

**Data sources for outcome indicators  
on Article 19:**

# **Living independently and being included in the community**



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The *Data Sources Guidance* was produced with the financial support of the European Union. Its contents are the sole responsibility of OHCHR and do not necessarily reflect the views of the European Union.



## **19.27 Number and proportion of adult persons with disabilities heads of household disaggregated by sex, age, disability and kind of entitlement (owner, tenant, etc), as compared to other persons.**

*Level 2: Indicator that could be produced with straightforward additions or modifications to existing data collection efforts*

The concept of head of household may be considered as a proxy indicator that illustrates, to some extent, that persons with disabilities are exercising choice when it comes to living arrangements and living independently. This is relevant given the complexity of assessing the subjective element of choice, particularly where options and resources are limited.

All household surveys (e.g. HIES, DHS, MICS) have a roster that records data on the household members' relationship to the household head. As long as the survey includes questions on disability, this indicator can be produced. Therefore, most countries should already be capable of producing the indicator, even if they have yet to do so.

One country that has reported on this indicator is Palau, where out of the 4955 total household heads, 154 (3 per cent) were persons with disabilities, according to the [2017 Palau Disability Report](#).

## **19.28 Number of persons living in social housing, disaggregated by sex, age and disability.**

*Level 2: Indicator that could be produced with straightforward additions or modifications to existing data collection efforts*

This information could be obtained using the administrative data from housing programs, provided that disability status is recorded. The example in table 1, from the United States of America, records the characteristics of households who reside in public housing or who receive rental assistance. The data comes from the Inventory Management System at the U.S. Department of Housing and Urban Development. Given that information on the number of household members is recorded, it would be straightforward to convert the data into the number of persons.

**Table 1: United States Housing and Urban Development Resident Characteristics Report, June 2020**

	Number of residents	Per cent of Total
<b>Family Type</b>		
Elderly, no children, non-disabled	127,053	16%
Elderly, with children, non-disabled	5,042	1%
Non-elderly, no children, non-disabled	117,213	14%
Non-elderly, with children, non-disabled	249,613	31%
Elderly, no children, disabled	141,805	17%
Elderly, with children, disabled	5,894	1%
Non-elderly, no children, disabled	130,151	16%
Non-elderly, with children, disabled	39,034	5%
Per cent of households in social housing units with a member with a disability		39%

Source: U.S. Department of Housing and Urban Development, *Residents Characteristics Report* (2020)

Notes: Terms used according to source

Another alternative is to use a survey. In the United Kingdom of Great Britain and Northern Ireland, relevant information was collected in the Annual Population Survey. This survey, available at <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilityandhousinguk/2019#housing-situation-by-disability>, reports that 24.7 per cent of persons with disabilities live in socially rented housing, as opposed to 8.2 per cent of persons without disabilities.

## **19.29 Number and proportion of adults with disabilities reporting satisfaction with their level of independence in their living arrangement, disaggregated by sex, age and disability.**

### ***Level 2: Indicator that can be produced with existing data but has not been reported on***

Self-reporting assessments within disability and/or quality of life surveys or studies can be useful in capturing the level of satisfaction of persons with disabilities with their living arrangements and level of independence, as a means to provide a proxy indication on the extent of the exercise of choice.

The WHO Model Disability Survey has a series of questions about satisfaction, such as “How satisfied are you with the conditions of your living place?”. It also contains questions about empowerment, including on how much control the person has over their life. These questions



can be found in modules 7000 and 8000, at <https://www.who.int/disabilities/data/model-disability-survey4.pdf?ua=1>.

