EQLS 2011/2012, Q29c

However, there are significant differences across the EU Member States. Further research is necessary to explore these variations. Particularly wide ‘disability gaps’ in agreement levels exist in **Bulgaria** (45 % of persons with disabilities, compared with 70 % of persons without disabilities), **Latvia** (55 % and 75%, respectively) and **Slovakia** (52 % and 68%, respectively). In contrast, in **Austria** and **Luxembourg**, persons with disabilities are more likely than persons without disabilities to agree that they are free to decide how to live their life.

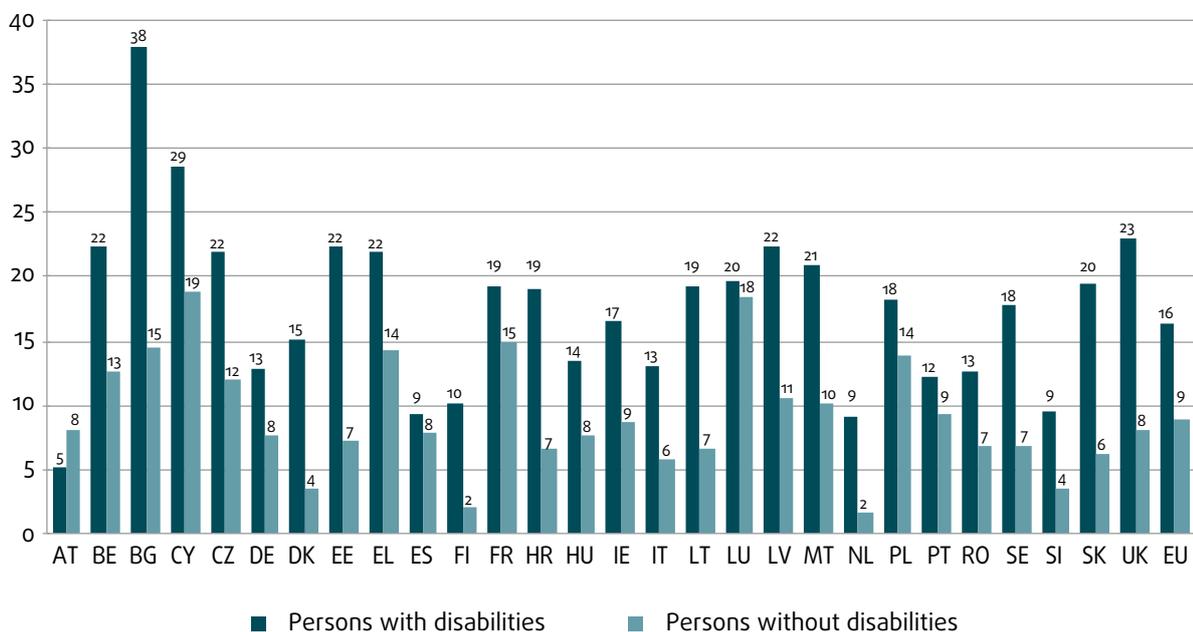
Educational level and economic status help to explain the differences between persons with and without disabilities. The percentage of persons who agree that they are free to decide how to live their life increases with education level and economic status. In general, persons with disabilities are less likely to have higher education qualifications or be employed. Only 28 % of persons with disabilities have completed a tertiary or equivalent education, compared with 41 % of persons without disabilities; and 49 % of persons with disabilities are employed, compared with 71 % of persons

without disabilities.<sup>12</sup> This signals that further efforts are necessary to equalise the life choices of persons with disabilities, particularly concerning the contributing factors of education and economic status.

## Feeling left out of society

Freedom to make decisions should go with, and support, “full inclusion and participation in the community” under Article 19. Persons with disabilities should not feel isolated or segregated from the community. However, in practice, persons with disabilities who live in private households are almost twice as likely to report that they “feel left out of society” as persons without disabilities, EQLS data show. At the EU level, 16 % of persons with disabilities agree or strongly agree with the statement ‘I feel left out of society’, compared with 9 % of persons without disabilities. There are large differences in agreement rates across Member States, but persons with disabilities are more likely to feel left out of society in all of them, except **Austria**.

Figure 2: Persons who agree or strongly agree with the statement: ‘I feel left out of society’ (%)



Note: Question 29: ‘Please tell me whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with each Statement: e) I feel left out of society.’ Possible answers are: 1. Strongly agree, 2. Agree, 3. Neither agree nor disagree, 4. Disagree, 5. Strongly disagree, 6. Don’t know, and 7. Refusal.

Source: EQLS 2011/2012. Q29e

Unequal experiences of isolation could result from social, economic or physical barriers within the community, or from a lack of effective supports for inclusion. In this context, persons with more severe impairments and those with a lower economic status might encounter greater barriers to participation. The data support this. They show that severity of impairment plays an important role in the extent to which persons feel left

out of society. Around a quarter (23 %) of persons with severe disabilities indicate that they feel left out of society. This is in comparison with 14 % of persons with moderate disabilities and 9 % of persons without disabilities. In terms of economic status, being unemployed makes persons significantly more likely to feel left out of society. This underlines the importance of employment opportunities for social inclusion.



# 2

## Choosing where and with whom to live



*“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.”*

*United Nations Convention on the Rights of Persons with Disabilities, Article 19 (a)*

The first part of Article 19 focuses on the right to choose freely where and with whom to live on an equal basis with others. This includes not having to live in a particular living arrangement. This links it closely to the decision-making rights established under Article 12 of the convention, on equal recognition before the law, as some persons with disabilities may need support to decide on, and communicate, their choice.<sup>13</sup>

The focus on choice gives rise to some difficult questions. The CRPD Committee’s draft General Comment on Article 19 acknowledged that the principle of choice of living arrangements theoretically entails the choice to live in an institution.<sup>14</sup> However, the draft also made it clear that the committee thinks that “institutionalization is incompatible with Article 19” because it results in segregation and a lack of control.<sup>15</sup> Moreover, the opening of Article 19 frames this notion of choice. It explicitly sets out the “equal right of all persons with disabilities to *live in the community*” (emphasis added). The wording concerning “the decision to live in institutional care settings” was removed from the adopted General Comment.<sup>16</sup>

Several disabled persons’ organisations (DPOs) have argued that portraying the possibility of living in an institution as a ‘choice’ neglects important factors constraining the options of persons with disabilities in practice. Many persons with disabilities lack sufficient

appropriate accommodation and services in the community and are concerned about being a burden on family members. This can make institutions the only viable option, rather than an active choice among different possibilities.<sup>17</sup> The CRPD Committee also specifically highlights the issue of forced institutionalisation. This can be because persons with disabilities who are deprived of legal capacity are placed in institutions by their guardians, or on mental health grounds.<sup>18</sup>

