EU-Arab Cooperation Forum on the
Rights of Persons with Disabilities
منتدى التعاون الأوروبي العربي
لحقوق الأشخاص ذوي الإعاقة

Conference Proceedings

Transition towards Independent Living within the Community for Persons with Disabilities

Beirut, 14-15 February 2023

UNITED NATIONS
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United Nations Special Rapporteur
on the rights of persons with disabilities

GOVERNMENT OF MALTA
MINISTRY FOR INCLUSION,
VOLUNTARY ORGANISATIONS
AND CONSUMER RIGHTS

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Introduction

The right of persons with disabilities to live independently in their community is one that is enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), more specifically in article 19 of that Convention. In the Arab region, persons with disabilities still face significant barriers that prevent them from fully realizing their right to independent living and inclusion within the community, even though all the countries in the region have either signed or ratified the CRPD. One of the main barriers to the realization of that right is a practice known as institutionalization. This term refers to the often-non-consensual stay of persons with disabilities in long-term residential institutions for extended periods of their lives in isolation from society. These conditions typically leave individuals without a pathway that would facilitate their exit from such institutions and ensure their inclusion within the community.

Considering the contrasting nature of this practice to the spirit of the CRPD, there has been a global call and effort to move away from residential institutions and towards alternative community-based systems of support for persons with disabilities and their families. The logic behind such a move towards de-institutionalization is that persons with disabilities attain a greater degree of self-determination, one that is more in line with the CRPD. Persons with disabilities would hence have the freedom to choose where they would like to live and have access to services such as education, health, training and mentoring through community centres. This call for de-institutionalization is one that is part of a bigger paradigm shift that disability activists have been demanding for a long time, the shift from the medical/charity model of disability to a human-rights based social model that acknowledges disability as the CRPD pictures it: “an evolving concept and that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.

Despite the importance of independent living and inclusion within the community, there remain large gaps in research and data on this topic. Such research and data are essential for evidence-based policies and programmes to ensure disability inclusion. To address this gap, the “Arab-EU Research Network on Disability”, which was established by ESCWA, the Government of Malta and the United Nations Special

Rapporteur on the rights of persons with disabilities, launched a call for papers in March 2022[1] to invite researchers, including those with disabilities, to submit their work. The best eight submissions were selected by a peer-review committee to be presented at a conference on the same topic.

The conference “Transition towards Independent Living within the Community for Persons with Disabilities” was held on 14–15 February 2023 in Beirut, Lebanon. Over 100 delegates from both Arab and European countries were part of this flagship conference, coming from various ministries, national disability councils, universities, research institutions, organizations of persons with disabilities (OPDs) and other civil society organizations. The conference sessions offered an opportunity to discuss the findings of these papers, in addition to various presentations on different countries’ experiences in transitioning to independent living and inclusion.

The eight selected submissions fall under four sub-themes: technology and inclusion; independent living for children and students; transition after university and finding work; and approaches to independent living in Europe. The following section provides a snapshot of each paper under these sub-themes.

Technology and inclusion

Under this sub-theme, Laura Alčiauskaitė, Tally Hatzakis, and Alexandra König explore the views of persons with disabilities on assistive technologies as a means to independent living. The paper sets the scene with two aspects of the relationship between persons with disabilities and assistive technologies. First, the fact that the CRPD grants persons with disabilities the right to equal access to assistive technologies. Secondly, the potential that assistive technologies provide persons with disabilities in terms of improvements in functioning, participation in education and work, increased independence and ultimately an enhanced sense of social inclusion. The authors then go on to provide an overview of the issues with the access to assistive technologies that persons with disabilities face. They cite previous literature that shows the existence of a digital divide between persons with disabilities and the general population, the lack of funding for assistive technologies and the lack of involvement of persons with disabilities in the research being conducted on this topic, among other issues. The authors then presents the findings of her research and go into detail explaining the most desirable assistive technologies among persons with disabilities, the preferences specific to different disabilities and the conditions required for persons with disabilities to display a willingness to use assistive technologies.

In "Access to knowledge through digital inclusion: The case of students with visual disabilities in Cadi Ayyad University, Morocco", Hanan Zaafarani analyses the digital accessibility available to students with visual impairments. Utilizing a qualitative approach, Ms. Zaafarani infers that although there exists an enabling environment that seeks to achieve digital inclusion for students with visual disabilities, there remains ample room for improvement. Ms. Zaafarani's recommendations on how to fill those gaps included techniques such as providing free Internet access to students with disabilities and improving the accessibility of a number of digital applications in the field of transportation.

Independent living for children and students

Under this sub-theme, Radoš Keravica looks at the practice of "pathologization" of disabled children and how it represents an obstacle to independent living. Building on the work of other researchers, Mr. Keravica examines this impediment through the epistemological framework of the socio-relational understanding of "disability". His examination also takes into account the rights that children possess under two human rights treaties: the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the United Nations Convention on the Rights of the Child (CRC). Mr. Keravica also conducted a qualitative study with children with disabilities and their parents from England and Serbia. His study reached the conclusion that "disability" is commonly perceived as a negative difference, that there is no consensus on the meaning of "independence" and "self-sufficiency", that children are often sidelined in medical encounters concerning them and that the practice of pathologization did indeed take place among some of the respondents.

Ikhlas Al Sawwaf's study on the other hand adopts a more quantitative methodology to explore aspects of independent living for students. In her paper entitled "A pilot study: The effectiveness of a proposed functional curriculum in giving female students with moderate intellectual disabilities functional/life skills in Saudi Arabia", she examines the effectiveness of implementing functional curriculums in enhancing the functional skills of students with moderate intellectual disabilities. To do this, Ms. Al Sawwaf compared the ability of a group of primary and secondary school students with moderate mental disabilities to acquire a set of functional skills before and after they attended a series of sessions based on her proposed functional curriculum. She also compared the data she collected to another set of data she collected from a control group that shared the same characteristics but were not exposed to the functional curriculum. The study revealed that students who were exposed to the functional curriculum showed an improvement in the skills required for independence compared to both the pre-exposure levels and the control group.

Transition after university and finding work

In their paper "Does disability affect labour market outcomes? Application of the case of Egypt", Aida Ramadan and Racha Ramadan use the Egypt Labor Market Panel Survey (ELMPS) 2018 to show that disability is associated with a lower probability of participation and employment in the Egyptian labour market. The authors note that persons with disabilities face barriers to enter the labour market despite the fact that a number of legal and institutional reforms and initiatives have been implemented in Egypt. Another key finding in this study is that once a person with disability is employed, their disability is not a significant determinant in the public sector. The authors conclude their study by recommending a holistic approach to promoting the employment of persons with disabilities alongside efforts to support entrepreneurship and micro-enterprises among them.

In Oman, Rahma Said Al Kalbani conducted a field study that explores the extent to which the concept of independent living has been realized in Omani society through examining the measures taken by the public service sector to enable persons with disabilities to work and form families after attending university. In agreement with previous studies, Ms. Al Kalbanis study entitled "Post-university life and independent living: A field study on persons with disabilities in the Sultanate of Oman" showed that the concept of independent living for persons with disabilities is limited to the extent of a person with a disability's ability to obtain primary, secondary and university education, and then obtain the opportunity to work and form a family, regardless of the capabilities in a person with a disability's possession. The study also showed that societal attitudes limit the ability of a person with a disability to be self-reliant, capable of making life decisions and being fully integrated into society.

> “Does disability affect labour market outcomes?”

Approaches to independent living in Europe

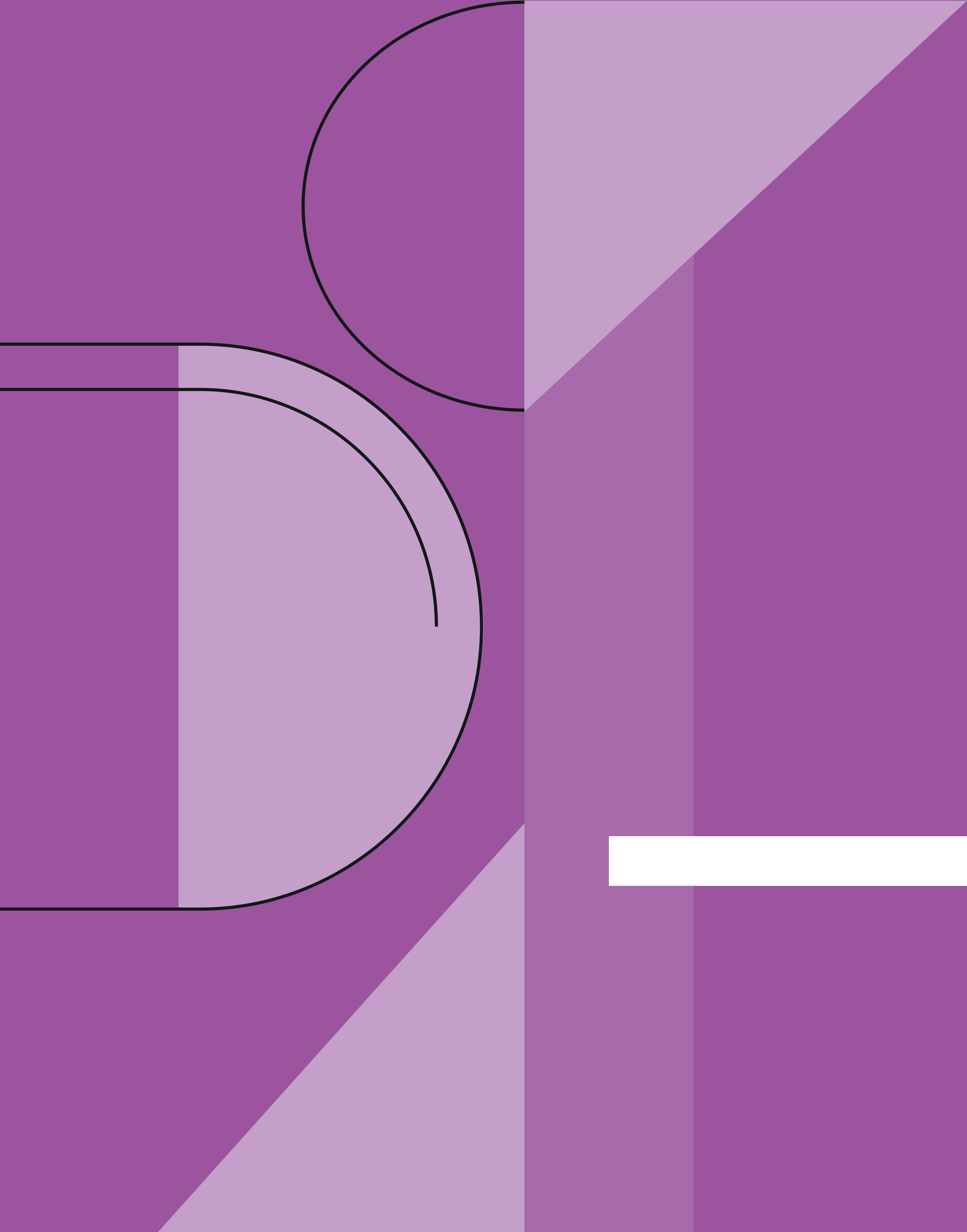
In "The commitment of the European Union to the Convention on the Rights of Persons with Disabilities and the right to live independently and be included in the community", Lazar Stefanović delves into how problematic interpretations of CRPD-compliant legislation may, in practice, be a framework for actions that are not compliant with the CRPD. Mr. Stefanović reveals a number of "avoidance techniques" that the European Commission utilized to stay away from sanctioning the use of European Structural and Investment Funds in a manner that is not aligned with the CRPD by some member countries. He then goes on to emphasize the role of non-governmental organizations and OPDs in internalizing the CRPD and advocating for the CRPD-aligned wording and measures in European Union financial regulation to improve the monitoring of the use of funds.