Many other surveys could be adapted to produce this indicator and are already producing related indicators, such as:

- The [Household, Income and Labour Dynamics in Australia Survey \(HILDA\)](#), which includes disability questions and questions about relationships with partners and children, amount of free time, feeling part of the local community and overall life satisfaction. It does not specifically ask about the level of independence or living arrangements.
- [The Italian Disability Survey](#) which asks about satisfaction with relationships with friends and relatives, economic conditions and leisure time but not about independence.
- The [European Social Survey](#) which asks about personal and social well-being, in round six of the survey, but not about disability. The respondents are asked to agree or disagree with the statement, “I feel free to decide how to live my life,” using a Likert scale.
- The Survey of Health, Ageing and Retirement in Europe asks about both disability and satisfaction, but only for those aged 50 and over. A study using this survey can be found at [https://www.netspar.nl/assets/uploads/P20160622\\_msc014\\_Zoetemeijer-1.pdf](https://www.netspar.nl/assets/uploads/P20160622_msc014_Zoetemeijer-1.pdf).
- In the United States of America, the [National Core Indicators Project](#) surveys people receiving support from state intellectual disability agencies. The In-Person Survey includes questions about choice, including “Did you choose (or pick) the people you live with (or did you choose to live by yourself)? Did you choose (or pick) the people you live with (or did you choose to live by yourself)?”.

## **19.30 Number and proportion of persons with disabilities accessing community-based support services, including personal assistance, out of the total number of requests made, disaggregated by sex, age and disability and support service provided.**

*Level 1: Indicator for which data are already being produced and reported on in at least some countries*

There are several surveys that report on the number and proportion of people accessing community-based support. A [survey from Australia](#) additionally collects data on support needed, so that unmet needs can be estimated and on the satisfaction with the assistance received. As an example, table 2 shows the proportion of children needing assistance by type.

**Table 2: Percentage of children aged 0-14 needing assistance by type, Australia, 2018**

Health care(c)	27.9
Self-care	32.0
Mobility	36.1
Communication	38.2
Cognitive or emotional tasks	59.3

Source: Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings* (2019).

Of the 264,300 children with disabilities aged 0-14 needing assistance, represented in table 2, 256,800 (roughly 97 per cent) received some assistance. Children with disabilities needing assistance were most likely to receive help with cognitive or emotional tasks (77.4 per cent), while almost half received assistance with communication (48.1 per cent) and mobility (45.3 per cent).

Spain collects similar data on applications for assistance, assessment resolutions, beneficiaries entitled to benefits, beneficiaries with recognized benefits and the type of services obtained (prevention of dependency and promotion of autonomy, personal, residential care, day and night centres, home help, telecare, etc.). This data is available at <https://www.ine.es/dyngs/IOE/es/operacion.htm?id=1259931141438>.

The [WHO Model Disability Survey](#) asks respondents about their need for support. It does not, however, report whether the support asked for or needed was provided. This survey asks, for example:

Does [NAME] need physical care or support, such as help with eating, dressing, bathing, moving around the house or assistance outside the house such as for using transportation?

Does [NAME] need emotional care or support, such as comfort, advice or counselling?

Another example, from the United States of America, is from the Kaiser Family Foundation, which annually surveys state Medicaid agencies. Table 3 presents an extract of collected information. The complete results table is available at <https://www.kff.org/health-reform/state-indicator/participants-by-hcbs-waiver-type/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.

**Table 3: Number of people receiving services from Medicaid Home and Community Based Waiver Services, United States, 2018**

Type of Waiver	Number of people receiving Medicaid Home and Community Based Services
Intellectual and Developmental Disabilities	785,800
Aged	162,500
Aged/Disabled	667,000
Physically Disabled	128,200
Children	17,100
HIV/AIDS	3,600
Mental Health	25,100
Traumatic Brain Injury/Spinal Cord Injury	17,500
<b>Total Participants</b>	<b>1,806,800</b>

Source: Kaiser Family Foundation, *Medicaid Section 1915(c) Home and Community-Based Services Waivers Participants, by Type of Waiver* (2018)

Note: Type of waiver as specified by the source.

Theoretically, this indicator could also be obtained through administrative data. Though no examples were found, it could be that some administrative systems could support this indicator. For example, the United States of America provides community-based support services through Medicaid Home and Community Based Waiver Services, via funds sent to states. Expenditure data for the program is collected at the federal level, but the number of persons receiving services is held at the state level. States have records of the number of people on the waitlist for services, but many do not share their waitlists publicly, as can be found at <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?current-Timeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>. The program does, however, share some statistics on the type of disabilities reported, as well as on the type of services used, at <https://www.macpac.gov/wp-content/uploads/2018/06/Medicaid-HCBS-Characteristics-and-Spending.pdf>.