Much attention focuses on ‘institutions’. However, the CRPD Committee separates the concept of ‘institutionalisation’ from any particular residential arrangement. Instead, it underlines that institutionalisation is “about losing personal choice and autonomy as a result of the imposition of a certain life and living arrangements” with particular ‘institutional’ characteristics.<sup>19</sup> These include isolation and segregation from community life, lack of control over day-to-day life, rigid routines that do not take personal preferences into account, and paternalistic approaches to service provision. In this understanding, persons with disabilities can be “institutionalised in their homes, if State parties fail to put in place the necessary supports and make the mainstream services and facilities accessible”.<sup>20</sup>

FRA’s human rights indicators look at two important aspects of the right to choose where and with whom to live:

- numbers of persons with disabilities living in institutions in the EU Member States;
- how satisfied persons with disabilities are with living arrangements in the community.

## Institutionalisation in numbers

Getting a clear picture of institutionalisation in the EU is a significant challenge.<sup>21</sup> Firstly, the terms ‘institution’, ‘institutional setting’ and ‘residential institutions’ are not used consistently across different countries and contexts, according to national data that FRA collected. Often, the same terms describe very different types of settings. These range from traditional, large-scale institutions to group homes, sheltered housing and other forms of living arrangements in which persons with disabilities reside together. FRA’s analysis is based on what each Member State defines as institutions. The agency’s overview of different types of institutional and community-based services for persons with disabilities in the EU explores these issues in more depth.<sup>22</sup>

Moreover, the data currently available are based on numbers of persons living in specific types of residential services for persons with disabilities. However, institutions cannot be identified by physical characteristics, such as size, location or appearance, the CRPD Committee and OHCHR have emphasised. Instead, the defining characteristics concern the choice that persons with disabilities have.<sup>23</sup>

Nevertheless, large numbers of persons with disabilities continue to live in institutionalised settings in the EU Member States, according to FRA desk research. For example, in the **Netherlands**, 81,085 persons were receiving ‘care for persons with disabilities’ during an uninterrupted stay in an institution in 2014. A further 32,580 were receiving ‘mental health care’.<sup>24</sup> In **Romania**, 17,202 persons with disabilities were living in 352 institutions at the end of 2014.<sup>25</sup> **Croatian** government data show that 6,816 persons with disabilities were living in social welfare homes at the end of 2013.<sup>26</sup>

In some countries, the data focus on specific groups of persons with disabilities, in particular on persons with intellectual and/or psychosocial impairments. These groups are particularly at risk of institutionalisation.<sup>27</sup> In **Poland**, 30,500 persons were residing in special support centres for persons with ‘mental disorders’ in 2014.<sup>28</sup> In **Slovenia**, in 2013, 2,178 persons with intellectual and physical disabilities were residents in special social welfare institutions (*posebni zavodi*). Another 1,226 persons were residents in special residential-vocational institutions for children with intellectual disabilities (*centri za usposabljanje, delo in varstvo*); 223 children were residing in special schools; and 615 persons were living in special residential institutions for persons with psychosocial disabilities.<sup>29</sup>

In some cases, the data give a sense of the significant role that institutionalised settings still play in providing services for persons with disabilities. **Irish** data for 2016 show that 7,612 persons with intellectual disabilities

were receiving full-time residential services, out of 27,863 persons with intellectual disabilities who were in receipt of support services and were registered on the National Intellectual Disability Database.<sup>30</sup> Of the 7,612 full-time respondents, 2,135 were living in residential centres and 4,279 in community group homes. In 2011, the Irish government committed to eliminating institutionalisation by 2018.<sup>31</sup>

The FRA indicators also aim to assess changes over time in the numbers of persons with disabilities who live in institutions. Although gaps in the data prevent firm conclusions, available evidence suggests a mixed picture. In some countries, data show a decrease in the numbers of persons with disabilities living in institutions. In the **Czech Republic**, for example, 12,956 persons lived in “homes for people with disabilities” in 2013, compared with 13,946 in 2010.<sup>32</sup> In **Hungary**, the number of persons in residential institutions for persons with physical, intellectual and sensory disabilities decreased from 15,169 in 2010 to 14,815 in 2013. However, the number of persons in psychiatric institutions increased over the same period, from 8,428 in 2010 to 8,515 in 2013.<sup>33</sup>

In some cases, falling numbers of persons with disabilities in institutions tie in with national deinstitutionalisation strategies and projects. In **Finland**, for example, the government has committed to ending institutionalisation of persons with disabilities by 2020. There, 1,464 persons with disabilities were living in institutions at the end of 2013, compared with 1,934 at the end of 2010. This represents a decline of a quarter.<sup>34</sup>

Similarly, the focus on deinstitutionalisation of children in **Bulgaria** resulted in the closure of the last of 25 specialised institutions for children with disabilities in 2016.<sup>35</sup> In contrast, figures for adults with disabilities in institutions remain high.<sup>36</sup> Between 2012 and May 2017 only two specialised institutions for adults with disabilities were closed. This left 79 institutions operating. As of May 2017, 2,059 persons lived in institutions for persons with intellectual disabilities; 1,022 in institutions for persons with mental health problems; 1,199 in institutions for persons with physical disabilities; and 118 in institutions for persons with sensory disabilities. The total number of 5,189 persons with disabilities living in institutions in May 2017 is only slightly lower than the 2010 figure of 5,729.<sup>37</sup>

However, data from many Member States, including **Estonia**, **Latvia**,<sup>38</sup> **Lithuania**,<sup>39</sup> **Luxembourg** and **Slovakia**, show a rise in the number of persons with disabilities living in institutions. In Estonia, 2,670 persons lived in ‘24-hour special care service’ settings in 2014, compared with 2,478 in 2010.<sup>40</sup> In Luxembourg, the number of persons living in residential institutions rose from 701 in 2010 to 785 in 2016.<sup>41</sup> Likewise, in Slovakia, the number of persons with disabilities living in residential institutions increased annually between 2010 and 2013, from



25,794 to 30,002.<sup>42</sup> Data from the **United Kingdom** show that persons with disabilities continue to be admitted to institutions. A total of 4,570 adults with disabilities aged between 18 and 64 were among the permanent admissions to residential nursing homes in England in 2014.<sup>43</sup>