As its name suggests – "Overview on Estonian legislative and policy support measures for enabling gradual realization of independent living: A public-private partnership approach for accessible and affordable independent living in Estonia" – Meelis Joost's study explores the right to independent living within the community in Estonia. The study finds that adopting a public-private partnership approach in Estonia has yielded promising results to provide accessible and affordable support for persons with disabilities to live independently within their communities. One of the challenges to providing services to persons with disabilities that is somewhat specific to the case of Estonia is the fact that it is a sparsely populated country. Mr. Joost recommends that the needs of persons with disabilities are mapped to ensure inclusion in the community at every local level.

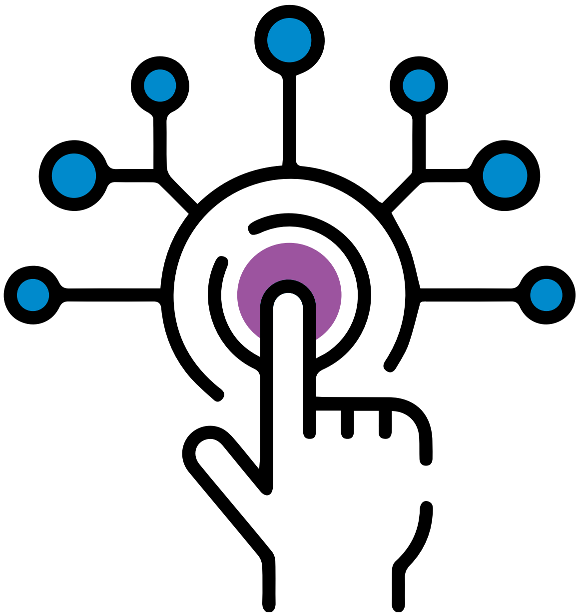
There remain considerable efforts to be made on the path to granting persons with disabilities their right to independent living, among other rights. The papers published in this volume, their authors and the "Arab-EU Network on Independent Living" aspire to fill the gaps in research on the obstacles, considerations and ultimately the solutions that facilitate this quest. These studies also support the Network's objective to enhance evidence-based policymaking and interregional knowledge exchange.

Endnotes

1 https://www.unescwa.org/events/transition-towards-independent-living-within-community-call-papers.



TECHNOLOGY AND INCLUSION



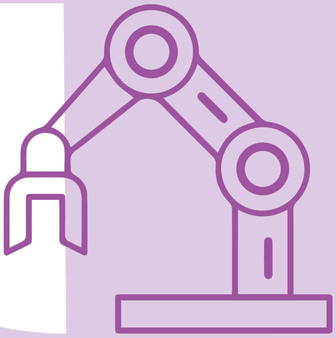
VIEWS OF PERSONS WITH DISABILITIES ON DIGITAL ASSISTIVE TECHNOLOGIES

WOULD THEY HELP THEM TO BECOME MORE INDEPENDENT?

Laura Alčiauskait
Tally Hatzakis
Alexandra König

Key messages

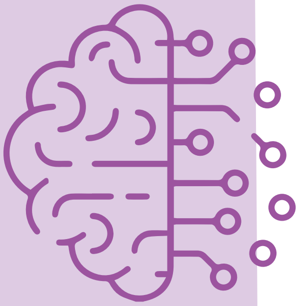
1



The most desirable assistive technologies across all types of disabilities are wearables, AI alerts, robots, and autonomous wheelchairs and vehicles.

2

Other disability-type specific preferences include AI alerts, location-based alerts, AR, robots and smart communication aids by persons with intellectual disabilities; automated captions and AI alerts by people with hearing impairments; and lastly accessible navigation systems, robots and AR solutions by people with visual impairments.



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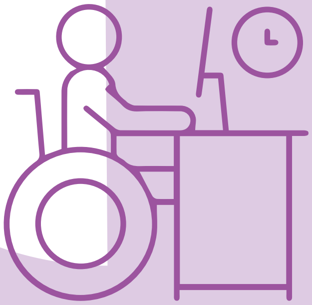


Persons with disabilities showed willingness to use digital assistive technologies if: (a) they feel competent to use these technologies, and (b) these technologies respond to their access needs and support their independence.

The research recommends that: (a) persons with disabilities are provided with smart technologies; (b) they are assisted to use digital technologies confidently; and (c) they are involved in the process of creating and developing assistive technologies.

Introduction

Persons with disabilities are the largest minority group; it is estimated that around 650 million people worldwide live with a disability (Disabled World, 2020). Eighty-seven million Europeans have some form of disability, and this means that one in four European adults has a certain type of disability (Council of the European Union and the European Council, 2022).

With the growing importance of smart assistive technologies for everyday life, ensuring equal access to information and services is an important area of concern both for persons with disabilities and for the society as a whole (Vicente & Lopez, 2010). Assistive technology can be defined as “any product whose primary purpose is to maintain or improve an individual’s functioning and independence, and, thereby, promote their wellbeing” (Khasnabis, Mirza & MacLachlan, 2015). For persons with disabilities, assistive technologies can greatly enhance their functioning, independence, social inclusion, and participation in education and the labour market. According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), equal access to assistive technologies is a human right (UN General Assembly, 2006).

Previous studies have also confirmed that smart assistive technologies can increase independence in activities and participation for persons with different disabilities. For example, AI robotics, robotic arms that can be attached to wheelchairs, adaptive sports and recreation equipment, devices that assist standing and transfers, smart monitoring and coaching technology, power add-on devices for manual wheelchairs and power mobility devices that operate in extreme terrain are just a few examples of technologies that have great potential to increase the independence for persons who have mobility impairments (Dicianno et al., 2019). In addition, prototypes of AR systems can locate products in a store for persons with motor disabilities (Rashid and others, 2016). AR systems can also be used as a navigating tool for persons with intellectual disabilities (McMahon, Cihak & Wright, 2015). The use of smart assistive technologies, such as the memo planner, can help structure the daily lives of persons with intellectual disabilities, and afford them opportunities to participate in everyday activities (Söderström and others, 2021).

For persons with visual impairments, modern assistive technologies are becoming more discrete and include a wide range of mobile computerized devices, such as mobile phones. Smart assistive technologies designed for users with visual impairments can be used to determine their location, their relation to the surroundings, generate navigation instructions and deliver all this information to them (Fernandes and others, 2019).

Smart assistive technologies can be also useful for persons with hearing impairment. According to Kumar and others (2022), Visual Speech Recognition systems have played a vital role in speech recognition systems in recent years, because they do not require an acoustic environment. A Visual Speech Recognition system is an automatic process of detecting spoken words by tracking the speaker’s lip movement. This technology provides persons who have hearing impairments with an alternative way of communication, i.e. visual communication.

Despite the fast progress of innovation and proven benefit of smart assistive technologies, previous research has revealed that compared to the general population, persons with disabilities tend to use digital technologies and the internet less frequently. In most countries, people with disabilities face a significant digital divide (Scalan, 2022; Duplaga, 2017). Therefore, it is important to take a look at the existing barriers that hinder persons with different types of disabilities from having equal access to using these technologies.

Previous studies revealed that digital devices were often inaccessible to persons with different types of disabilities (Raja, 2016; Kane and others, 2009). Inaccessibility may be due to obstacles in hardware, software, or both (Dobransky & Hargittai, 2016). Even relatives or caregivers can hinder access, as they often make the choices, particularly for youngsters with disabilities, denying them the opportunity to access a computer or the internet (Gutierrez & Martorell, 2011; Chiner, Gmez-Puerta & Cardona-Molt, 2017). This can have knock-on effects on other domains. As an example, a recent study from Sweden revealed that persons with disabilities were still unlikely to use the internet for purposes like internet banking or online shopping (Johansson, Gulliksen & Gustavsson, 2020).

Another issue is related to the fact that assistive technologies for persons with disabilities are often developed by people who have no disability. This produces an environment in which the perspectives of researchers with disabilities, particularly when they clash with the normative ways of approaching accessible technology, are denigrated, dismissed, or treated as invalid (Ymous and others, 2020). However, there is a growing number of cases in which persons with disabilities are actively involved in the development process, namely co-designing. Co-designing is a promising way to engage users with disabilities to become active participants in the open innovation, given that they are experts in their own access needs (Alčiauskaitė, Vasconcelos & Andersen, 2021).