## 19.31 Number and proportion of persons with disabilities provided with assistive devices and technologies for independent living, out of the total number of requests made, disaggregated by sex, age, disability and assistive product provided.

*Level 1: Indicator for which data are already being produced and reported on in at least some countries*

[Australia fields a survey](#) collecting this data. According to the 2018 survey, 53.1 per cent of the population used aids or equipment because of their condition. This varied by type of living arrangement, with 58.3 per cent of respondents living alone using aids, 49.3 per cent of respondents living with others using aids, and 94.8 per cent of respondents living in cared accommodations using aids. The survey also reports on the type of aids used.

The [WHO Model Disability Survey](#) is an example of a survey that could collect similar information. It makes the distinction between needed services and supports and actually obtaining those services and supports.

A [survey from Turkey](#) reports on supports and accommodations at work. A sample of findings is reproduced in table 4. Such a survey could be expanded to look at assistive technology and supports in all aspects of life.

**Table 4:** Percentage of working conditions/arrangements needed by registered disabled individuals at the job which working/able to work by type of disability, Turkey, 2010

Working conditions / arrangements	Total	Visual disability	Hearing disability	Language and speech disability	Orthopaedic disability	Intellectual disability	Mental and emotional disability	Chronic illness	Multiple disability
	Working jobs which are not required any heavy physical works or powers	55.7	49.8	42	49.3	66.3	47.3	41.4	64.8
Taking more short breaks during the working time because of health problems	33.3	27.2	27.3	36.6	34.4	25.6	37.4	39.9	35.5
Working part-time jobs	27.6	26.5	24.9	26.1	26.7	31	30.8	26.1	29.6
Getting supports from someone at some stages of the work	16.2	17	26.2	24	14.2	18.9	19	10	19.4



Working conditions / arrangements	Total	Visual disability	Hearing disability	Language and speech disability	Orthopaedic disability	Intellectual disability	Mental and emotional disability	Chronic illness	Multiple disability
Using official permissions more than 30 days for treatments	16	16.8	12.8	16.1	18.6	6	13.5	20.1	16.4
Working jobs which do not include any business travels or field studies	13.5	14.4	16.1	17.6	17.8	6.5	14.6	14.4	10.8
Working jobs at the home	13.5	15	14.8	16.6	10.3	20.6	15.4	10.7	13.2
Using special supports and equipment for performing affairs	10.7	17.4	19.5	17.7	11.2	8.5	4.7	6.3	9.7

Source: Turkish Statistical Institute, “Survey on Problems and Expectations of Persons with Disabilities”, 2010

In countries that provide assistive technology, data on the number of people requesting them could also come from administrative data. According to a report on assistive technology provision, available at <https://www.tandfonline.com/doi/full/10.1080/17483107.2018.1470264>, in middle- and low-income countries assistive technology provision mostly occurred via non-governmental organizations, with limited reach and a narrow scope of assistive products (e.g., wheelchairs or prosthetics). This fragments the market and masks part of the needs for assistance. A possible exception is the Nordic countries, who have a governmental provision of assistive technology. However, data from those countries could not be found.

### **19.32 Number and proportion of persons with disabilities currently residing in institutions (e.g. psychiatric inpatient settings, residences for persons with intellectual disabilities, etc. from large scale facilities to group homes), disaggregated by sex, age, disability, and type of institution/facility.**

*Level 3: Indicator for which acquiring data is more complex or requires the development of data collection mechanisms which are currently not in place.*

A major European study, “[Deinstitutionalisation and community living – outcomes and costs](#)”, was undertaken in 2007 and found that, in many countries, even when data existed at a regional or local level (generally through administrative records), they were not necessarily collected at a national level.