## Satisfaction with accommodation

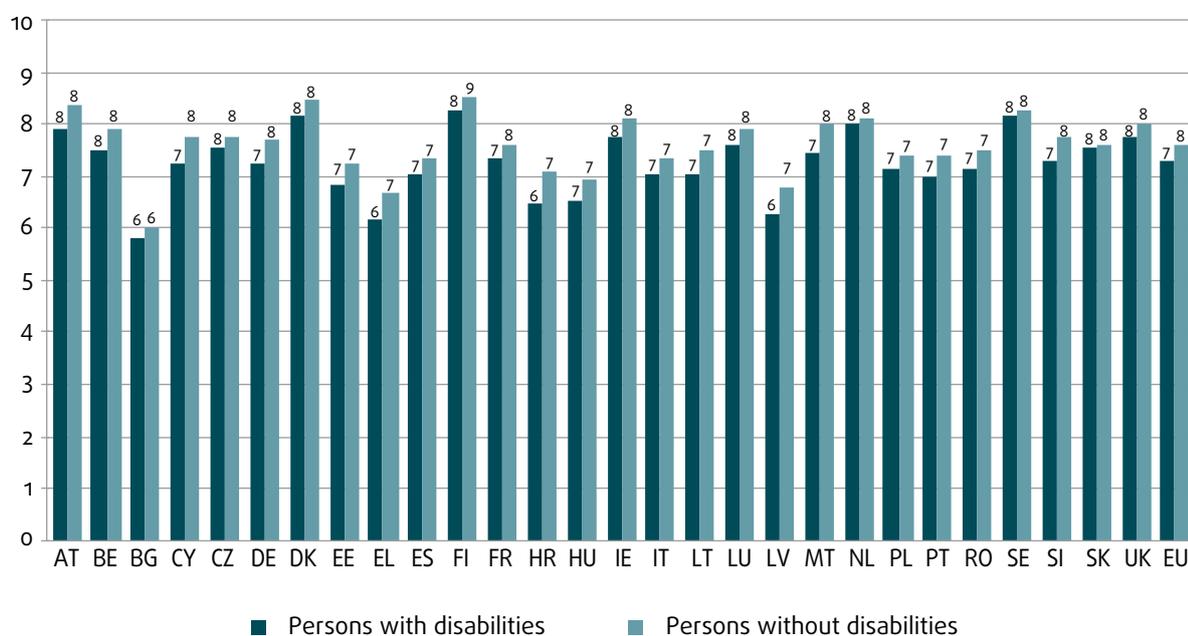
Being able to choose where to live – and not to live in an institution – is only one part of living arrangements under Article 19. A second crucial element is satisfaction with accommodation. Satisfactory accommodation is a prerequisite for living independently and being included in the community for everyone in society. However, disability may change a household’s needs – for example, in terms of location, accessibility or need for disability-related adaptations. This can potentially have cost implications. These data concern a very different group of persons with disabilities. They reflect the experiences of persons living in private households in the community rather than of those in institutions.

Persons with disabilities report lower average levels of satisfaction with their household accommodation than

persons without disabilities, according to FRA analysis of data from a 2013 module of EU-SILC. This applies to the EU as a whole and in every Member State. Across the EU, the average level of satisfaction with accommodation among persons with disabilities is 7.3 out of 10, compared with 7.6 for persons without disabilities. This is a comparatively small gap, but it suggests that there is a need to assess the suitability of housing stock and planning policies to meet the accommodation needs of persons with disabilities more successfully.

Factors such as age, gender, household size and degree of disability are all relevant to housing choices. For example, older persons are more likely to own their own accommodation, which tends to increase satisfaction levels. However, the data indicate that, for this measure, poverty risk (after social transfers) is particularly significant in determining satisfaction levels. Persons with disabilities are more likely to be at risk of poverty than persons without disabilities, largely because of lower employment levels.<sup>44</sup> At the EU level, the average level of satisfaction with accommodation for persons with disabilities at risk of poverty is 6.5 out of 10, compared with 6.9 for persons without disabilities at risk of poverty and 7.7 for persons without disabilities not at risk of poverty.

Figure 3: Mean value of satisfaction with accommodation



Note: Question PWo40: ‘Overall what is your degree of satisfaction of: Your accommodation? Please answer on a scale from 0 to 10. 0 means “not at all satisfied”, 10 means “completely satisfied”.’

Source: EU-SILC UDB 2013 – Version 3 of January 2016, Q PWo40



# 3

## Accessing community support services for persons with disabilities



*“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.”*

*United Nations Convention on the Rights of Persons with Disabilities, Article 19 (b)*

The second part of Article 19 stresses the right of persons with disabilities to have ‘access’ to various services to support independent living and inclusion, and to prevent isolation from the community. This places two key obligations on the 27 EU Member States that have ratified the CRPD. Firstly, a range of services must be in place and available to all persons with disabilities. Secondly, all such services should “respect [persons with disabilities’] inherent dignity and individual autonomy and aim to achieve effective participation and inclusion in society”.<sup>45</sup>

In practice, achieving these obligations requires a profound shift in the way services for persons with disabilities are designed and provided. Options include providing persons with disabilities with personal budgets to purchase support services, expanding the number of service providers within a managed market, and opening up a free market for service provision.<sup>46</sup>

Two of FRA’s indicators address important components of these obligations:

- how many persons with disabilities use community-based services in the EU, focusing on personal assistance, physical adjustments to the place of residence and assistive devices;
- whether or not persons with disabilities receive sufficient help with daily living tasks.

Another indicator, which looks at the availability of help from persons outside the individual’s household, is presented in the main report on FRA’s statistical outcome indicators on Article 19.<sup>47</sup>

### Use of community-based services for persons with disabilities

Some form of community-based services for persons with disabilities is available in all EU Member States, FRA desk research shows. In-home services and day-care centres are available in all 28 EU Member States, for example, FRA’s summary overview of services for persons with disabilities in the EU indicates.<sup>48</sup> Less traditional services, such as peer support and counselling, are also in place in around half of Member States. However, knowing what services are available is not sufficient for assessing the implementation of Article 19. Persons with disabilities must actually be able to access these services. This makes user numbers an essential component of measuring independent living outcomes.

Building up a clear picture of the numbers of persons with disabilities using different types of community-based services presents a considerable conceptual and practical challenge. A great variety of services are labelled ‘community-based’, FRA’s summary overview shows.<sup>49</sup> Some of these services are based on the principles of individualisation and facilitate user control. However, this is not true of all services.