One more frequently reported barrier is related to the lack of funding and cost of assistive technologies, lack of awareness about the possibilities provided by digital technologies, and inadequate assessment (Boot and others, 2018).

Despite previous research exploring the barriers and benefits of assistive technologies for improving the independence of persons with different types of disabilities (Bryant, Brunner & Hemsley, 2020; Gebresselassie & Sanchez, 2018), there is still a lack of knowledge about their intention to use these technologies (Harris, 2010). Such research is challenged to study why some persons with disabilities are more likely to make use of technology than others, and it is important to investigate the motivational conditions for technology so as to assess behavioural intentions (Chen & Chan, 2011).

> **Hence, in this study we aimed to answer these two research questions:**
>
> Are persons with different types of disabilities willing to use digital assistive technologies?
>
> What types of digital assistive technologies would they find applicable to their disabilities and access needs?

1. Methodology

This survey forms part of the TRIPS project (https://trips-project.eu/). TRIPS stands for "TRansport Innovation for Persons with disabilities needs Satisfaction". The project aims at making public transport more accessible to persons with disabilities, the elderly, and other persons who face barriers while using public transportation. The project aims to conduct research on the needs and attitudes towards digital mobility solutions, review the state-of-the-art on accessibility, mobility, and related digital and assistive technologies and policies, as well as devise an index to measure mobility.

A. Survey design

The present study used data from an online mobility survey that addressed persons with disabilities. A total of 13 different assistive technologies were presented, each of which introduced by a short text describing its operation and potential use, in case a respondent has not heard about it:

1. Smart communication aids - Imagine a system that can augment your voice to help you communicate with others and with machines faster and with more ease.
2. Location-based alerts - Imagine an app that assesses if you are at risk of harm and provides you with guidance or alerts your personal assistant or staff to assist you.
3. Augmented reality - Imagine a pair of glasses that can tell you or show you information about the world around you, for example show you a certain route, the location of accessible facilities or how to find a station manager.
4. Exoskeletons - Imagine wearing a body suit that can help you stand, walk, and lift or handle objects with ease.
5. Robots - Imagine having a robot personal assistant to help you with cooking, eating, cleaning, shopping, carrying stuff, playing games and chatting.
6. Wearables - Imagine having a wristband or ring that can automatically open and close doors, make payments, and even pull out a ramp for you.
7. 3D-printed prostheses - Imagine that a printer can print prosthetics that perfectly fit your body.
8. Autonomous wheelchairs and vehicles - Imagine being able to navigate from point A to B without the need for steering the wheels.
9. Artificial intelligence sign language translation - Imagine a system that can translate movements, gestures, and sign languages into text and vice versa.
10. Artificial intelligence alerts - Imagine a system that can alert you in your local language via your phone or wearable when your name is called, your bus stop is announced or a fire alarm goes off.
11. Automated captions - Imagine a system that can automatically produce text captions on videos.
12. Accessible navigation systems - Imagine having a tool that can recognise objects, and provide navigation and information on how to avoid obstacles.
13. Smart canes - Imagine having a long mobility cane with sensors to help you know what is happening around you by giving you audible or tactile warnings.

The respondents indicated their level of use intentions of these assistive technologies on a 5-point Likert scale with the response options "never" (1), "rarely" (2), "sometimes" (3), "frequently" (4) and "always" (5). Additionally, if the respondents felt the technology in question was not relevant for their access needs, they could choose "Non-applicable".

The survey was developed in close collaboration with local disability user groups in seven European cities (Bologna, Brussels, Cagliari, Lisbon, Sofia, Stockholm and Zagreb). The survey was translated into 15 different languages, namely Bulgarian, Croatian, Dutch, English, French, German, Greek, Italian, Lithuanian, Polish, Portuguese, Romanian, Russian, Spanish and Swedish.

B. Procedure

The survey was conducted online, using the software SoSci Survey, and it was posted on the official website of TRIPS project. It was accessible to users with visual impairment who use screen readers. The survey could be completed by persons with disabilities or by another person answering on their behalf. Respondents who had no disability were excluded from participation by means of a filter question, which leads directly to the final page of the survey. Completing the survey took about 20 to 30 minutes. To avoid missing data, all questions were mandatory.

Invitations informed users about the purpose of our study and about the TRIPS project overall, as well as about the projects' data management policy and practices, and the use and management of their data in line with the General Data Protection Regulation (GDPR). Participants were also given contact details should they need to contact someone for clarifications and extra information. Participants were asked for their consent at the beginning of the study, although data were collected anonymously.

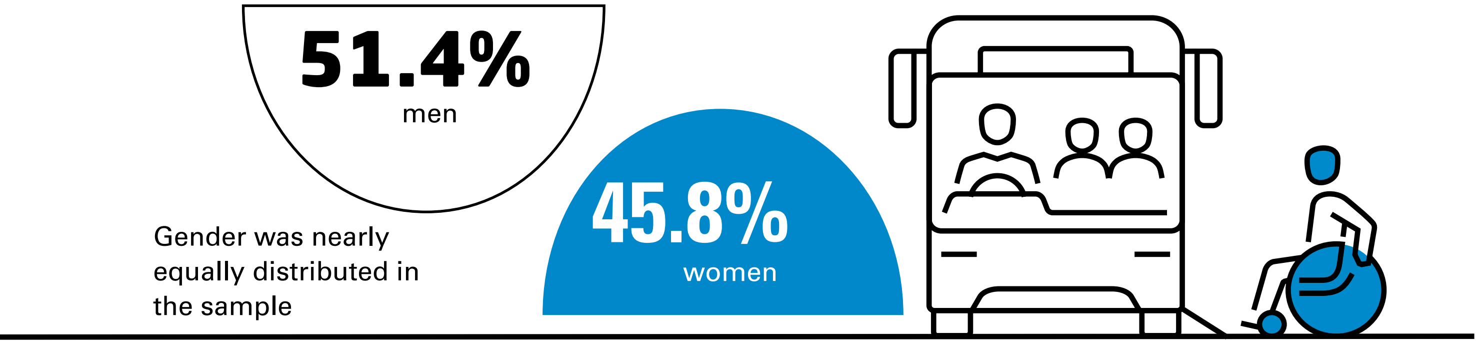
The survey was distributed locally to disability user groups in the seven cities via the local teams, in seven European project cities (Bologna, Brussels, Cagliari, Lisbon, Sofia, Stockholm and Zagreb), and more generally through the European Network on Independent Living (ENIL) and other European-wide organisations working with persons with different disabilities and access needs. The survey was also actively distributed through ENIL's social media pages and other channels, such as regular members' mailing and the monthly newsletter. In general, more than 121 local, regional and international organizations contributed to disseminating the survey in question.

2. Results

A. Participants

The final sample comprised 553 individuals. The majority of respondents filled in the surveys by themselves as persons with disabilities (87.7%). However, in 68 cases (12.3%) responses were given by other persons answering on behalf of the person with disability. Persons answering on behalf of a person with disability represented primarily respondents with intellectual disabilities (58%, n= 21), implicating that the majority of persons with intellectual disabilities did not participate on their own.

As shown in Figure 1, respondents from 21 countries were represented in the sample. However, the number of the study participants varied greatly between the countries. The countries with the highest numbers of study participants were Italy (n= 128), Germany (n= 90) and Croatia (n= 88). In contrast, only one



Gender was nearly equally distributed in the sample

person participated per each of Bosnia and Herzegovina, Poland, Romania, Russia and Switzerland.

Gender was nearly equally distributed in the sample with slightly more men (51.4%) than women (45.8%). The gender distribution, however, varied as per the forms of disability. The share of male respondents was higher for the group of respondents with visual impairment (58.4%), yet lower for mental health issues (38.3%) and intellectual disabilities (44.4%). The age range of respondents was between 16 and 99, with the mean age amounting to 46.41 years (SD= 15.7 years).

Figure 2 shows the distribution of respondents for each type of disability. Before conducting the survey, we contacted six different European organizations working with persons with different types of disabilities to ask which terms these persons preferred to be used when referring to their disabilities. We used these terms throughout all of the TRIPS project, including this research (Alčiauskaitė and others, 2020).

