Data sources guidance for outcome indicators on article 19:

Living independently and being included in the community

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19.28: Number and proportion of adults with disabilities who are heads of households, disaggregated by sex, age, disability and type of entitlement (owner, tenant, etc.), as compared to other persons

Level 2: Indicator can 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. Household Income and Expenditure Surveys, Demographic and Health Surveys and Multiple Indicator Cluster Surveys) have a roster that records data on household members' relationship to the household head. If the survey includes questions on disability, this indicator can be generated. Therefore, most countries should already be capable of generating the indicator, even if they have yet to do so.

One country that has reported on this indicator is Palau, where out of the 4,955 total household heads, 154 (3 per cent) were persons with disabilities, according to the 2017 Palau Disability Report.

19.29: Number and proportion of adults with disabilities reporting satisfaction with their level of independence in their living arrangements, disaggregated by sex, age and disability

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

Self-reporting assessments within disability 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 of the extent to which they are free to choose their living arrangements.

The model disability survey, developed by the World Health Organization (WHO) and the World Bank, contains 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.

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

The Household, Income and Labour Dynamics in Australia Survey, 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. Respondents are not asked specifically about their level of independence or living arrangements;

The disability survey in Italy, in which respondents are asked about their satisfaction with relationships with friends and relatives, economic conditions and leisure time, but not about independence;

The European Social Survey, in which, in the sixth round of the survey, respondents are asked about personal and social well-being, but not about disability. They 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, in which respondents are asked about both disability and satisfaction, but only for those aged 50 years and over. One study using this survey is "Life satisfaction of disabled and non-disabled elderly in Europe" by Jelle Zoetemeijer;

The National Core Indicators project, which surveys persons in the United States of America who are 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)?"

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, 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 with data on the number and proportion of persons gaining access to community-based support. A survey from Australia additionally collects data on the support needed, so that unmet needs can be estimated, and on the satisfaction with the assistance received. Table 1 shows the proportion of children needing assistance by type.

Table 1: Percentage of children aged 0-14 needing assistance by type, Australia, 2018

Type of assistance	Percentage
Health care *	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.

*Children aged 5 years and over.

Of the 264,300 children with disabilities aged 0–14 years needing assistance, represented in table 1, 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 types of services obtained (prevention of dependency and promotion of autonomy, personal care, residential care, day and night centres, home help, telecare, etc.). The data are available on the website of the Instituto Nacional de Estadística.

In the model disability survey , developed by WHO and the World Bank, respondents are asked about their need for support. The survey does not, however, report on whether the support asked for or needed was provided. Respondents are asked, for example:

1. "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?"
2. "Does [name] need emotional care or support, such as comfort, advice or counselling?"

Another example, from the United States, is from the Kaiser Family Foundation, which annually surveys state Medicaid agencies. Table 2 presents an extract of collected information from the complete results table.

Table 2: Number of persons receiving services from Medicaid home and community-based waiver services, United States, 2018

Target population	Number of persons receiving Medicaid home and community-based services
Intellectual and developmental disabilities	785,800

Target population	Number of persons receiving Medicaid home and community-based services
Aged	162,500
Aged/disabled	667,000
Physically disabled	128,200
Children	17,100
HIV/AIDS	3,600
Mental dealth	25,100
Traumatic brain injury/spinal cord injury	17,500
Total number of participants	1,806,800

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, data for this indicator could also be obtained through administrative sources. Although no examples were found, it is possible that some administrative systems could support this indicator. For example, the United States provides community-based support services through Medicaid home and community-based waiver services, through funds sent to states. Expenditure data for the programme are collected at the federal level, but data on the number of persons receiving services are held at the state level. States have records of the number of persons on the waiting list for services, but many do not share their lists publicly. The programme does, however, share some statistics on the types of disabilities reported, as well as on the types of services used.

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, also referred to under indicator 19.30, to collect data on this indicator. According to the survey from 2018, 53.1 per cent of the population used aids or equipment because of their condition. This varied by type of living arrangements, 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 is used also to report on the type of aids used.

The model disability survey is an example of a survey that could be used to collect similar information. It makes a distinction between the services and supports that are required and those that are actually obtained.

A survey from Türkiye reports on supports and accommodations at work. A sample of the findings is reproduced in table 3. Such a survey could be expanded to address assistive technology and supports in all aspects of life.

Table 3: Percentage of working conditions/arrangements required by registered disabled individuals at their job, by type of disability, Türkiye, 2010

Working conditions / arrangements required	Total	Visual disability	Hearing disability	Language and speech disability	Orthopaedic disability	Intellectual disability	Mental and emotional disability	Chronic illness	Multiple disability
Jobs that do not require heavy physical work or significant strength	55.7	49.8	42	49.3	66.3	47.3	41.4	64.8	53.7
Taking more short breaks during 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
Using official permissions for treatments more than 30 days	16	16.8	12.8	16.1	18.6	6	13.5	20.1	16.4
Working jobs that do not include any business travel or field studies	13.5	14.4	16.1	17.6	17.8	6.5	14.6	14.4	10.8
Working at 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 jobs	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 Disabled People 2010 (Ankara, 2010). Available at https://docplayer.biz.tr/416198-Ozurlulerin-sorun-ve-beklentileri-arastirmasi-survey-on-problems-and-expectations-of-disabled-people-2010.html.