In practical terms, responsibility for support services lies largely with national and local authorities, FRA analysis shows. It may involve a variety of different providers.<sup>50</sup> This creates difficulties in collating comprehensive data

at the national level. Furthermore, many of the available data are organised by type of service rather than by type of user. Therefore, it is not possible to identify numbers of persons with disabilities among overall user numbers. In **Austria**, for example, a total of 145,723 persons received mobile care and assistance services in 2015. However, the statistics do not distinguish between persons with and persons without disabilities.<sup>51</sup> These issues are further discussed in ‘The need for more and better data’ and in the FRA report *From institutions to community living: funding and budgeting*.<sup>52</sup>

Looking at three different types of community-based service gives a sense of the situation in the EU. They are personal assistance, physical adjustments to the place of residence and assistive devices.

Personal assistance is the only type of community support service specifically mentioned in Article 19 of the CRPD. This reflects its particular importance for ensuring independent living, particularly for persons with more severe impairments. The CRPD Committee has expressed concern at limitations on the availability of personal assistance. These include restricting support to persons with certain types of, or particularly severe, impairments.<sup>53</sup>

Some form of personal assistance is available in 22 Member States, according to data that FRA collected.<sup>54</sup> The number of personal assistants varies considerably across countries. This reflects different populations as well as the importance afforded to personal assistance. In **Sweden**, personal assistance has been available by law since 1994. There, 16,158 persons used the state-funded personal assistance scheme in 2014. The scheme involves assistance for more than 20 hours a week.<sup>55</sup> **Croatia** recently started developing a personal assistance scheme. In early 2015, 631 persons with severe disabilities used the service.<sup>56</sup> Similarly, **Latvia** introduced assistance services nationwide in 2013. In the first year, such services were provided to 3,069 persons with disabilities.<sup>57</sup> Some Member States have established personal assistance schemes as pilot projects – for example, in **Portugal**. In other Member States, schemes are available in selected regions and are therefore not available countrywide. This was the case in **Belgium** and **Poland** at the time of data collection.<sup>58</sup>

The use of personal assistance services has increased significantly in several Member States. In **Finland**, the number of persons using personal assistance services nearly tripled between 2008 and 2013. In 2013, 15,195 persons were using personal assistance services, compared with 13,457 in 2012; 11,304 in 2011; and 8,985 in 2010.<sup>59</sup> Similarly, data from the **Czech Republic** show that the number of users of personal assistance rose from 1,422 in 2007 to 7,182 in 2013, which is a five-fold increase.<sup>60</sup>

Article 19 of the CRPD does not itself refer to assistive devices or physical adjustments to the place of residence. However, the CRPD Committee states in its General Comment on Article 19 that “[t]he provision of affordable and available quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries as enshrined in article 20 [on personal mobility] is a pre-condition for the full inclusion and participation of persons with disabilities in their respective communities.”<sup>61</sup> When available at a reasonable cost, physical adjustments and assistive devices promote the right to independent living by enabling persons with disabilities to live in their chosen place of residence in the community. Examples are personal mobility, hearing or visual aids and specialised computer software.

Most Member States have no regularly updated, publicly available and disaggregated data available on the number of persons with disabilities who receive physical adjustments and assisted devices. This reflects familiar challenges to data collection, linked to decentralisation of services and lack of disaggregation of recipients by disability. The data also focus on budgets for adaptations and assistive devices rather than on the number of recipients.

Nevertheless, the more comprehensive data available in a small number of Member States indicate the availability of adjustments and assistive devices. On the adjustments side, 73,400 requests for housing adaptation grants were approved in **Sweden** in 2013, data from the National Board of Housing, Building and Planning indicate.<sup>62</sup> Local governments in **Poland** received 38,128 requests for the elimination of barriers in architecture and communication for persons with disabilities. About 45 % (17,478) were granted.<sup>63</sup> This marked an increase from the approval rate of about 30 % in 2010, when 13,452 of 43,834 requests were granted.<sup>64</sup>

Slightly more information is available on numbers of persons receiving assistive devices. In **Belgium**, for example, in 2014, 11,246 persons in Wallonia, 34,415 in Flanders and 1,169 in Brussels received financial aid for assistive devices, data from the regional disability agencies show.<sup>65</sup> While this marked an increase on 2010 levels in Wallonia and Brussels, the figure fell around a quarter in Flanders.<sup>66</sup>

During 2016, 19,549 persons in **Latvia** received technical aids, while 6,889 were on a waiting list.<sup>67</sup> In comparison, in 2013 the government purchased 12,226 technical aids, issued 13,729 and repaired 901, while there were 8,828 outstanding requests for technical aids.<sup>68</sup> Unsurprisingly, the smaller populations of **Cyprus** and **Malta** mean lower numbers of assistive devices are provided. A total of 694 persons filed successful applications for assistive equipment in Cyprus in 2013.<sup>69</sup> In Malta, 374 persons obtained funds from the special apparatus fund in 2014.<sup>70</sup>