Figure 1. Number of respondents per country

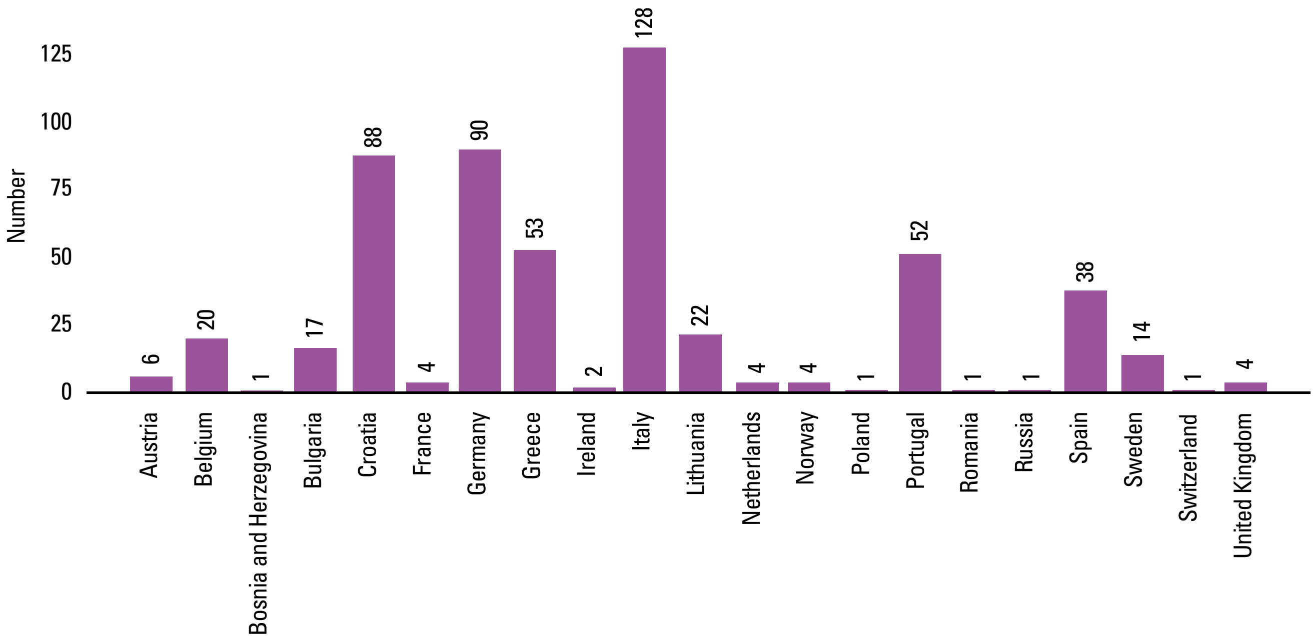
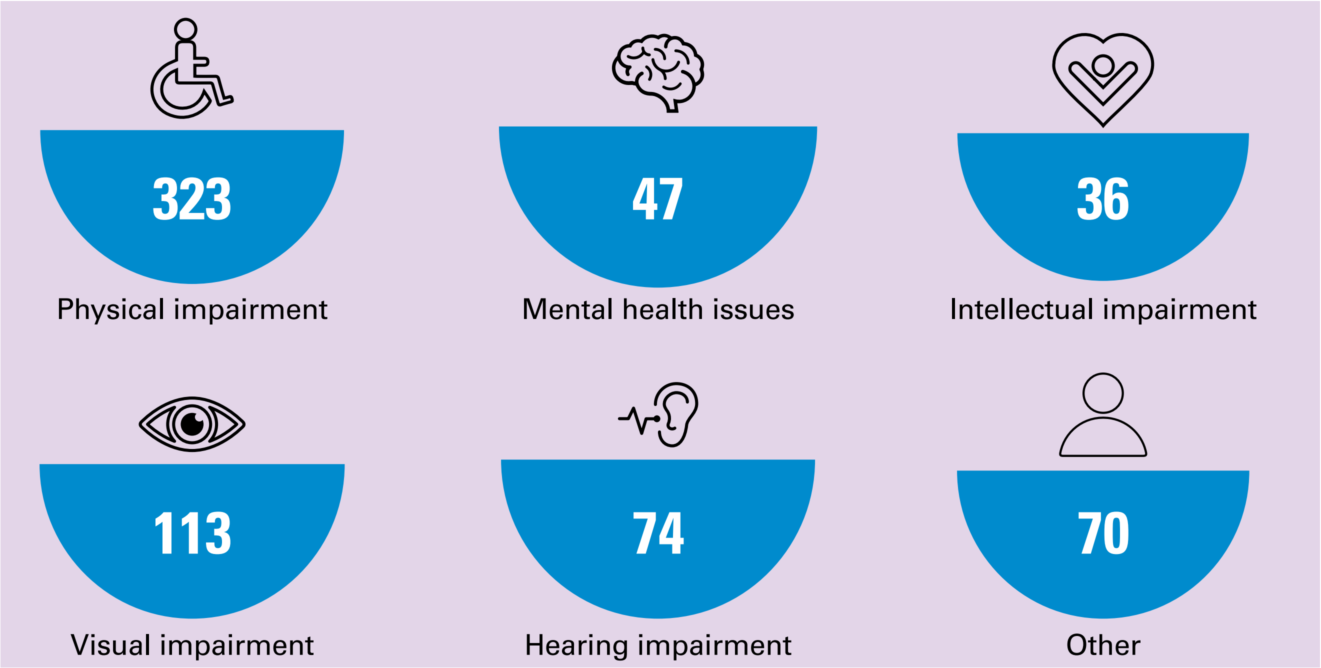


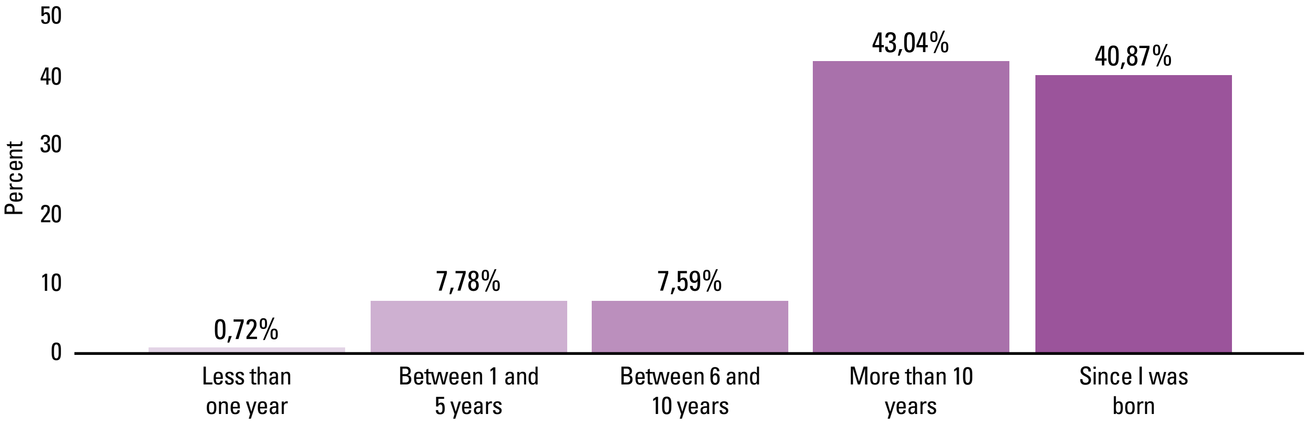
Figure 2. Number of respondents per type of disability



The majority of respondents were with physical disabilities (n= 323, 58.4%), 113 persons (17%) were with visual impairments, and slightly fewer respondents (n= 74, 11.6%) had hearing impairments. The minority of respondents were with intellectual disabilities (n= 36, 6.5%), or had mental health issues (n= 47, 8.5%).

With regard to the time participants have lived with their disabilities, the analysis revealed that the majority of respondents were either born with their disability (40.9%) or had been living with a disability for more than 10 years (43.0%) (figure 3).

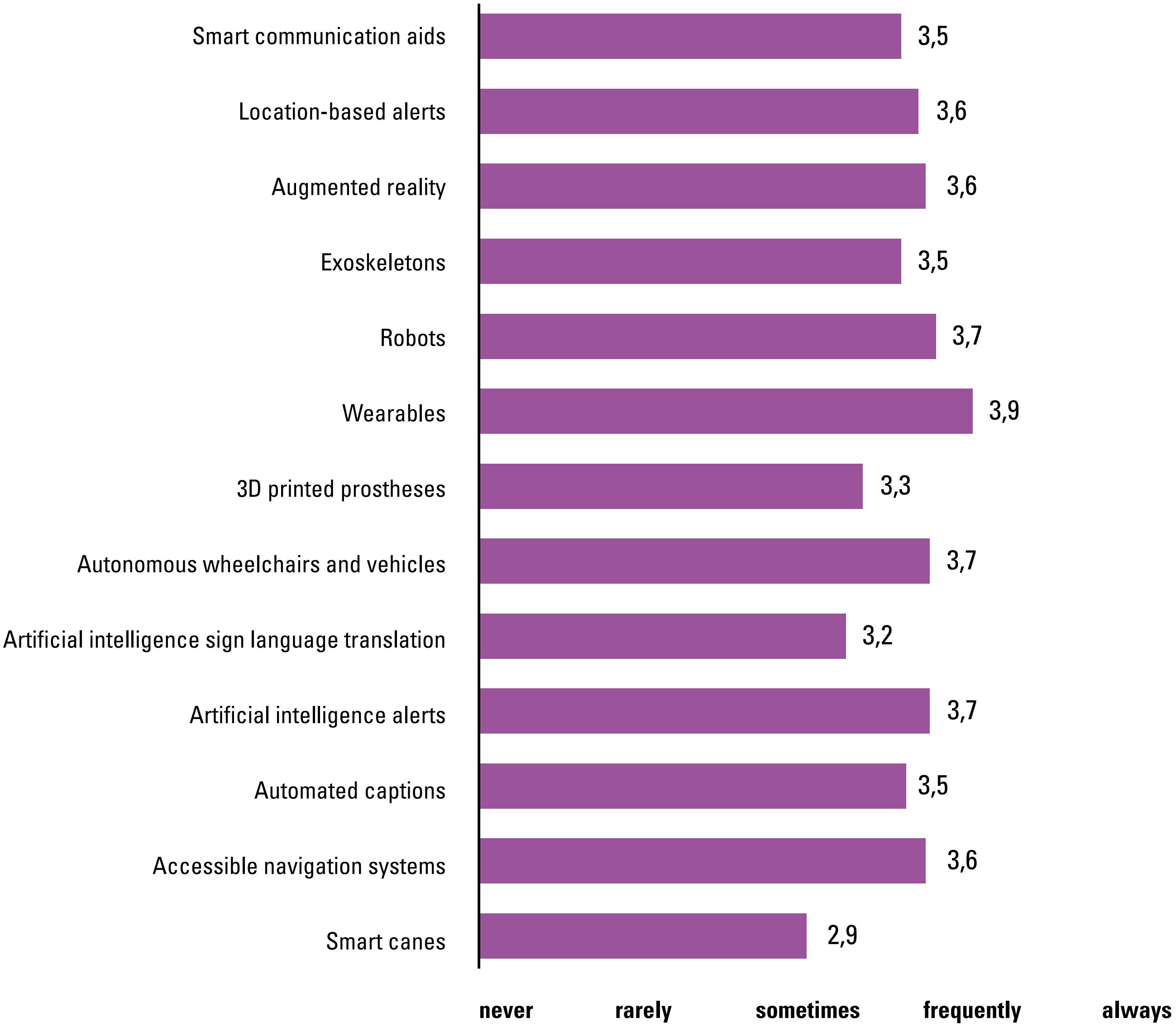
Figure 3. Duration of how long a respondent has had a disability



B. Users' assessment of digital assistive technologies

When it comes to digital assistive technology, the respondents were asked to state which of the assistive technologies from the list they would use and how often would they use it. As shown in figure 4, most of them picked the option "sometimes". Regardless of the type of disability, the most favourable choice from the list were wearables (M= 3.9, SD= 1.3), AI alerts (M= 3.7, SD= 1.3), robots (M= 3.7, SD= 1.5), as well as autonomous wheelchairs and vehicles (M= 3.7, SD= 1.4).