In countries that provide assistive technology, data on the number of persons requesting such technology could be obtained from administrative data sources. According to a report on assistive technology provision in middle- and low-income countries, assistive technology provision has mostly occurred through non-governmental organizations, with limited reach and a narrow scope of assistive products (e.g. wheelchairs or prosthetics). This fragments

the market and masks some of the need for assistance. A possible exception occurs in the Nordic countries, whose Governments provide 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 – from large scale facilities to group homes), disaggregated by sex, age, disability and type of institution or facility

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

A major European study entitled "Deinstitutionalisation and community living: outcomes and costs" was undertaken in 2007. It found that, in many countries, even where data existed at the regional or local level (generally through administrative records), they were not necessarily collected at the national level.

While the data in the report are now out of date, the report itself provides a good example of how to encourage countries to report on the issue. Most European countries do not routinely collect the data reported, but they did so specifically for this study. The data are available in the country reports.

An example of the data for Bulgaria in the report can be found in table 4 below.

Table 4: Data available for type of institution, by gender and age, Bulgaria, 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			

Type of institution	Total	*Gender*			*Age*			
		Male	Female	Gender unspecified	Children	Younger adults	Adults over 18	Age unspecified
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 and social care for children	1,213							1,213
Group homes	120							120
Social and 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	
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. Volume 3: Country Reports (Canterbury, Tizard Centre, University of Kent, 2007), p. 41.

Notes: Categories as specified in the source.

The national deinstitutionalization strategy and action plan of North Macedonia includes data on the number of children and adults in institutional care, as presented in table 5.

Table 5: Number of children and adults in institutional care by degree of disability, North Macedonia, 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: North Macedonia, Ministry of Labour and Social Policy, National Deinstitutionalisation Strategy of the Republic of Macedonia for 2018–2027 "Timjanik" and Action Plan (Skopje, 2018), p. 20.

A more recent report from Finland shows that, at the end of 2018, there were 3,735 clients with "mental disabilities" receiving intermittent services in supervised and supported housing. There were 1,859 clients 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, totalling 8,664 at the end of 2018. A reported 89 per cent of institutional care clients were housed through a public service provider.

19.33: Number and proportion of persons with disabilities who have left institutions (e.g. psychiatric inpatient settings and residences for persons with intellectual disabilities) and entered into independent living arrangements, out of the total number 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, 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 has used administrative data that can capture this indicator. The Centers for Medicare and Medicaid Services – the agency that provides funding for people with intellectual or developmental disabilities, for institutions and for 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 who had been transitioned into community settings.

The first transitions occurred in late 2007. As of June 2018, 91,540 institutional residents had transitioned into communities in 44 states and the District of Columbia. Some 14,856 of them were persons with intellectual or developmental disabilities, who moved from either institutions for persons 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. The Community Living Policy Center published a report on these data.

19.35: Number of persons with disabilities using mainstream services and their proportion of the total number of service users, disaggregated by sex, age, disability and type of service, as compared to other persons

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

Data on this indicator can be sourced from different mainstream services (e.g. governmental administrative services, education and health). They contribute to the provision of an overall picture of the inclusiveness and responsiveness of services to persons with disabilities.

According to the *World Report on Disability*: "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." ((World Health Organization, 2011), p. 46)

A finding indicating inclusive delivery of the particular service could be one in which the percentage of users with disabilities is similar to the percentage of persons with disabilities in the general community (considering age, geographical coverage, etc.). For example, the enrolment rate of persons with disabilities in regular education indicates the inclusiveness of the education system. However, several other factors come into play, including the particular purpose or characteristic of the service. It might be the case, for example, 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 (indicators 24.27 and 24.28), health (indicator 25.22), rehabilitation (indicators 26.11 and 26.12) and social protection (indicator 28.16).

19.36: Level of satisfaction of persons with disabilities with mainstream services, disaggregated by type of service, sex, age and disability

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

Australia fields a survey to collect information on this indicator (the same survey referred to under indicators 19.30 and 19.31). The country also undertakes a local government community satisfaction survey, which includes questions on the services received by older persons. While it does not ask respondents about disability-related services, it could easily be adapted to do so.

The United Kingdom of Great Britain and Northern Ireland implements a local government satisfaction survey that asks respondents about local services for children and older persons. While it does not ask respondents about disability-related services, it could easily be adapted to do so.

Moreover, as with indicator 19.35, this indicator can be populated through data gathered for indicators on other articles that address satisfaction within various services.

Government at a Glance, a publication of the Organization for Economic Cooperation and Development, is an example of a source with data. Based on a representative sample of 1,000 citizens in each country, respondents are asked about their level of satisfaction with health-care, education and justice systems and the police. However, it does not include disability data, and to allow for disaggregation by disability the sample would have to be larger.

Many surveys contain questions about satisfaction with health care. A list of the surveys that allow cross-national comparisons of patient satisfaction can be found in a report by the Norwegian Knowledge Centre for Health Services. Most of these surveys do not include disability.

In the United States, both the Medicare Current Beneficiary Survey and the National Health Interview Survey include disability questions and questions about satisfaction with health care.