While the data in the report is outdated, it provides a good example of how to encourage countries to report on this issue. Most European countries do not routinely collect the data reported but did so specifically for this study, see those [country reports](#).

An example of the relevant table from the report for Bulgaria can be found in table 5.

**Table 5: Bulgaria: Data available by service type – breakdown by gender and age, 2001-2005**

Type of institution	Total	Gender			Age			
		Male	Female	Gender unspecified	Children	Younger adults	Adults over 18	Age unspecified
Homes for children and adolescents with mental retardation	1,766	920	693	153	1,766			
36-week residential schools for children with sensory disabilities and intellectual disabilities	2,856				2,856			
Homes for children and adolescents with physical disabilities	130	43	29	58	130			
Social-vocational training institutions	1,347	541	267	539		1,347		
Wards in homes for medical-social care for children	1,213							1,213
Group homes	120							120
Social vocational boarding schools								
Psychiatric wards in hospitals								
Homes for adults with sensory disabilities	148	47	85	16			148	
Homes for adults with mental retardation	2,513	1,220	1,200	93			2,512	
Homes for adults with physical disabilities	1,800	760	724	316			1,600	200
Homes for adults with dementia	869	352	386	738			869	

Type of institution	Total	Gender			Age			
		Male	Female	Gender unspecified	Children	Younger adults	Adults over 18	Age unspecified
Homes for adults with psychic disorders	1,376	549	799	28			1,376	
Psychiatric hospitals								
Totals	14,138	4,432	4,183	465	4,752	1,347	6,506	1,533

Source: Julie Beadle-Brown and Agnes Kozma, eds., *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*, vol. 3, *Country Reports* (Canterbury, Tizard Centre, University of Kent, 2007), p. 41

Notes: Categories as specified in the source.

Macedonia’s “National Deinstitutionalisation Strategy of the Republic of Macedonia 2018–2020 ‘Timjanik’ and its Action Plan”, sets out data on the number of children and adults in institutional care, as presented in table 6.

**Table 6:** Macedonia: Number of children and adults in institutional care by degree of disability (2005)

Group	Number of residents in institutional care
Children with disabilities	42
Children with social difficulties	200
Children without parental care	146
Children with social and educational difficulties/children in conflict with the law	54
Adults with disabilities (under 65 years)	356 in institutions plus 122 in old age homes
Adults with long-term mental health difficulties or distress	650 beds
Old age	988
Total	2,358

Source: The Republic of Macedonia Ministry of Labour and Social Policy, *National Deinstitutionalisation Strategy of the Republic of Macedonia for 2018–2027 ‘Timjanik’ & Action plan* (Skopje, 2018), p.20

A more recent [report from Finland](#) shows that at the end of 2018, the total number of clients of non-round-the-clock services for those with “mental disabilities” in supervised and supported housing was 3,735. There were 1,859 customers in supervised housing, which was 6.4 per cent less than in 2017. At the end of 2018, there were 1,876 residential clients and the number of clients remained almost the same as in the previous year. At the end of 2018, there were a total of 631 clients in “institutions for the mentally handicapped”, which was 14.6 per cent

less than in the previous year. The number of assisted housing clients with intellectual disabilities increased by 2.1 per cent and was 8,664 at the end of 2018. A reported 89 per cent of institutional care clients were housed in a public service provider.

### **19.33 Number and proportion of persons with disabilities who have left institutions (e.g. psychiatric inpatient settings, residences for persons with intellectual disabilities, etc.) and entered into independent living arrangements, out of the total of persons with disabilities institutionalized, disaggregated by sex, age and disability.**

**and**

### **19.34 Number and proportion of persons with disabilities released from institutions and provided with community based support services, including personal assistance, to the extent requested by the person, disaggregated by sex, age and disability and support service provided.**

*Level 1: Indicator for which data are already being produced and reported on in at least some countries.*

The United States of America has used administrative data that can capture this indicator. The Centers for Medicare and Medicaid Services - the agency providing funding for people with Intellectual or Developmental Disabilities institutions and home and community-based services - had a “money follows the person initiative” to move people living in nursing homes or institutions into the community, with appropriate services. The federal government gave grants to states, which were then required to submit an annual report that included the number of people transitioned.

