

# Disability Inclusion Helpdesk, October 22

## Evidence digest focus issue: Care and Disability Inclusion

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### Guest blog

Elisabeta Moldovan is a self-advocate and co-president of Ceva de Spus, a self-advocacy NGO in Romania. Ceva de Spus is formed of adults with all kinds of impairments. It focuses on deinstitutionalisation, accessibility and raising awareness on disability inclusion. She is also a board member of European Platform of Self-Advocates (EPSA).

#### What are the main issues people with disabilities face in relation to care?

In Romania, accessing care is difficult for people with disabilities because we don't have enough services, such as healthcare, rehabilitation, and community integration. There are multiple barriers to accessing the limited services that do exist from the accessibility of clinics to people's attitudes towards people with disabilities. Because of this many people stay isolated and even die in their homes.



Despite Romania ratifying the UN Convention on the Rights of Persons with Disabilities, we have a big problem with the institutionalisation of people with disabilities. There are around 16,600 people with disabilities living in state residential institutions, including people with intellectual disabilities. Every year, around 1,500 people die in these institutions. The Romanian state sees care for people with intellectual disabilities as keeping them apart from others; people with intellectual disabilities are not seen as people who could live in the community.

In institutions the care is non-existent, people are just left there. I know this from my experience and my work since. I spent 25 years living in an institution. In those times I was always left alone, nobody took care of us. If I was ill, they didn't believe me and I didn't get the care I needed. Unfortunately, even today this is happening in many institutions.

The Romanian state doesn't want to create the services we need or close the institutions. For some, the institutions are an easy solution; they don't understand the issues. I have gone to parliament to speak many times but after a few months, attention moves away from the issue. Globally, care is not a priority for many governments. It is seen as a personal issue not a political issue so we don't see the action we need.

Another important issue is that people with disabilities are often not given the chance to make their own decisions, especially people with more complex disabilities. Even around smaller things, like choosing what type of drink to take. What the carer wants takes priority.

**What would a better, more empowering, version of care look like to you?**

Decent services that are person-centred are the key to good care. There should be community based services and home-based care if that is needed. This could be 24-hour care but that depends on the needs of the person. When there are community based services, there is no need for institutions.

We launched a programme called UnLoc, which supports people with disabilities who have lived in institutions to live in the community. We provide individual, person-centred support. For some people that is 24 hour care and others are supported only when they need and ask for it, for example, to visit the doctor or bank. They have the choice to turn down services and the opportunity to come back for more support if they need it another time.

Providing care is not just about taking people from institutions and offering them a protected home. People with disabilities don't need to be protected like a child, they need to be given choice and offered support on the basis of the needs. It's about giving people with disabilities freedom, choice, and not keeping them separate from others. Regardless of whether someone has a disability, every person can live in the community, and it is their right.

**What can different groups do to improve access to quality care?**

Governments should look into creating and financing community based services. They need to make disability, and social issues like care, a priority. At the moment, their focus is on business and finance. Issues like care end up at the end of the priority list.

It is important for organisations to hold raise the awareness of governments and hold them to account. It is hard to keep doing this when politicians and key decision makers change regularly but we have to keep telling them what people with disabilities want. The last solution is to start legal actions against the state to demand that our rights are met. Organisations should come together behind a strong single message - such as deinstitutionalisation. It is hard to do when people are busy or have different priorities, but it is more powerful if everyone works together.

People with disabilities should go and should ask for their rights. They should go to meet the stakeholders and help them understand our needs. It would be really powerful if we all went to the streets to strike and demand our rights. The message I would like readers of this guest blog to take away is: let people with disabilities be free. Don't keep them in institutions, offer them support if they need but respect their independence too.

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## The latest evidence and guidance on disability inclusion and care

### COVID-19

Chowdhury et al., (2022) undertook an **intersectional analysis of the experiences of people with disabilities and caregivers during Covid-19 in Bangladesh and Liberia**. With COVID-19 significantly affecting people with disabilities by creating additional barriers in access to services and increasing risks of poor health and social outcomes, there has been minimal research on the needs and experiences of this population group and how these are shaped by intersecting axes of inequity. This study sought to address this gap by using a creative participatory method of photovoice remotely to document experiences of COVID-19 through the lens of people with physical and psychosocial impairments and their caregivers as co-researchers. The findings present themes relating to inaccessibility, social connection, hopes and fears. The nexus between disability and poverty was exacerbated for many in both settings, while psychosocial impacts of COVID-19 included increased stigmatisation and isolation. However, themes of faith, support and adaptability were also highlighted in stories of community care, nature and healing.