Figure 4. Users' intention to use digital assistive technologies



We also assumed that persons with different types of disabilities would prefer different assistive technologies, as not all are applicable to their access needs. Therefore, in this study we also enquired which assistive technologies respondents regarded as non-applicable, i.e. not appropriate for their disability, in aims at seeing which of these assistive technologies should be excluded from consideration as it is mentioned in the table.

As expected, respondents saw that smart canes and automated captions were specialised tools for persons with visual and hearing impairments. Meanwhile, robots, AR and AI alerts seemed to be applicable for respondents across all types of disabilities. Somewhat less expected, accessible navigation systems were welcome by persons with visual impairments and by persons with intellectual disabilities. AI alerts were deemed applicable by those with intellectual disabilities who were also open to other assistive technologies, like location-based alerts, AR, robots, smart communication aids and even autonomous wheelchairs.

Automated captions and AI alerts were seen as useful tools by respondents with hearing impairments. Persons with visual impairments would welcome accessible navigation systems, robots and augmented reality solutions. Meanwhile, those with physical impairments would prefer a variety of specialised solutions, such as autonomous wheelchairs and exoskeletons, to more general ones, such as wearables, robots, location-based services and to some extent augmented reality.

Assistive technologies that were considered non-applicable as per the type of disability

Type of disability	Digital assistive technology												
	Smart canes	Accessible navigation systems	Automated captions	AI alerts	AI sign language translator	Autonomous wheelchairs and vehicles	3D-printed prostheses	Wearables	Robots	Exoskeletons	Augmented reality	Location-based alerts	Smart communication aids
Intellectual impairment	36.1	42.9	25.0	8.3	30.6	13.9	25.0	11.1	2.8	16.7	11.1	5.6	16.7
Mental health issues	46.8	38.3	31.9	21.3	40.4	25.5	38.3	14.9	12.8	21.3	10.6	12.8	29.8
Hearing impairment	48.6	40.5	9.5	17.6	21.6	48.6	50.0	39.2	33.8	47.3	32.4	23.0	32.4
Visual impairment	15.9	6.2	25.7	13.3	41.6	39.8	50.4	31.0	16.8	54.9	9.7	22.1	37.2
Physical impairment	61.6	39.9	43.7	37.5	52.0	13.3	40.2	9.3	7.4	13.9	20.7	15.4	36.2

3. Discussion

The World Health Organization (WHO) defines assistive technology as 'assistive products and related systems and services developed for individuals to maintain or improve functioning, and thereby promote well-being' (WHO, 2016). It can be more specifically defined as technology that is used on an ongoing basis to support individuals with disabilities to become more independent. Despite the continuous process of innovation and development of new assistive technologies, it is important to assess if persons with disabilities are actually willing to use these technologies.

To find this out, we asked respondents with different types of disabilities whether they would use 13 types of digital assistive technologies. Most respondents, irrespective of the type of their impairments or disabilities, would welcome and frequently use wearables, AI alerts and robots. Previous studies have also confirmed that persons with certain disabilities might highly benefit from these assistive technologies. For example, Cook, Encarnação & Adams (2010) agreed that robots could assist persons with mobility impairments in play and academic activities. They not only allow them to actively participate in the activities, with direct impact on the development of their cognitive, social and linguistic skills, but also provide a means to assess children's understanding of cognitive concepts when standard tests cannot be used due to physical or language limitations.

Despite the high intention to use wearables, and the increasing use of such technology for work, home and leisure activities, there is still room for improvement. As augmentative tools for engagement, control and information, these technologies should not only be usable, but also accessible and inclusive for persons with different disabilities. If designed correctly, wearables may allow greater civic and community participation for users with disabilities (Moon, Baker & Goughnour, 2019).

Accessible navigation systems were welcome by persons with visual impairments and also by persons with intellectual disabilities. AI alerts were particularly welcome by those with intellectual disabilities who were also open to other assistive technologies, like location-based alerts, AR, robots, smart communication aids and autonomous wheelchairs. We should also emphasise that these views may also reflect caregivers' needs, as in many cases caregivers replied on behalf of persons with disabilities. In this study, 21 responses were given by other persons answering on behalf of a person with intellectual disability. Ideally, the said persons were supposed to reflect the views of the persons with intellectual disabilities, but it is still likely that they have expressed their personal opinion as well, even if unintentionally (Gjertsen, 2019).

When it comes to assistive technologies, persons with intellectual disabilities are unfortunately rather underrepresented, but previous studies revealed that smart assistive technologies can be very beneficial to them. According to Morash-Macneil, Johnson & Ryan (2018), assistive technologies can help support the employment skills of individuals with intellectual disabilities by increasing their work performance in respect to productivity, navigation, time management and task completion.

Automated captions and AI alerts were deemed useful tools by those with hearing impairments. Those with visual impairments welcomed accessible navigation systems, robots and AR solutions. Persons with physical disabilities welcomed a variety of specialised solutions from autonomous wheelchairs to more general ones, such as wearables, robots, location-based services and AR to some extent. As expected, smart canes and automated captions were seen as specialised tools for those with visual and hearing impairments. Somewhat less expected, accessible navigation systems were welcome not only by persons with visual impairment, but also by persons with intellectual disabilities. AI alerts were particularly welcome by those with intellectual disabilities who were also open to a host of other assistive technologies, like location-based alerts, AR, robots, smart communication aids and autonomous wheelchairs.

Our findings confirm the previous research stating that digital assistive technologies can promote educational, psychological and social benefits for persons with disabilities (McNicholl and others, 2021; Jamwal and others, 2020). However, the users and assistive technology officers must be aware of certain factors, such as inadequate training, device inadequacies, external support availability and the challenge of negotiating multiple information sources, which can hinder effective use of these technologies (McNicholl and others, 2021). Assistive technology practices should focus on harnessing the potential of mainstream devices as assistive technologies for all persons with different disabilities, thus facilitating inclusion and reducing stigma.

4. Recommendations

It is very important to emphasise that creating and developing digital assistive technologies is only the first step in equipping persons with disabilities with devices and technologies to support and increase their personal independence. Therefore, research into users' digital and social barriers is equally important (Kett, Cole & Turner, 2020). Among the different kinds of disabilities, persons with intellectual disabilities in particular have less access to digital devices. The majority of persons with disabilities are willing to use modern technology to help them in mastering their everyday life, and most of them feel optimistic about technological innovations. However, as we have seen in previous studies, not everyone feels competent to use them.

Moreover, it should be noted that the sample consisted of individuals who had access to computers or caregivers and relatives who accessed the survey for them. Thus, it can be assumed that the share of persons with disabilities who do not have access to computers or smartphones is even higher in the general population. Thus, before developing and operating digital mobility services and assistance systems, we need to remove the digital divide so as to facilitate access to digital systems to all.

To improve the use of digital assistive technologies, we recommend that assistive technology suppliers, social services and education systems collaborate to: (a) provide users with disabilities with smart technologies (e.g. smartphones) to enable them to increase their use of technologies and reduce the digital divide; (b) raise their confidence and skill in using digital technologies; and (c) ensure that these assistive technologies suit the access needs of users with different types of disabilities.

Digital technologies offer the opportunity to move away from a “one-size-fits-all” model, and this is especially important as persons with disabilities have varied needs and experiences. Thus, technology must be adaptable to their individual circumstances. To make sure that digital technologies are applicable to users' access needs, it is important to get accessibility experts and persons with disabilities themselves involved in the development process. Such an approach, in which persons with disabilities constitute an integral part of the development process, will yield products and services that can facilitate increased accessibility, independence and community participation (Moon and others, 2019).

5. Limitations

Despite providing promising results, this study has several limitations. Firstly, as in most accessibility research, people with intellectual disabilities were underrepresented in this study. Unlike with other groups of disabilities, this group was younger in age and their caregivers responded on their behalf. We suspect that caregivers were mostly women, who may have special needs that we have not sufficiently captured here, and may require a separate study and analysis in the future.

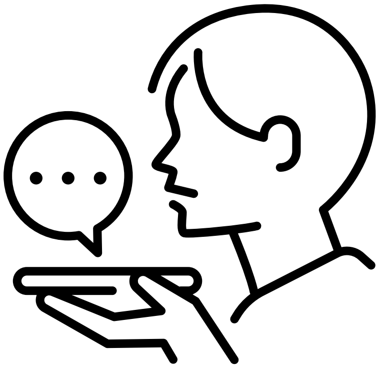
One more limitation of this study is that we have not elaborated on the users' intentions to use the digital assistive technologies, as the survey did not include asking participants to justify their chosen answers. Hence, in future research, it is important to find out more about how familiar persons with disabilities are with digital assistive technologies, and what other possible factors could impact their choice of using this particular assistive technology or not.

Finally, it should be further emphasised that the sample is most probably biased by the self-selection of participants. Thus, poorly connected people or people with limited access to the internet might not have received the invitation. The rather low average age of respondents indicates that the survey may have had some problems in reaching older persons with disabilities.

6. Conclusions

In conclusion, respondents to this survey confirmed their willingness to use digital assistive technologies in their daily life. Most respondents, irrespective of the type of their impairments or disabilities, would welcome and frequently use wearables, AI alerts and robots. In other cases, persons with different impairments prioritized different solutions as they suited different access needs of theirs. These findings prove that in order to enable users with disabilities to own smart assistive technologies, it is crucial to reduce the digital divide and raise users with disabilities' digital competence and confidence in using smart technologies. Only then, assistive technologies can have beneficial effects on facilitating social interactions and bringing about a sense of equality and inclusion. Moreover, universal design should be accelerated to facilitate the use of assistive technologies for persons with different disabilities.