The first transitions occurred in late 2007. As of June 2018, 91,540 institutional residents had transitioned in 44 states and the District of Columbia. Some 14,856 of these were persons with Intellectual or Developmental Disabilities, who moved from either institutions for people with intellectual disabilities or nursing homes into community settings, such as their own home, a family home, or a small group setting. The remaining 76,684 persons had physical, mental, or

adult-onset cognitive disabilities and were primarily transitioned out of nursing homes. For a report on these data see consult the publication at <https://heller.brandeis.edu/community-living-policy/images/pdfpublications/2019julyevidencefortheimpactofmfp.pdf>.

## **19.35 Number of persons with disabilities using mainstream services, and proportion out of the total of service users, disaggregated by sex, age, disability, and type of service, as compared to other persons.**

*Level 2: Indicator that can be produced with existing data but has not been reported on*

This indicator seeks to gather information across different mainstream services (e.g. governmental administrative services, education, health) and contributes to giving an overall picture of their inclusiveness and responsiveness to persons with disabilities.

The [World Report on Disability](#) states that “Administrative data collections can provide information on users, types and quantity of services and cost of services. In mainstream administrative data collections, standard disability identifiers can be included to monitor access to services by people with disabilities.”

A result in which the proportion of users with disabilities is similar to the proportion of persons with disabilities in the total population (considering age, geographical coverage, etc.) could indicate inclusive delivery of the specific service; e.g. enrolment rate of persons with disabilities in regular education indicates inclusiveness of the education system. However, several other factors come into play, including the particular purpose or characteristic of the service (e.g. it might be the case that persons with disabilities represent a higher proportion of users of rehabilitation services).

Elements of this indicator can be drawn from a series of indicators across various articles, related to different government services, including Education (24.27, 24.28), Health (25.22), Rehabilitation (26.11, 26.12) and Social protection (28.16).



## 19.36 Number and proportion of requests for reasonable accommodation granted to persons with disabilities in using mainstream services.

*Level 2: Indicator that can be produced with existing data but has not been reported on*

Administrative data systems for managing reasonable accommodation funds or for registering requests for reasonable accommodations can be used as a source for these data. However, no examples of countries reporting on this were found.

## 19.37 Level of satisfaction of persons with disabilities with mainstream services disaggregated by type of service, sex, age and disability.

*Level 2: Indicator that could be produced with straightforward additions or modifications to existing data collection efforts*

As mentioned in Indicator 19.31, [Australia fields a survey](#) collecting information from this indicator. The country also fields a [Local Government Community Satisfaction Survey](#) which includes questions on the services received by the elderly population. While it does not ask about disability-related services, it could easily be adapted to do so.

The United Kingdom of Great Britain and Northern Ireland fields a [local government satisfaction survey](#) that asks about local services for children and the elderly. While it does not ask about disability-related services, it could easily be adapted to do so.

Moreover, as with indicator 19.35 and 19.36, this indicator can be drawn from indicators from other articles, looking at satisfaction within various services.

The [Gallup World Poll](#) is an example of a source that looks across sectors. Based on a representative sample of 1000 citizens in each country, it asks about the level of satisfaction with health care, education and justice system and police. However, it does not have disability data, and to allow for disaggregation by disability the sample would have to be larger.

Many surveys ask about satisfaction with health care. A list of the surveys that allow cross-national comparisons of patient satisfaction can be found at [https://www.ncbi.nlm.nih.gov/books/NBK464781/pdf/Bookshelf\\_NBK464781.pdf](https://www.ncbi.nlm.nih.gov/books/NBK464781/pdf/Bookshelf_NBK464781.pdf). Most of these surveys do not include disability.

In the United States of America, both the [Medicare beneficiary survey](#) and the [National Health Interview survey](#) include disability questions and questions about satisfaction with health care