In January 2022, a research paper **investigated whether there were disability-related inequalities in health services during the COVID-19 pandemic** was published in the Disability and Health Journal. The study compared access to COVID-19 and non-COVID-19 related health and mental health services for people with and without disabilities. The results found that people with disabilities were more likely to be hospitalised if symptomatic, to experience current symptoms of psychological distress, to report being lonely, and to be at risk of comorbidities compared to people without disabilities. The study recommended health services and social policy address mental health needs and social isolation of people with disabilities to address and reduce the inequalities between people with disabilities and people without disabilities.

The London School of Economics (LSE) published the report **Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities** in 2021. The research found that COVID-19 pandemic had a severe impacts on millions of people living in institutional settings globally, including those with disabilities, children, and older people. The pandemic has exacerbated many of the existing failings of these settings: restrictions on individuals’ rights, damage to their physical and mental health, shortened life-spans, and constraints on social and economic activity. It found that residents in these settings were exposed to disproportionate risks of COVID infection, severe illness, and premature death. The research has led to a call for a national and global commitment to deinstitutionalisation. The report found that a key barrier to deinstitutionalisation is prejudice against those with disabilities and ageism, resulting in a lack of societal commitment to change the status quo. The executive summary is also available in **Easy Read**.

**De-institutionalisation**

In September 2022, the CRPD Committee published **guidelines on deinstitutionalisation, including in emergencies**. Drawing on the experiences of people with disabilities before and during the COVID-19 pandemic, the guidelines are intended to guide and support States parties, in their efforts to realize the right of persons with disabilities to live independently and be included in the community, and to be the basis for planning deinstitutionalization processes and prevention of institutionalisation.

UNICEF and Eurochild jointly carried out the DataCare project to map alternative care data and data systems across the 27 Member States of the European Union and the United Kingdom. The findings of the research were captured in a policy brief – **Children in alternative care: Comparable statistics to monitor progress on deinstitutionalisation across the European Union** and a technical report – **Better data for better child protection systems in Europe: Mapping how data on children in alternative care are collected, analysed and published across 28 European countries**. **Country Overviews** summarise the data and key findings of the mapping for each country in the EU and the UK, and a video presentation of key findings is available **here**.

The European Expert Group on transition from institutional to community-based care published a **report on the transition from institutional care to community-based services in 27 EU member states** in 2020. The report found that there were at least 1,438,696 people living in institutions, a number which does not seem to have substantially changed over the past 10 years. The report highlighted key concerns and potential solutions, including the importance of person-centred and individualised support for all, including people with complex support needs, as the only way to ensure full inclusion and participation in the community.

Inclusion Europe published **Life after violence: a study on how women with intellectual disabilities cope with the violence they experienced in institutions** in 2018. The report, which is based on in-depth interviews with 10 women, provides a number of recommendations starting with inclusive education from early age and putting an end to the institutionalisation and segregation of women with intellectual disabilities. The study is also

available in [easy read](#).

## Health

Aenishänslin, Amara and Magnusson (2020) [undertook interviews with 38 individuals with differing physical impairments in three locations across Sierra Leone](#). The interviews found that participants faced several barriers to accessing and using rehabilitation services, for example, the cost of rehabilitation and transportation to these services, varied experiences of rehabilitation staff, and the limited knowledge and availability of rehabilitation services. They found a need to address the barriers associated with affordability of rehabilitation through financing rehabilitation and transportation and exploring low-cost care delivery models. The study also recommended a national priority list to improve availability and coordination of rehabilitation services, improving knowledge about disability and rehabilitation services in wider communities, and addressing discriminatory attitude and stigma affecting people with disabilities through community interventions.

People with disabilities experience widespread poor access to healthcare services in low- and middle-income countries, because of the inaccessible environments and discriminatory belief systems and attitudes. [A meta-synthesis of qualitative studies exploring the barriers to primary healthcare services experienced by people with disabilities in LMICs](#). The study found three barriers that affect people with disabilities' choice whether to seek healthcare services or not and the quality of intervention provided by healthcare providers. These are: cultural beliefs or attitudinal barriers; informational barriers; and logistical barriers. The study recommends firstly to consider these barriers and how they affect people with disabilities and their households. Secondly, with this consideration, nuanced and effective interventions can be made to improve access to primary healthcare that addresses these barriers.