## Meeting the support needs of persons with disabilities

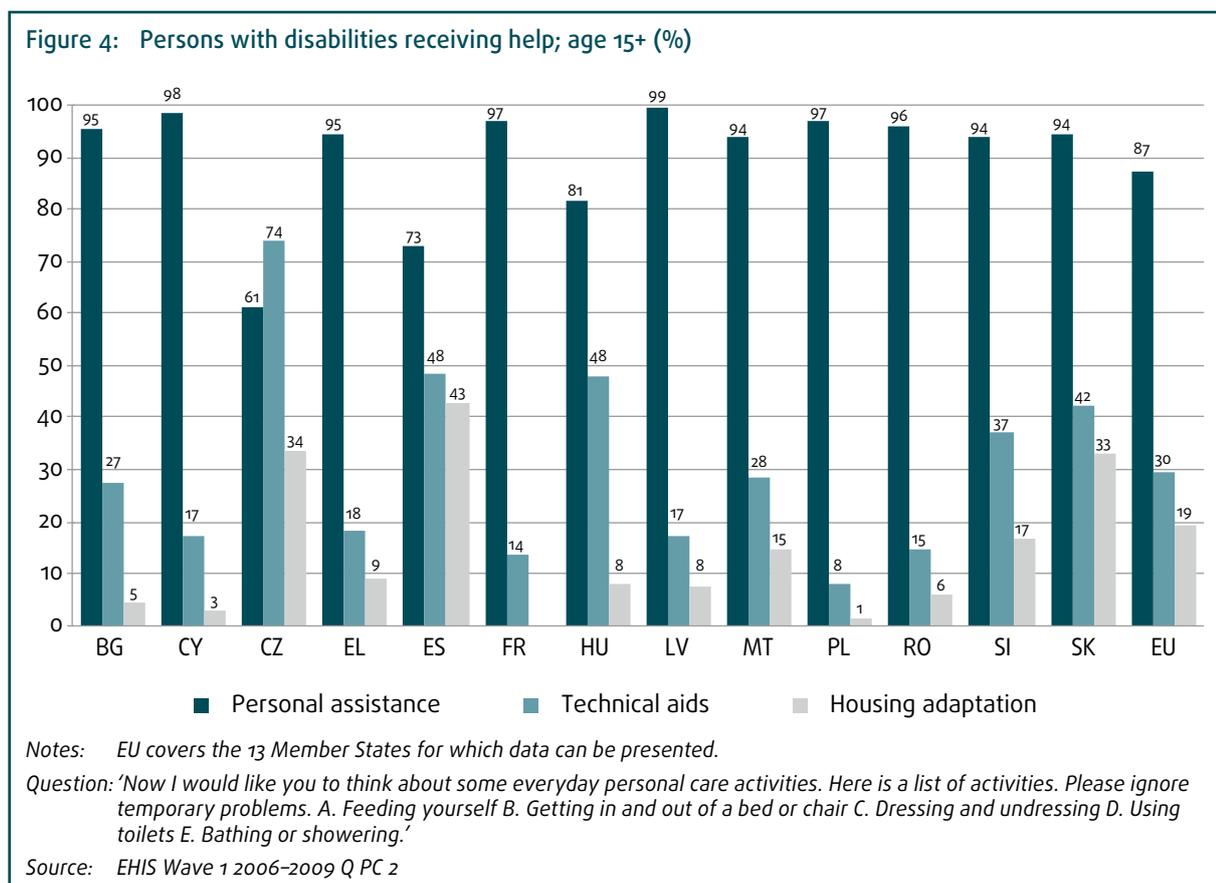
Data on user numbers tell only part of the story, however. For a fuller picture, information is needed on whether or not available services are sufficient to meet the support needs of persons with disabilities. This includes both availability and quality of services. In other words, are the necessary services available in the community and do they actually provide persons with disabilities with the necessary support?<sup>71</sup> Such data can inform policy development and the planning of services to support persons with disabilities to live independently.

FRA analysed existing data on whether or not the help that persons with disabilities receive in their home is sufficient to meet their needs. Such needs may vary according to the type of task and the type of help needed. The EHIS asked respondents if they received help with daily tasks including feeding themselves, getting into and out of a bed or chair, dressing and undressing, using toilets, and bathing or showering. It asked respondents about three types of help – personal

assistance, technical aids and housing adaptations – and then if this help was sufficient.

Two important factors need to be taken into account when reading the data on personal assistance. Firstly, it includes any help received from other persons. This covers unpaid and/or informal help, including from family members, partners or other informal supporters, as well as any paid or professional help with daily living tasks. Secondly, the assistance that these data capture may not reflect the choice and control of the person receiving the support.

In the 13 EU Member States where EHIS data are available, a large proportion (61 %) of persons with disabilities receive some help with at least one daily task. Among this group, 87 % receive help in the form of personal assistance, 30 % benefit from technical aids and 19 % from housing adaptations. Additional research is necessary to explore the particularly high level of persons with disabilities who receive help in the form of technical aids (74 %) in the **Czech Republic**. The total figures add up to more than 100 %, as individuals may receive more than one kind of help.



Despite the relatively high proportion of persons with disabilities who receive some form of help, many feel that it is not sufficient. One in four (25 %) of persons with disabilities receiving one of the forms of help included in the survey feel that this help is not enough, FRA analysis shows. Personal assistance is the main type of help that is lacking among persons with disabilities who report that they do not receive enough help. This is followed by housing adaptation and technical aids. Looking at persons with disabilities who do not already receive help, a third (33 %) declare that they need it. Of this group, the vast majority (85 %) say that they need personal assistance. Around a third say that they need technical aids or housing adaptation (33 % and 31 %, respectively).

These findings underline the importance of further developing personal assistance services, even among those who already receive some form of help. Women and older persons with disabilities who do not receive help are most likely to declare that they need more help. Particular steps to address their requirements may be necessary. Further research could also explore the gender aspects of responses, in particular whether or not women are more likely to declare a need for, and request, help than men.

**Table: Persons with disabilities receiving/ needing help; age 15+ (%)**

Persons with disabilities receiving help	Get enough help 75.1	Not enough help 24.9
Persons with disabilities not receiving help	Need Help 32.5	Do not need help 67.5
Persons with disabilities not receiving help but saying they need specific types of help	Need personal assistance 84.6	No need for personal assistance 15.4
	Need technical aids 32.9	No need for technical aids 67.1
	Need housing adaptation 31.1	No need for housing adaptation 69.0

Note: Missing values are excluded when calculating percentages.

Source: EHIS Wave 1 2006-2009 Q PC 2, PC 3 and PC 4

## Accessing community services and facilities for the general population

*“Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”*

*United Nations Convention on the Rights of Persons with Disabilities, Article 19 (c)*

The final component of Article 19 requires that services and facilities for the general population are equally available to persons with disabilities and are responsive to their needs. These include services ranging from education, transport, health and housing to public libraries, shops and cultural sites. Making such services inclusive reduces the need to develop the specialised support services required under Article 19 (b). It also increases the opportunities of persons with disabilities to participate fully in society.

Equal availability of services is closely linked to accessibility and equality and non-discrimination, as set out in Articles 9 and 5 of the convention. The CRPD Committee’s General Comment on Article 9 and its General Comment on Article 19 highlight the mutually reinforcing nature of accessibility and independent living. They underline that services are not available to persons with disabilities if they remain inaccessible.<sup>72</sup> Ensuring accessibility in practice may require reasonable accommodations in response to the needs of persons with disabilities. Reasonable accommodations include modifications and adjustments to ensure that persons with disabilities can exercise rights on an equal basis.