In conclusion, respondents to this survey **confirmed** their **willingness** to use **digital assistive technologies** in their **daily life**



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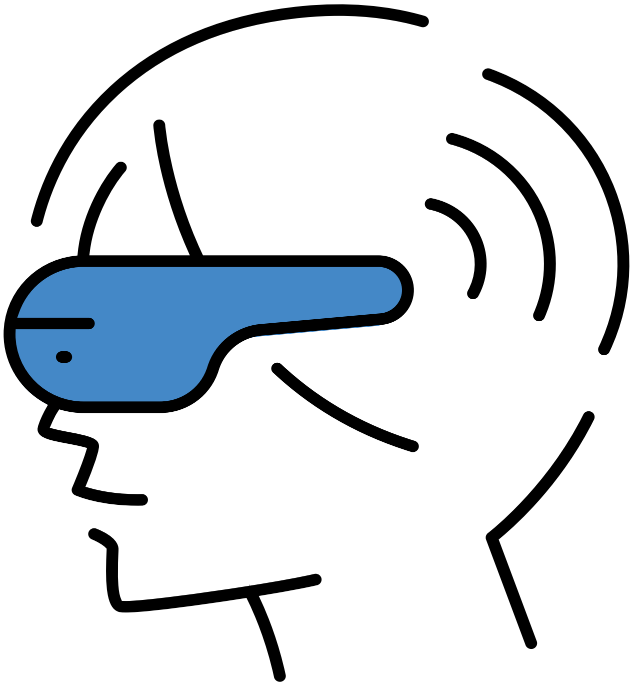


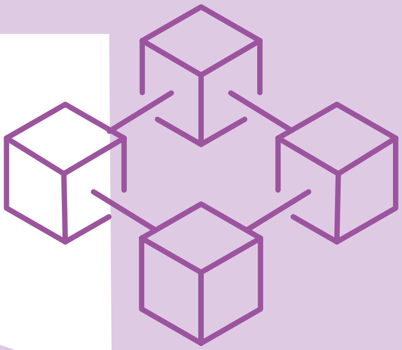
ACCESS TO KNOWLEDGE THROUGH DIGITAL INCLUSION:

THE CASE OF STUDENTS WITH VISUAL DISABILITIES IN CADI AYYAD UNIVERSITY, MOROCCO

Hanane Zaafrani
Mhamed Alouiz

Key messages

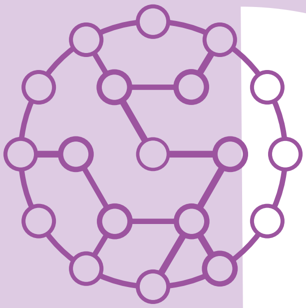
1



Lack of suitable technology infrastructure and insufficient use of technology in education.

2

Lack of enabling environment for digital inclusion of students with visual impairment; lack of free internet for students in general, and for students with visual impairments in particular.



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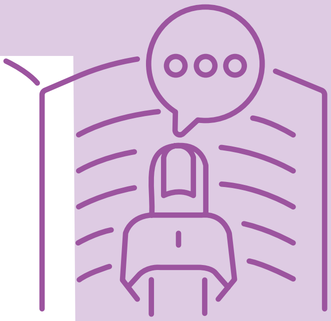


Challenges accessing specialized digital applications for transport and communication, making it difficult for students with visual impairments to travel to and from the university campus.

Introduction

Access to education for students with visual impairments and their inclusion in the education process is a subject of concern for the education sector in Morocco, and for Cadi Ayyad[1] University in particular. Morocco has ratified the Universal Declaration of Human Rights and a number of other international human rights treaties, in addition to various memorandums and agreements that stipulate the right of persons with disabilities to live a decent life. One such instrument is the Convention on the Rights of Persons with Disabilities (CRPD), which states in article 19, entitled "Living independently and being included in the community", that States Parties "recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community".[2]

At the national level, Morocco has adopted legislation to empower and protect persons with disabilities, and specific provisions relating to persons with visual impairments were introduced in the 1980s, with the adoption of Act No. 81–5, "Social Protection for the Blind and Visually Impaired", in 1980.[3] Nowadays, disability inclusion has become a key issue for education technology specialists and within educational institutions, and they have mainstreamed it into their policies and programmes to improve the quality of higher education.

This study aims to examine access to digitization for students with visual impairments at Cadi Ayyad University, and the resulting impact on the quality of their educational careers and lives in general, and to assess how well and through which mechanisms digitization is being applied to the learning process at the university.

Cadi Ayyad University has set up a Centre for Inclusive Education and Social Responsibility.[4] Professors, administrators and students have worked together to develop a multi-year strategy and programme of work for inclusive education, to promote inclusion of persons with disabilities in systems of education, training and academic research, and empower them to exercise their right to acquire suitable education, skills and abilities. The strategy aims to provide students with disabilities with the services they need at every stage of their university career.

Students need to meet certain basic conditions, including in terms of e-accessibility and basic computer and software literacy, to allow them to participate in educational activities and acquire academic knowledge. In today's information society, challenges arise when it comes to disseminating and using digital tools and enabling students with visual impairments to access university education on an equal basis with other students.

We must therefore ask the following questions: to what extent do universities provide the means for students (in general, and those with visual impairments in particular) to access education services and benefit from facilitation measures such as digital applications, in order to promote equal opportunities and enable equal academic attainment? How do students with visual impairments access digitization at Cadi Ayyad University? Is this access provided as standard, or on a limited basis, despite its vital role since the onset of changes during the Covid-19 pandemic?

This also leads us to the following subsidiary questions:

- To what extent do students with visual impairments use artificial intelligence (AI) to access education, and do they do so in the same way as other students at Cadi Ayyad University?

- To what extent does a lack of specialized learning tools prevent these students from accessing digitization?
- Are problems accessing digitization related to the particular circumstances of students with visual impairment, or the university's ability to address them?

1. Basis of the study

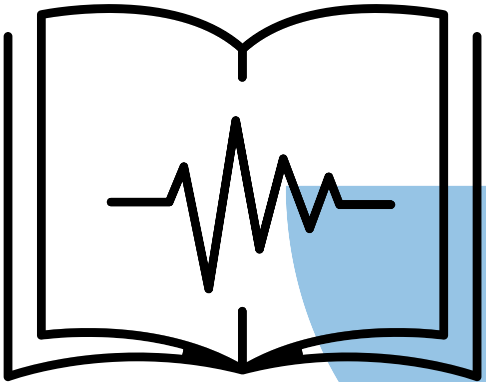
A. Previous research

A number of studies have been carried out around the world on the issue of access to digitization for students with visual impairment.

Mahanta, Abhijeet and others studied a voice assistant designed to enhance visual perception for students with visual impairment. This Android application helps persons with visual impairments move around and live more independently by capturing input data onto a smartphone in real time, for example reading a restaurant menu or helping the user to make a hotel reservation or find their personal belongings. It also recognises objects in the user's surroundings, and uses a voice control mechanism to provide feedback, allowing the user to perform a range of tasks by voice command.[5]

Shneha Padma and others studied how AI can improve the lives of persons with partial visual impairments and alleviate difficulties in their daily lives, particularly when they encounter unexpected situations as a result of entering unfamiliar environments which can expose them to safety risks. For example, some modern AI systems can detect an approaching individual and, if that person appears to take an attack stance, alert the visually impaired person to the danger and direct him or her to take appropriate action. This study also touches on artificial emotional intelligence, also known as 'emotion recognition' or 'emotion detection' technology, which is built using AI techniques such as image processing, deep learning, voice output and voice recognition, and uses big data to store images and sound files. According to the study, major companies such as Microsoft, Facebook and Accenture are making efforts to help persons with disabilities (including those with visual impairments) to use AI[6] to improve their lives and live independently in society.

According to Samigulina and others, innovative intelligent systems should be developed to help persons with visual impairments engage in distance learning. To that end, they propose a comprehensive AI based approach to create an accessible learning environment and identify the intellectual, physical and psychological characteristics of digital and informational cognition and awareness, based on the cognitive approach.[7]



With regard to Morocco-based research, Mustafa Orhay and others conducted a study entitled, "Teaching at the Institutions of Cadi Ayyad University During the Covid-19 Pandemic. Stage 1 Research: Pedagogical Continuity in Distance Learning", which examined the role of distance learning, a teaching model that emerged as the only means of ensuring pedagogical continuity, in tackling biases in the use of technology. The Centre for Pedagogical Studies, Evaluation and Research at the university carried out a study which aimed to analyze the distance learning approach, identify its strengths and weaknesses and address them by adopting appropriate administrative and educational practices. The study was accompanied by a survey which focused on the three main factors involved in pedagogical continuity, namely teachers, students and institutional measures. Questionnaires were used to collect the views of research professors and students, and interviews were conducted with institutional and management officials. The study concludes with a series of recommendations for institutional managers, universities, teachers and researchers.[8]

B. Concepts

This study uses the concepts of 'digitization', 'artificial intelligence' and 'students with visual impairments' as defined below. Definitions of other concepts are provided as they occur throughout the text.

1. Digitization

According to Terry Kenney, digitization is the process of using automated software to convert a variety of different information sources (such as books, periodicals, images and sound recordings) into machine-readable format using a system of bits – the basic unit of information used in any computer-based information system. The process involves using specialized devices and technology to convert information into a set of binary digits.[9]

2. Artificial intelligence

The term 'artificial intelligence' (AI) was coined at the Dartmouth Summer Research Project on Artificial Intelligence in 1956, and can be defined as "the science of making machines do what humans do with a certain degree of intelligence". Aimed at using machines to solve certain problems more effectively than humans can, AI is now used in many different fields, including human and social sciences, information technology (IT), mathematics and cognitive sciences. It is not merely a field of research, but an entire approach geared towards the ambitious goal of understanding and simulating human perception and creating cognitive processes similar to those used by humans.[10]

3. Students with visual impairments

This term refers to students who have lost their sense of sight either completely,[11] in which case they read Braille, or partially, in which case they can read written material after making certain adjustments, for example by increasing text size (either automatically by zooming in, or manually using a magnifying lens). The medical definition, which is based on visual acuity, does not account for static information relating to how an individual performs tasks in a given social environment. It has therefore been necessary to come up with an educational definition of visual impairment, which focuses on how those individuals acquire language and knowledge.[12] In the context of education, a student with complete visual impairment is defined as one whose disability prevents them from learning through conventional methods, and who therefore requires educational materials, teaching methods and the general university environment to be specially adapted.[13] According to the functional definition, a person with complete visual impairment is someone whose blindness is so severe that they can only read using Braille.