A study published in Canadian Family Physician [explored the experiences of patients with disabilities in receiving primary care \(PC\) in Canada](#). The objective of this study was to gain understanding of the perceptions and experiences of patients with disabilities. The study involved walking with 18 patients through the clinic, as they would on a typical visit, and encouraging them to describe their feelings and experiences. Findings showed a strong positive relationship, particularly with the health team and administrative staff, profoundly affected perceived access to and experience of care. Multidirectional, clear and respectful communication independently improved patients experiences dramatically. Through team relationships and communication, the access, coordination, and physical barriers were eased, however some physical barriers remained. The study concluded that some healthcare teams are unaware of how relationships and communication affect every aspect of healthcare for people with disabilities and suggested that highlighting these findings with providers and organisations might prompt a more patient-centred model of care.

Dassah et al., (2022) [looked into the recommendations of health care providers and persons with disabilities for improving access to primary health care services in rural northern Ghana](#). They found that people with physical impairments face multiple barriers to

health services including physical, structural, knowledge, attitudinal and financial barriers. However, there is limited evidence on how to improve access to primary health care services for persons with physical impairments. By interviewing 33 persons with physical disabilities and health care providers, they identified 4 major themes. According to the participants, health services could be more accessible by: i) Making it more affordable; ii) Increasing the availability of providers and services; iii) Providing more education about system navigation; and iv) Improving access to accessible health facilities and equipment. Policy makers need to consider support for non-medical services (i.e., cost of transportation). There is an urgent need for policy makers and key stakeholders to include persons with disabilities in designing and implementing policies and programs to ensure that they are meeting their needs.

Philip, King and Durham (2022) conducted a **qualitative review using an intersectional lens to explore the lived experiences of people with disabilities with human immunodeficiency virus (HIV) in accessing HIV services**. The intersections they explored were related to HIV, disability, gender, stigma and poverty, and highlighted how stigma, poverty, and gender collide in a hierarchy of identities to impede accessibility to HIV services. The review recommended that governments within Africa commit to including persons with disabilities with HIV in National Strategic Plans (NSPs), which will support disability-inclusive HIV programming. The review found that the inaccessibility of HIV services for people with disabilities is multifaceted and intersectional. Interventions that consider the different social identities such as gender and socioeconomic status of people with disabilities may be more impactful. Understanding the specific dimensions of access that impacted both the demand and supply side will facilitate efficient HIV programming for people with disabilities.

The Learning Disability Practice published a study in August 2022 which **looked at the service users’ experiences in supporting people with intellectual disabilities and mental health conditions**. The aim of the study was to actively involve adult service users with an intellectual disability in improving the understanding of service providers, practitioners and carers of their experiences of mental health services. The study used semi-structured interviews with seven participants to produce data on their views on the mental health services they had received. The data showed an increased awareness among service providers, practitioners and carers of the mental health and emotional concerns experienced by individuals with intellectual disabilities. The participants’ data showed the diverse negative experiences experienced by people with intellectual disabilities related to the recognition of their need for mental health care. Future recommendations include research into the perspectives of people with coexistent intellectual disabilities and mental health conditions.

**Ageing**

The European Disability Forum provided **recommendations for the European Care Strategy for Ageing, Disability and Long-term Care**. There are many commonalities between the barriers faced by older people and those faced by persons with disabilities, and significant overlap between the two populations. The recommendations aim to outline the main overlapping issues faced by older people and persons with disabilities, including

women, and to present a series of recommendations for how they feel these should be addressed in the new EU Care Strategy.

**Relationships with Care-Givers**

A study by Sampaio and Guilhem published in April 2022 looked at **how care relationships influence the autonomy of people with tetraplegia**, focusing on the dynamics that trigger the violation, maintenance and promotion of autonomy. The study outlines several models of care relationships, such as the protectionist model, based on the biomedical model of disability; the participatory model, involving the patient's views and seeking to understand the practical aspects of daily life; and the emancipatory model, which seeks to empower people who are tetraplegic, highlight potentialities, and encourage autonomy. Based on these different models, the study outlines different types of care interventions that aim to maintain and promote the autonomy of people with tetraplegia through supported care.