The importance of accessibility for making services available prompted the European Commission to propose a European Accessibility Act in 2015.<sup>73</sup> The draft act aims to set common requirements and create market opportunities for businesses that develop accessible products and services. The act makes explicit reference to Article 9 of the CRPD. If the act is adopted as proposed by the European Commission, it will cover products and services including cash machines and banking services, computers and operating systems, smartphones and telephony services, TV equipment, transport, audio-visual services, and e-books and e-commerce.<sup>74</sup>

FRA analysed data from the EU-SILC on the access of persons with disabilities to some of the most commonly available services and facilities: grocery shopping, banking, postal, primary healthcare and transport services. There are a variety of reasons why persons may lack access to such community services, including how accessible or responsive they are to persons with disabilities and the extent to which other members of the household are able to assist.

On average, persons with disabilities in the EU are more likely than other persons to have difficulty in using general services commonly available to the public. At the EU level, 43 % of persons with disabilities say they have difficulty in using at least one of the five common types of services (see previous paragraph), compared with 33 % of persons without disabilities. This difference of 10 percentage points signals that there is work to do in ensuring that general services are available to persons with disabilities on an equal basis with others and that they have the support they need to access such services.

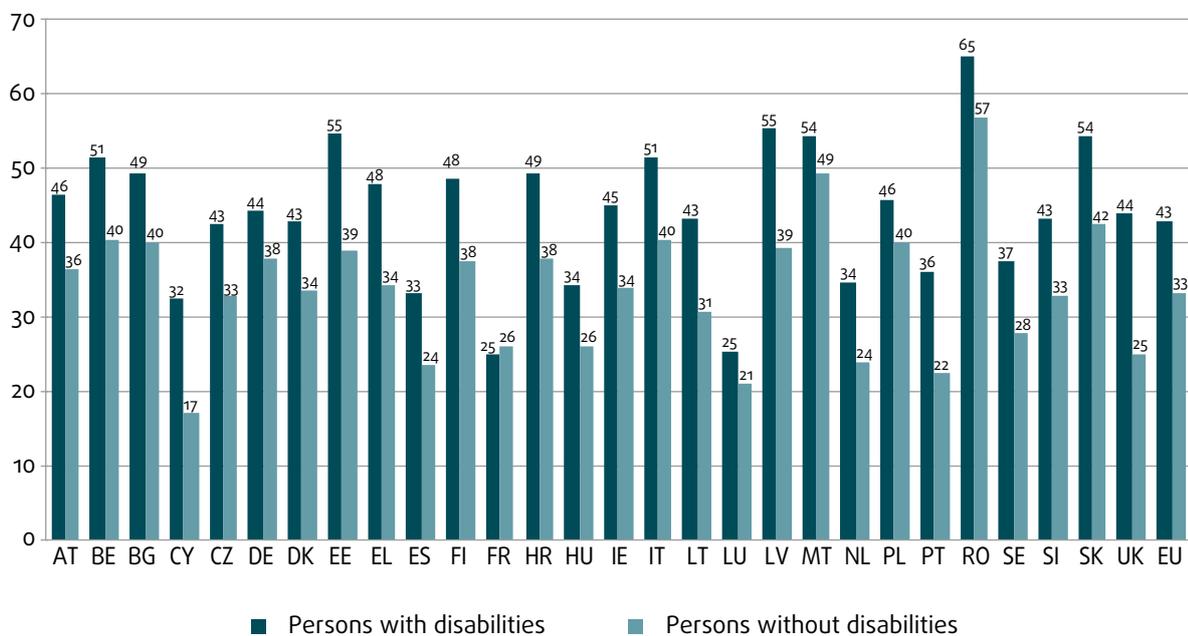
The ‘disability gap’ varies across EU Member States and different services. It is comparatively low in **Luxembourg, Malta** and **Poland**, and non-existent in France.<sup>75</sup> In contrast, persons with disabilities are at least 15 percentage points more likely to report difficulties in accessing services than persons without disabilities in **Cyprus, Estonia, Latvia** and the **United Kingdom**.

Persons with disabilities most often face difficulties accessing public transport services (26 %, compared to 19 % of persons without disabilities), postal services (25 %, compared to 18 % of persons without

disabilities), and primary healthcare services (23 %, compared to 16 % of persons without disabilities). The availability of services in the neighbourhood may play an important role in these figures – for example, reduction in local postal services linked to increased use of new information technologies. Primary healthcare services present the biggest gap between persons with and without disabilities. This gap is especially important as persons with disabilities may particularly rely on health services.

The type of household in which persons live has an impact on the difficulties they face in accessing services, highlighting the role that family members and housemates can play in helping to access services. Persons with disabilities living in single person households are much more likely to experience difficulties using one or more of the five common types of services than adults who live with other adults or with children. Age is also a significant factor when combined with household type. Almost half (48 %) of persons with disabilities aged over 65 living alone face difficulties accessing services, compared to 39 % of persons with disabilities aged under 65 living alone, and 28 % of persons without disabilities aged under 65 and living alone.

**Figure 5: Persons who live in a household having difficulty to access at least one service (grocery services or banking services or postal services or primary healthcare services or public transport); age 16+ (%)**



Note: Question: HC090–130 Possible answers are: 1 With great difficulty, 2 With some difficulty, 3 Easily, 4 Very easily. Aspects linked to the prices, like the affordability, should not be considered. Only the physical access and the adequacy of the opening hours should be taken into account but technology enabled access may be considered (by internet, phone etc.).

Source: EUSILC UDB 2012 – version 4 of January 2016 (HC090, HC100, HC110, HC120, HC130)

Another EU survey, the 2012 Flash Eurobarometer, looked at Europeans' perception of the accessibility of general community services for persons with disabilities, collecting data from a representative sample of the general population. The survey shows that almost all respondents (93 %) agree that barriers make it more difficult for persons with a disability to attend schools, to have a job, to vote and/or to freely move around and go on holiday, all components of being able to participate in society on an equal basis with others. In addition, almost all respondents agree that public authorities (96 %) and manufacturers and service providers (93 %) should be required to provide and sell goods and services that are accessible to persons with disabilities.<sup>76</sup>

## The need for more and better data

Reliable, accurate, timely and comparable data are crucial for effective, evidence-based policymaking. Failing to collect disaggregated statistical and other data capturing the independent living outcomes of all persons with disabilities, regardless of the type and severity of their impairment or place of residence, is likely to undermine reforms and impede efforts to meet their needs. It is also indispensable to measuring progress in implementing the right to independent living.

The CRPD includes a specific provision – Article 31 – requiring States Parties to “collect appropriate information, including statistical and research data” to enable policymakers “to formulate and implement policies to give effect to the [convention]”. These data can in turn support and facilitate the development and application of human rights indicators to measure CRPD implementation.