This study offers a practical definition of students with visual impairment, based on the aforementioned medical, educational and functional definitions, and taking into consideration the situation at Cadi Ayyad University, which forms the field reference and organizational framework of this study, and serves as the selection pool for the sample group.

C. Problem

Having reviewed the aforementioned studies, which highlight the challenges encountered by students with visual impairments in the context of digital learning, especially since educational institutions moved towards digital formats as a result of the Covid-19 pandemic, the main problem for researchers is to devise procedural mechanisms to enable students with visual impairments to engage in AI-assisted digital learning.

D. Context

This study will assess how much access students with visual impairments have to digital learning and how well they are included in the education process at Cadi Ayyad University, particularly at its open access faculties in Marrakesh, such as the Faculty of Letters and Human Sciences, Faculty of Arabic Language, and Faculty of Judicial, Economic and Social Sciences. The study focuses on the efforts made by those faculties to include students with visual impairment, who constitute one of the most vulnerable social groups, with the highest rates of illiteracy and university drop-out.

Universities are key components of society and represent one of its most important institutions, since they are bound up in an integrated and structured system of social norms which are used to uphold basic values of society. They serve an integrative function, by empowering students and equipping them with a set of cognitive and technical skills that they need to take part in education, work and society.

E. Methodology

This study was conducted based on the methodology of semi-guided interviews with students with visual impairment. The field work was carried out between 12 and 24 February 2022.

The study uses the research technique of purposive sampling, which refers to “a sample chosen intentionally and specifically because it is believed to truly represent the target population group. This is a type of non-probability sampling, whereby the researcher selects certain individuals on the basis of their specific characteristics and disregards all those who do not have those characteristics. The resulting sample thus has all the necessary features to form the appropriate research base. Purposive sampling – also known as intentional sampling – is essentially used to enable the researcher to select a sample that is fully representative of a community that has specific and known characteristics, rather than using simple random sampling methods”.[14]

The study involves 14 out of a total 30 students (both male and female) with visual impairments at Cadi Ayyad University in Marrakesh, listed as follows:

Name	Gender	Year of birth	Region	Father's profession	Level of study & term	Programme of study	Faculty	Mother's profession	No. of siblings with disabilities
M. B.	Female	1999	Marrakesh	Tailor	Bachelor's, 6th term	English	Letters and Human Sciences	Domestic worker	0
S. B.	Female	1991	Marrakesh	Deceased	Bachelor's, 6th term	Arabic	Letters and Human Sciences	Housewife	0
F. A.	Female	1999	Marrakesh	Retired civil servant	Bachelor's, 6th term	English	Letters and Human Sciences	Housewife	0
M. A.	Male	1994	Casablanca	Civil servant	Bachelor's, 4th term	Sociology	Letters and Human Sciences	Housewife	0
S. A.	Male	1999	Sidi Zouine	Night guard	Bachelor's, 2nd term	History	Letters and Human Sciences	Housewife	0
Y. A.	Male	2002	Marrakesh	Tourism sector	Bachelor's, 2nd term	English	Letters and Human Sciences	Tourism sector	0
A. M.	Female	1998	Sidi Bou Othmane	Deceased	Bachelor's, 2nd term	Arabic	Letters and Human Sciences	Housewife	0
Y. F.	Male	1994	Sidi Zouine	Guard	Bachelor's, 6th term	Islamic studies	Letters and Human Sciences	Housewife	0
M. N.	Male	1998	Marrakesh	Retired	Master's, 2nd term	English	Letters and Human Sciences	Housewife	0
H. A.	Male	1998	Ourika	Deceased	Bachelor's, 6th term	Arabic law	Judicial, Economic and Social Sciences	Housewife	0
Kh. A.	Male	2001	Marrakesh	Civil servant	Bachelor's, 6th term	Arab public law	Judicial, Economic and Social Sciences	Housewife	1
S. R.	Male	1998	Marrakesh area	Farmer	Master's, 4th term	Public law	Judicial, Economic and Social Sciences	Housewife	1
A. Z.	Male	1999	Marrakesh	Deceased	Bachelor's, 4th term	Arabic law	Judicial, Economic and Social Sciences	Small restaurant owner	0
N. A.	Female	1992	Harbil	Salesman	Bachelor's, 6th term	Arab private law	Judicial, Economic and Social Sciences	Housewife	1

Source: Field research, February 2022.

According to well-known principles in sociological research, the required sample size depends on the type of methodological and analytical approach used, and on the process of "saturation". According to Guest, Bunce and Johnson, saturation occurs after a maximum of 12 interviews with sample units, and the core themes begin to emerge after the sixth interview, especially in a narrow field of research with a homogenous target population. In the context of this field research, saturation was reached after 14 full interviews, at which point the information became repetitive.[15]

2. Results

This section is divided into two parts: firstly, a data analysis of students with visual impairments at Cadi Ayyad University and the way in which they interact with their university environment, including a brief overview of the subjects they study, their gender, region and linguistic preferences; and secondly, an in-depth analysis of each student's interaction with their university in terms of e-accessibility, with a view to assessing the availability of digital services to help those students overcome challenges related to their visual impairments.

A. Analysis of sample data

14 interviews were held with a sample group consisting of 14 male and female students with visual impairments at Cadi Ayyad University, Marrakesh, Morocco.

Programme of study

The students were enrolled in a varied range of different degree programmes, namely: law (5 students), English (4), Arabic (2), Islamic studies (1), history (1), and sociology (1).

It is worth noting that the majority of students with visual impairments were studying law or English, as opposed to other subjects such as geography, which is a technical cognitive science that relies on examining and drawing maps and other cartographic material. While those materials can be digitized, both the nature of the subject and its reliance on the colour spectrum make it a challenging subject for students with visual impairment.

One may assume that the students opted for the above-mentioned subjects partly because the learning materials used do not pose perception difficulties for those with visual impairments, and partly because of the general broad appeal of the English language, which is gaining in popularity; with its vital role in the present and future business world and close ties to the jobs market, English is an attractive subject for students in general, and those with visual impairments in particular.

Gender

The sample, which consists of nine males and five females, is reflective of the higher proportion of males who have access to and enter into higher education.

Degree type

12 of the students surveyed were studying at bachelor's level, and only two at master's level. It should be noted that the number of students typically decreases with each stage of education, as students leave the education system. With regard to the low representation of students with visual impairments on master's courses, one of the female interviewees explained this by saying that master's degrees posed a challenge in terms of exams, textbooks and attendance: "We can't

do a master's course, they won't select us, and it would be very difficult for us to reach that stage of education".

Region

Most of the students in the sample group were from the urban centre of Marrakesh, which shows that these students have better access to higher education and more of them remain in education than their peers in rural areas, since the latter live in more disadvantaged conditions.

B. E-accessibility for students with visual impairment: comparison with the overall situation at the university

1. Tools used by students to interact with the university

Modern technology (and digitization in particular) has improved education quality, as digital learning tools and platforms have enabled students to interact remotely with university teaching and administration. According to the survey responses, the university website has made students' lives easier: "We find it fairly easy to find the university registration site, access our results and use the timetable, especially at the Faculty of Letters and Human Sciences where you can download resources from the online platform, unlike the platform of the Faculty of Judicial, Economic and Social Sciences, which is still unavailable, most of us can't log onto it".[16]

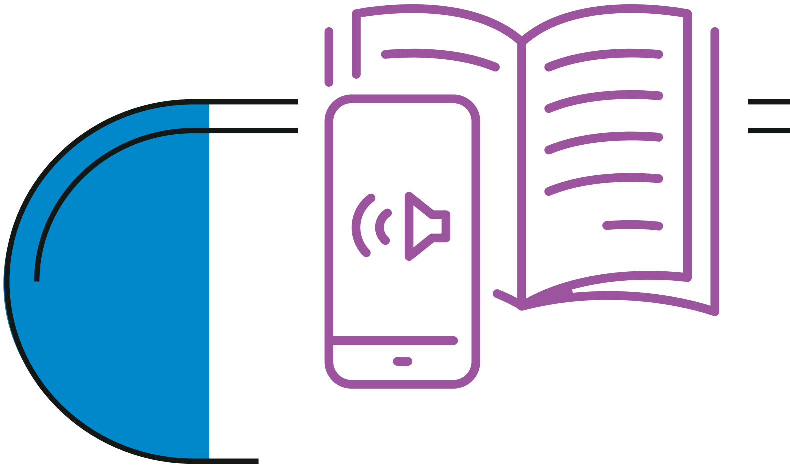
To acquire knowledge in an academic setting, one must not only have a certain level of desire to learn, but also commit to a long course of study. According to the interview responses, each student with visual impairments had their own idea of what studying and university degrees meant to them. This is because, according to Amartya Sen,[17] students' personal and social lives are closely connected to their studies and each person needs to learn using methods that accommodate their individual characteristics and develop their own specific skills. To enable this, efforts must be made to facilitate the learning process and place education within their reach. According to one of the interviewees, one of the main challenges for students with disabilities is, "a lack of ongoing care and attention by the university institutions which were created for that very purpose".[18] A key way of providing that care is through the use of technology.

Below are a number of assistive tools, including IT software and applications, that can help students with visual impairments to access digitized materials.

2. Ways to include students with visual impairment: e-accessibility and access to services

To improve access to digital education, specialized applications for students with visual impairments have been developed to help them use the internet, access global libraries and databases, and consult theoretical studies and lectures provided by the university in digital format, thus giving them a great deal of independence. The interviewees reported that lessons were made available in PDF, PowerPoint and doc.x format, as well as some on video. Volunteers or family members assisted them by recording lessons and books in Arabic, and lessons in English were easier to read. The national digital library provided access to the EBSCO website, but no access was given to the university libraries.[19]

Students with visual impairments engage with university learning differently and have a different learning experience to other students; for example, most students with visual



impairments follow their lessons at home and only attend university in person to sit exams.