Lake et al. (2021) **explored the wellbeing and mental health service experiences of adults with intellectual and developmental disabilities during COVID-19**. COVID-19 adversely impacted the health and wellbeing of people with intellectual and developmental disabilities. While there is emerging research examining how to support the mental health of this population during the pandemic, the perspectives and experiences of people with intellectual and developmental disabilities have been largely absent. Nine interviews were conducted virtually with adults with intellectual and developmental disabilities to explore the impact of the COVID-19 pandemic on their wellbeing and mental health. Three main themes arose in their findings: 1) the impact of the pandemic on daily life and wellbeing; 2) a need for connection; and 3) availability and access to mental health support. Participants described significant challenges to their health and wellbeing related to the pandemic and public health measures, but also demonstrated resilience to the new adversity. The findings highlighted ways to support the wellbeing of adults with intellectual and developmental disabilities and how social determinants impact mental health.

Horner-Johnson et al., (2021) **conducted an initial exploration of the experiences of women with different types of disability when they attempt to obtain contraception**. The study included focus group discussions with 17 women with disabilities. Participants identified challenges to obtaining high-quality contraceptive services in three main thematic areas: accessibility and accommodations, clinician attitudes, and health insurance. Participants with physical disabilities encountered inaccessible clinic rooms and examination tables, and those with sensory impairments or intellectual and developmental disabilities described inaccessible clinic forms and information. Participants from multiple disability groups described negative attitudes of health care providers and health insurance limitations. The processes and infrastructure of contraceptive services were based on an assumption of an able-bodied norm, which can be harmful. The study concluded that increased attention to the reproductive health needs of women with disabilities is important for improving health care equity and quality.

Moosa-Tayob and Risenga (2022) published a paper in African Journal of Disability, which looked at the **challenges of caregivers providing care to children with disabilities at**

**non-governmental organisations in Tshwane townships, South Africa.** Understanding these challenges is crucial for developing empowerment programmes for caregivers, which will ensure that children with disabilities receive comprehensive, optimal care and that caregivers experience a good quality of life. This study followed an exploratory, descriptive and contextual research design within a qualitative methodology. The study revealed six themes that represent the challenges experienced by caregivers, namely (1) initial impressions, (2) rendering care, (3) stress, (4) lack of outside support, (5) coping and (6) poor community recognition. Support from the Departments of Health and Social Development and other institutions providing community rehabilitation services to townships should be provided to caregivers in order to empower them with skills and knowledge to effectively address the challenges they face so that they can render optimal care to the children they care for.

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## The latest evidence and guidance on disability inclusion: Other topics

### Convention on the Rights of Persons with Disabilities (CRPD)

The International Disability Alliance (IDA) released a paper in August 2022 on **how to apply CRPD standards to programmatic processes, for development and humanitarian practitioners, international organisations, OPDs and donors.** It gives practical examples on how to operationalise CRPD based inclusive programming in the context of the project cycle for development and humanitarian practitioners, international organisations, OPDs, and donors.

Barrell (2022) explored **whether we are in danger of rolling backwards on global disability inclusion progress** and what has been learned from the UK government's new strategy of 18 commitments to "meaningfully engage, empower and enable people with disabilities to exercise and enjoy their full rights and freedoms on an equal basis with others, without discrimination and across the life-course."

### COVID-19

Hereth et al., (2022) have published an article to **argue that long COVID-19 needs to be better recognised, understood and supported, and should stimulate a rethink of our approach to disability.** Such recognition would also re-enforce the obligation of the state to extend and expand supportive infrastructure and policy for people with other disabilities. The articles concludes that there is a need for just social policies grounded in contemporary theories of disability, designed by people with disabilities for people with disabilities, can also form the basis for advocacy and policy change beyond the pandemic.

### Economic Empowerment

The International Disability (IDA) published **Equalizing access to the labor market for persons with disabilities: a technical paper on implementing Article 27 of the CRPD** in



June 2022. This paper is informed by the experiences of IDA and the OPD Engagement Officers in the Inclusion Works program. It draws from the extensive range of primary and secondary data generated within the Inclusive Futures initiative, including focus group discussions with OPDs in Bangladesh, Kenya, Uganda and Nigeria. The paper highlighted the need to shift inclusive employment from placing people in jobs to true inclusion. This will require system-level changes across all aspects of the labour market: laws and policies, skill building, recruitments, investing in an accessible workplace, creating support services that are critical for persons with disabilities to access the labour market, disability inclusion among employers, and more. Furthermore, it requires greater understanding of non-discrimination and unpacking of reasonable accommodation to address the requirements of a diversity of disability groups; and building strong relations between OPDs and employers.