In practice, however, living up to this commitment presents a challenge and significant data gaps remain. The CRPD Committee has repeatedly noted the lack of comprehensive and comparable data on persons with disabilities in its recommendations to both the Member States and the EU. It also consistently calls on States Parties to “pay attention to the links between Article 31 of the Convention and target 17.18 of the Sustainable Development Goals to increase significantly the availability of high-quality, timely and reliable data disaggregated by, inter alia, sex, age and disability”.<sup>77</sup>

The Sustainable Development Goals are 17 globally-agreed objectives to help eradicate poverty and achieve sustainable development by 2030, which the EU “is determined to fully implement [...] across the range of its internal and external policies”.<sup>78</sup>

*“The Committee recommends that the European Union develop a human rights based indicators system in cooperation with persons with disabilities and their representative organizations, as well as a comparable comprehensive data collection system, with data disaggregated by gender, age, rural or urban population and impairment type.”*

*CRPD Committee (2015), Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1, 2 October 2015, para. 73*

In the course of developing and applying FRA's human rights indicators on Article 19 of the CRPD, the agency analysed the information from a range of sources, including national administrative registers, monitoring reports and European-wide surveys, as well as data provided directly by public authorities. This experience reveals a number of particular issues with respect to data collection and availability (see also the parallel report *From institutions to community-living: funding and budgeting*). These reinforce the findings of FRA's previous indicator work on the right to participation in political and public life (Article 19 of the CRPD), highlighting areas policy actors need to address.

Several issues relate specifically to data availability:

- Lack of publicly available data, meaning that information needs to be specifically requested from relevant authorities.
- No systematic compilation of data at the national level, particularly where responsibility for relevant services is decentralised. This makes it difficult to provide a complete picture across the country.
- Where data on specific social services are collected, they are rarely disaggregated by categories of beneficiaries, making it impossible to identify the number of persons with disabilities using a particular service.
- Where they are available, data are often disaggregated by age groups and gender, but rarely with regard to type or degree of impairment.



Other issues concern the comparability of data within and between Member States:

- A lack of commonly agreed definitions means that there is a lack of consistency in the terms used to refer to services for persons with disabilities, impeding comparisons across and sometimes even within EU Member States.
- The very broad range of potential sources of relevant information includes data collected using different methodologies, covering different time-frames, and with widely varying scope and levels of detail.

A last set of issues relate to whether existing data collection methodologies can adequately capture and reflect the experiences of persons with disabilities:

- There is a profound lack of data on the number of persons with disabilities living in institutions. This includes administrative data, which are often incomplete or out-of-date, and statistical data that draws on surveys based on private households to the exclusion of institutions.

- Methods for collecting survey data may exclude some persons with disabilities. For example, persons with hearing impairments may not be able to participate in surveys conducted by phone, persons with visual impairments may have difficulties completing paper surveys or online surveys that are not screen-reader compatible, and persons with intellectual disabilities may not be able to complete surveys that are not available in easy-read format.
- Information about persons with disabilities' experiences of independent living is absent –for example, on the quality of services they receive.

Taken together, these issues impede a systematic assessment of progress in implementing the right to independent living. It is therefore necessary to improve the existing methodological arsenal and provide adequate resources to ensure the provision of targeted, comparable data – broken down by age, gender, and type and severity of impairment – that can accurately and reliably populate indicators showing how the rights of persons with disabilities are fulfilled.



# Conclusions

Realising the right to independent living has profound implications for persons with disabilities. It means that persons with disabilities can exercise choice and control over their living arrangements, the support they use and the community services they can access, putting them at the centre of decisions about their lives. This represents a repudiation of the paternalistic models of 'care' that have long dominated how persons with disabilities and the services they may require are viewed.<sup>79</sup>

*"Article 19 reflects the essence of the Convention, in which persons with disabilities are regarded as subjects of rights. [...] Fulfilment of the obligations under Article 19 [...] provides the conditions for the full development of the personality and capabilities of persons with disabilities."*

OHCHR (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community*, A/HRC/28/37, para. 6

This report shows that there is still a long way to go before the right to independent living is fully implemented in the EU. Limited choices about where to live, a lack of available and appropriate support services, and barriers to accessing general services available in the community combine to prevent persons with disabilities from participating in the community on an equal basis with others. But the report also charts a way forward, by indicating how policymakers can collect and make use of data to inform their policies and measure progress made. Common efforts by EU and national data collection systems to gather harmonised, standardised and regular data can play a crucial role in informing and guiding actions to make independent living a reality for persons with disabilities in the EU.



# Annex 1: FRA's human rights indicators on Article 19 of the CRPD

FRA's human rights indicators aim to enable assessment of the fulfilment of Article 19 of the CRPD. They also highlight gaps in the availability of data in the 28 EU Member States.<sup>80</sup> The information to apply them stems from two strands of data collection. Part of the research was based on desk research drawing together data from publicly available sources, or through direct contact with national authorities. The statistical information draws on three existing EU social surveys.

## Outcome indicators based on national data

Some of the indicators are based on data collected by FRA's research network (Franet) through publicly available sources or through specific information requests to public authorities. The analysis presents information in relation to three outcome indicators in relation to the number, and increase and decrease over the last five years, of: (1) persons with disabilities living in residential institutions; (2) persons with disabilities using support services; and (3) persons with disabilities who were granted physical adjustments or assistance devices for their place of residence. The lack of available data means that others of FRA's outcomes indicators on Article 19 cannot currently be applied.<sup>81</sup>

## Statistical outcome indicators

In parallel, FRA developed statistical outcome indicators based on existing data available from several multinational European social surveys.<sup>82</sup> This built on FRA's work – in cooperation with the European Commission-funded Academic Network of European Disability Experts – to populate indicators relevant to Article 29 of the CRPD on participation in political and public life.<sup>83</sup> By adopting a comparative statistical approach drawing on existing data from European social surveys, the aim is to provide new indicators for use in multinational rights monitoring.<sup>84</sup>

## Development of the indicators

The indicators are based on four components of Article 19, namely: cross-cutting issues, living arrangements, support services (for persons with disabilities) and general services (available to the public). On this basis, FRA conducted an extensive mapping of possible data sources and relevant variables. The selected indicators seek to measure choice and control in community living, inclusion and participation, isolation and segregation, and access to services.

## Relevant European social surveys

This report presents five of these outcome indicators from three European population-based surveys: the European Statistics of Income and Living Condition (EU-SILC)<sup>85</sup>; the European Health Interview Survey (EHIS)<sup>86</sup> and the European Quality of Life Survey (EQLS).<sup>87</sup>

The main report presenting the statistical outcome indicators will provide a detailed assessment of the data quality for each survey and the 12 separate indicators against four criteria: objective and relevance, accuracy, comparability, and availability.<sup>88</sup> A brief summary of the overall issues suffices here:

- **Objective and relevance:** Each indicator provides an estimate of outcomes for persons with disabilities, compared to other persons and contextualised with reference to other explanatory factors. Taken together, they measure a wide range of outcomes in terms of independence and inclusion for persons with disabilities living in the community, and the extent to which these are equal with other persons. They are highly relevant to policymakers and rights monitors in establishing the extent of unequal outcomes and potential areas of policy intervention.

- **Accuracy:** The indicators derive from existing European social surveys that are subject to quality assurance by national statistical offices or other agencies administering the surveys. Overall, all of the indicators draw on data from well-established and high quality social surveys with sufficiently large samples to provide meaningful results
- **Comparability:** The analysis gave priority to surveys covering all 28 EU Member States and yielding statistically valuable results. For example, although both the EU-SILC and the EQLS cover all Member States, the sample of the EU-SILC is much more robust, mainly due to a significantly larger sample size. As such, EU-SILC enables much more refined analysis – for example, by gender, age, education, etc.
- **Availability:** Microdata from the different surveys are available to the public or on request for academic research. Given the added value of new indicators, the analysis prioritised information not yet published in this form by other studies. It gave precedence to surveys that allow for the analysis of trends, or which provide a baseline for such comparison in the future.

## Definition of disability

In common with Eurostat-administered surveys and with other studies in this field, the indicators are based on the survey ‘definitions’ of disability, which focus on “disability measured through a concept of general activity limitation”.<sup>89</sup>

Each survey used for these indicators includes a broadly similar question that is used to disaggregate outcomes for persons with and without ‘limitations’, as a proxy for persons with or without disabilities. EQLS asks ‘Do you have any chronic (long-standing) physical or mental health problem, illness or disability?’ If the respondent answers ‘Yes’, the following question on limitations is asked: ‘Are you limited in your daily activities by this physical or mental health problem, illness or disability?’ In the EU-SILC and EHIS, the two questions are presented but not linked. Unless otherwise stated, indications for persons with disabilities include persons declaring severe or moderate limitations in everyday activities. While this is not wholly equivalent to the UN CRPD definition of ‘persons with disabilities’, it is the established approach to measurement used in most statistical studies and in Eurostat’s disability database.<sup>90</sup>

## Data analysis

Each indicator provides an estimate of outcomes for persons with disabilities, compared to other persons and contextualised with reference to other explanatory factors. Where possible, data are disaggregated by gender, age and severity of impairment. Further analysis by education level, economic status, urbanisation and household type was conducted where relevant. This analysis is included in the main report of the statistical outcome indicators.

Analysis is presented for the EU and, where possible, for individual Member States. Sample sizes mean that breakdowns by variables such as age and education level are typically not possible at the national level.



# Annex 2: FRA's project on the right to live independently and be included in the community

FRA has a mandate to provide assistance and evidence-based expertise to EU institutions and Member States when they implement EU law and policy.<sup>91</sup> This includes EU action to implement the CRPD, which the EU accepted in 2010. FRA has provided evidence and expertise concerning implementation of the CRPD in a number of key areas, including political participation,<sup>92</sup> legal capacity,<sup>93</sup> involuntary placement and treatment,<sup>94</sup> independent living,<sup>95</sup> non-discrimination<sup>96</sup> and violence against children with disabilities.<sup>97</sup>

In this context, FRA started work in 2014 on a project exploring how the 28 EU Member States are fulfilling the right to independent living. It specifically focuses on deinstitutionalisation. This project incorporates three interrelated activities:

- Mapping what types of institutional and community-based services for persons with disabilities are available in the 28 EU Member States. This mapping provides EU and national policy actors with baseline information to help them to identify where to focus their efforts to promote the transition from institutional to community-based support. A summary overview of this mapping was published in October 2017.<sup>98</sup>
- Developing and applying human rights indicators to help assess progress in fulfilling Article 19 of the CRPD and to highlight gaps in current provision and availability of data in the 28 EU Member States.<sup>99</sup> These indicators were also published in October 2017.<sup>100</sup>
- Conducting fieldwork research in select EU Member States (Bulgaria, Finland, Ireland, Italy and Slovakia) that are at different stages of the deinstitutionalisation process to develop a better understanding of the drivers of and barriers to the transition from institutional to community-based support for persons with disabilities. The findings of this in-depth research will come out in 2018.

This report examines the evidence gathered under the second activity: developing and applying human rights indicators on the right to independent living.

## Developing and applying human rights indicators

FRA's indicator-related work is based on the framework for human rights indicators that the OHCHR developed.<sup>101</sup> FRA first used this model for the CRPD in 2014, when it developed and applied human rights indicators to Article 29 of the CRPD on the right to take part in political and public life.<sup>102</sup>

FRA's project on the right to independent living of persons with disabilities broadly corresponds to the three main elements of the OHCHR indicator framework. This framework is based on three clusters of indicators: (1) structural indicators focusing on the State's acceptance and commitment to specific human rights obligations; (2) process indicators on the State's efforts to transform commitments into desired results; and (3) outcome indicators measuring the results of these commitments and efforts on individuals' human rights situation.

The three reports stemming from the FRA indicators on Article 19 of the CRPD reflect this approach. The first report in the series focuses on structural commitments to achieving deinstitutionalisation. The second report focuses on financing and highlights Member States' budgetary efforts to implement these commitments. The present report assesses the situation on the ground.



# Endnotes

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## HELPING TO MAKE FUNDAMENTAL RIGHTS A REALITY FOR EVERYONE IN THE EUROPEAN UNION

All but one of the EU Member States, and the EU itself, have ratified the CRPD, committing themselves to achieving independent living for persons with disabilities. Doing so requires a meaningful and sustainable shift from institutional to community-based living arrangements. This report is the final report in a series of three reports on different aspects of deinstitutionalisation. The first and second reports highlight the obligations the EU and its Member States have committed to fulfil, and look at how funding and budgeting structures can turn these commitments into reality. This report assesses to what extent Member States have implemented the right to independent living, focusing on the effect commitments and funds are having on persons with disabilities' daily lives. Taken together, the reports provide important insights that can support ongoing processes of change.

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