## Safeguarding

The Safeguarding Resource and Support Hub (RSH) published a **Tip Sheet on Disability-Inclusive Safeguarding** in October 2022. The tip sheet highlights some key tips for non-government organisations (NGOs) and civil society organisations (CSOs) in South Sudan on how they can ensure that their organisational safeguarding measures are disability-inclusive. This tip sheet focuses on disability-inclusive, safe programming. It was informed by consultations with NGOs who are working with persons with disabilities in South Sudan.

In August 2022, the Resource and Support Hub (RSH) held a webinar on the topic of **Protecting persons with disabilities from Sexual Exploitation, Abuse and Harassment in humanitarian crisis**. The webinar aimed to raise awareness on the factors that make people with disabilities more likely to experience Sexual Exploitation, Abuse and Harassment (SEAH) and how to ensure people with disabilities are safeguarded in humanitarian crisis. It provided recommendations for humanitarian actors to take to ensure full protection of people with disabilities from sexual exploitation, abuse and harassment and their inclusion in programmes. The slides and Q&A document are available for download.

The PSEA WoS Interagency Network has produced an animated video for children, raising awareness of preventing sexual exploitation, abuse and harassment. The video is available [here](#) in Arabic.

## Technology

In June 2022, Paul Jaeger published a book titled '**Disability and the Internet**', which examined the complex and contradictory relationships between people with disabilities and the Internet. From websites, to mobile devices, cyberspace has revolutionised the lived experience of disability, both for the better and worse. The book traces the historical and legal evolution of the digital disability divide in the realms of education, work, social life, and culture. It explores avenues of policy reform and technology development by connecting individual experiences with the larger story of technology's promise and limitation for providing equal access online.

Jamwal et al., (2020) published a **scoping review, which explored the impact of smart**

**home and communication technology on the outcomes of people with disabilities and complex needs.** Recent and continued advancement of technology, particularly smart home and communication technologies, presents new ways in which some of the barriers faced by people with disabilities can be overcome. Overall, technology appeared to enable greater independence and participation and improve quality of life among people with disabilities and complex needs. Despite this, ethical considerations were raised, including privacy concerns associated with monitoring technology. A number of factors impact the successful implementation of technology, including personalisation, flexibility and ongoing support to the person with a disability and their households.

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## Disability inclusion policy news

The **Disability Debrief** has launched a database of disability news as a portal for emerging disability news. It also includes links previously shared through Disability Debrief newsletter throughout the year.

The FCDO published a policy paper in May 2022 which outlines their **plan to include people with disabilities in their work 2022 – 2030**. This is the Easy Read version of the **Disability Inclusion and Rights Strategy** published in February.

There will be several side events focusing on disability inclusion and climate justice at the United Nations Climate Change Conference (UNFCCC COP27) in November 2022. This includes the following side events and meetings:

- **From Exclusion to Leadership: People with Disabilities Develop an Agenda for Inclusive Climate Action** on 10 November at 17:30 CET.
- **Disability inclusive actions for a greener future** on 12 November at 17:00 CET.

The European Disability Forum (EDF) reported on **emerging evidence that people with disabilities are being more severely affected by the cost of living crisis** in October 2022. In a meeting with European NGOS, a number of issues relating to the rising costs of electricity and goods and services in general. This includes disability allowances and salaries diminishing in value or staying the same despite rising prices and assistive technologies becoming more expensive, pushing persons with disabilities deeper into poverty. Elevated energy costs limit the use of heating, aggravating chronic pain and health issues. The EDF have developed a survey on national responses to the cost of living crisis, which can be completed in any European language [here](#).

The Inclusive Futures programme will be hosting a panel discussion on **promoting equitable access for people with disabilities to family planning services to achieve universal health coverage** at the International Conference on Family Planning (ICFP) 2022. More information on the panel and associated resources can be found on the Inclusive Futures website [here](#).

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## About the Disability Inclusion Helpdesk:

The Disability Inclusion Helpdesk provides research and technical assistance on disability inclusion to the UK Foreign, Commonwealth, and Development Office as part of the Disability Inclusive Development Programme. All our published reports are available on [our website](#). Contact us via: [enquiries@disabilityinclusion.org.uk](mailto:enquiries@disabilityinclusion.org.uk)