According to one of the students in the sample, education means, “the ability to advance in intellectual, social and financial terms”.[20] Studying is an effective way for individuals and families to improve their financial circumstances and sociocultural standing. However, viewed from a purely economic standpoint, education does not appear to offer students with visual impairments the ability to improve their life circumstances as much as they might hope, because they lack certain qualifications that are not related to their level of education, but rather to their health.

With that in mind, one must question the part played by society in constructing the concept of disability, since the social model of disability takes into account not only medical and biological factors, but also society’s perception of persons with disabilities. Thus, society as a whole – including persons with disabilities themselves – is involved in building disability as a social construct, which can form a barrier that prevents them from fully exercising their rights and participating in social life. Solutions must therefore be sought to prevent persons with disabilities from being excluded and marginalized; while various educational and institutions and training centres are doing so in theory, in practical terms these individuals still face significant hurdles that impede them from achieving their goals on multiple fronts.

With regard to barriers to e-accessibility, one of the interviewees reported that students with visual impairments at Cadi Ayyad University struggled to access information because they had not received sufficient computer training.[21] To address this problem, all students – without exception – should be offered equal opportunities in education and training. According to contemporary educational sociology, inequalities in teaching are mainly the result of how education programmes are structured, since they focus on exclusion resulting from the educational institutions’ approaches, rather than from external factors.[22]

Families play a key role in supplying students with visual impairments with the necessary financial means to pursue their studies and access education opportunities. Entering into academic culture may require students to distance themselves from their original culture in order to fully adopt the culture and values associated with education; this makes education a type of acculturation.[23] When done positively, this allows universities to perform their essential function of helping students to increase their earning potential and achieve success in their personal, professional and marital lives.[24]

One of the main factors contributing to unequal access to digitization is the lack of an effective and well-developed services structure incorporating advanced digital technology. These insufficiencies make it difficult for persons with disabilities to access transport services, public spaces and other facilities, as highlighted by many academics, activists, and disability rights defenders.[25]

3. Tools and technologies for students with visual impairments

Specialized IT tools, including mobility and communication apps, can help students with visual impairments improve their daily lives, strengthen their social connections, support one another and become better included in educational institutions. Large companies such as Microsoft, Facebook and Whatsapp have been endeavouring to use modern technology to help improve many aspects of these individuals' lives.

The majority of interviewees reported using screen-reader apps such as TalkBack and VoiceOver on their smartphones (both Android and iPhone), and NVDA and JAWS on computers (using either Windows or Mac operating systems). Three of the interviewees used an iPhone, and eleven used an Android smartphone. Half of the interviewees used a computer, and some used Moovit transport app.

Some students at Cadi Ayyad University have difficulty travelling to university since they do not have access to these transport and mobility apps. According to one interviewee, "it's difficult to get to the faculty, we have to get there by ourselves, using smartphones and digital maps, for example we use Moovit which tells us where to find the bus stop, but there are other much more accurate apps, like Lazarillo, which we can't use".[26]

To overcome these problems, the university must do more to meet the expectations of students by tackling linguistic inequalities, drawing attention to the challenges faced by students with visual impairment (and other students) and providing them with the tools and services they require. Currently, the university has neither the relevant specialized language services nor the necessary structures and teacher training to use them, with the excuse that the group concerned is only a minority.

4. What students with visual impairments expect from the university

As a key component in development, education is a priority for the State. However, a number of barriers stand in the way of equal opportunities for students in the higher education sector, including at Cadi Ayyad University. These factors include overcrowding, inadequate basic facilities and a lack of access to modern technology to help students engage in academic knowledge and research.

Despite the existence of facilities and support services for students with visual impairment, these students still face numerous difficulties that must be investigated and addressed. For example, the university could provide paid subscriptions to apps such as @Voice Aloud Reader, Envision AI, and Kibo, all of which use AI and optical character recognition (OCR) technology to help students read and learn, by analysing images and converting them into sound files and easy-to-read texts. These apps, which are not currently provided by the university, could help to bridge the gap between students' expectations of the university and what the university provides in reality.

While the university has made attempts to reform and modernize, there remains a clear lack of equal opportunities between students with visual impairments and other students at the university, which hampers their empowerment and impedes their access to education. This has damaged the relationship between students and the university, undermined their trust in the institution and depleted their energy. Access to digital learning at the university's institutions should therefore be reviewed.

If one considers that development involves expanding the availability of education and training and providing the means to access it without discrimination among students on the basis of gender, disability or other factors, as stipulated by the CRPD, then the university is still failing to meet this requirement.

3. Recommendations

Having considered the characteristics of the study sample (i.e. students with visual impairments at Cadi Ayyad University) and explored e-accessibility-related issues by analysing interviews with individuals in the sample group to assess their level of inclusion in the university, we have concluded that digitization should be introduced into academic education as follows:

- Convert periodicals and publications into digital format, which not only reduce paper and printing costs but also caters to the specific needs of students with different forms of visual impairment, since digitalized written materials can then be converted into Braille or audio files as required.

- Provide free internet to students in general, and students with visual impairments in particular.

- Provide students with access to AI-assisted mobility and learning apps for the duration of their course of study.

- Run workshops to teach students with visual impairments how to use all available digital resources, including AI-based apps, to overcome their educational challenges.

- Provide students with the necessary digital tools and equipment to encourage them to study, especially those in deprived living conditions.

- Create an enabling environment for digital learning using AI-assisted apps, and promote learner independence.

- Set up online discussion groups for distance learners to develop their group work skills.

- Emphasize the importance of self-study.

- Improve the quality of virtual teaching.

- Move towards remote teaching as an option that can be used for certain courses, while also equipping universities for inclusive in-person teaching that caters to various disabilities, including visual impairments. This approach can also be referred to as 'multi-track inclusion'.

- Adopt a new strategy to replace conventional teaching methods with more advanced ones.

- Draw on local, regional and global experience in the field of AI-assisted apps and their use in teaching in general, and teaching students with visual impairments in particular.

- Provide appropriate infrastructure to aid the use of IT tools in education.

- Coordinate with multiple stakeholders in society, including families and transport authorities, so as to meet social inclusion targets for students with visual impairment.

While Cadi Ayyad University has made notable efforts to develop and improve its systems in line with its capacity, the results in addressing this vital issue remain inadequate, especially as regards students with visual impairment; the challenges they face remain largely unaddressed, whether in terms of access to digital learning, fulfilment of their basic needs, or recognition of their rights.

The issue of access to knowledge through digital inclusion of students with visual impairments is perhaps illustrative of Moroccan university culture in general, and Cadi Ayyad University in particular. These institutions have a responsibility to help these students fulfil their academic potential and live independently in society.

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Endnotes

1 Cadi Ayyad University is based in Marrakesh, and covers all the provinces and prefectures of the Marrakesh-Safi region, which is one of the administrative authorities in Morocco's new regional structure adopted in 2012. Marrakesh-Safi has a population of 4 222 217 inhabitants, and is divided into one prefecture and seven territories. With 22 per cent of the population aged 19 and over, demand for higher education is set to rise in the coming decade.

2 Convention on the Rights of Persons with Disabilities (CRPD), United Nations General Assembly, 2006. Morocco's second national disability survey, published in 2014 as part of its reporting obligations under the Convention, and conducted by the Ministry of Solidarity, Social Inclusion and the Family, noted that persons with disabilities represented 6.8 per cent of the population, among which 1.8 per cent were able to access university, with the remainder ceasing education after preparatory school or high school.

3 https://maroc-diplomatique.net/elaboration-dune-politique-publique-integree-visant-promouvoir-droits-des-personnes-en-situation-de-handicap. In its preamble, the Moroccan Constitution of 2011 stipulates the need to develop a unified society where all individuals enjoy security, liberty, equal opportunities, respect, dignity and social justice, based on the principle of correlation between rights and duties. Dahir 1-08-143 of 2011 decrees the publication of the CRPD and its Optional Protocol. Morocco has also adopted Framework Law 97–13 on protection for persons with disabilities. To implement the relevant recommendations, Morocco adopted a 2015–2030 strategy on education and training, which includes a specific project (project 5) on guaranteeing the right of persons with disabilities and special needs to access education and training.

4 Ceirs@uca.ma. The Centre for Inclusive Education and Social Responsibility (CEIRS) at Cadi Ayyad University was established by a university council decision of 3 May 2019, in accordance with university policy and as part of the integrated strategy for inclusive education and social responsibility, in order to act as the technical branch for practical implementation of the strategy within all institutions of the university (both presidency and university institutions). The higher education and academic research programme, as part of the national action plan, includes project 4 entitled, "Empowering students with disabilities or special needs to pursue education". See Cadi Ayyad University annual report 2021, project 4 on empowerment and reference guide for national tracking indicators.

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15 Guest, G., Bunce, A. and Johnson, L., "How many interviews are enough? An experiment with data saturation and variability", Field Methods, 18 1, 2006, pp. 59–82. In Ahjeij, Hassan and Fazza, Jamal (2019), Textbook on Qualitative Research in Social Sciences: Theory and Practice, first edition, pp. 65–62.

16 Interviews 1, 2, 3 and 4, field research, February 2022.

17 Sen, Amartya (1985). Commodities and Capabilities, p. 3. The concept of human capital, which refers to "the sum of a worker's innovative and productive capacity and acquired abilities", is used in the broader sense as it covers creative ingenuity, technical expertise and general knowledge, among other types of knowledge. Human capital is thus a stock that must be built, expanded, utilized and created so that it can grow. Teaching must be geared towards learning different skills in order to meet individuals' needs and aspirations and fulfil their potential for thought and reasoning. Methods must be adapted and implemented to enable interactive participation. This cannot be achieved without promoting access to education.

18 Interview 3, field research, February 2022.

19 Field research, February 2022.

20 Interview 8, field research, February 2022.

21 Interview 10, field research, February 2022.

22 https://www.uca.ma. Mentioned in a lecture by Professor Khadija Zahi, Lectures in Educational Sociology, fourth year, 2019–2020.

23 Bourdieu, Pierre and Passeron, Jean-Claude (1970). La reproduction: Éléments pour une théorie du système d'enseignement (Le sens commun), p. 19.

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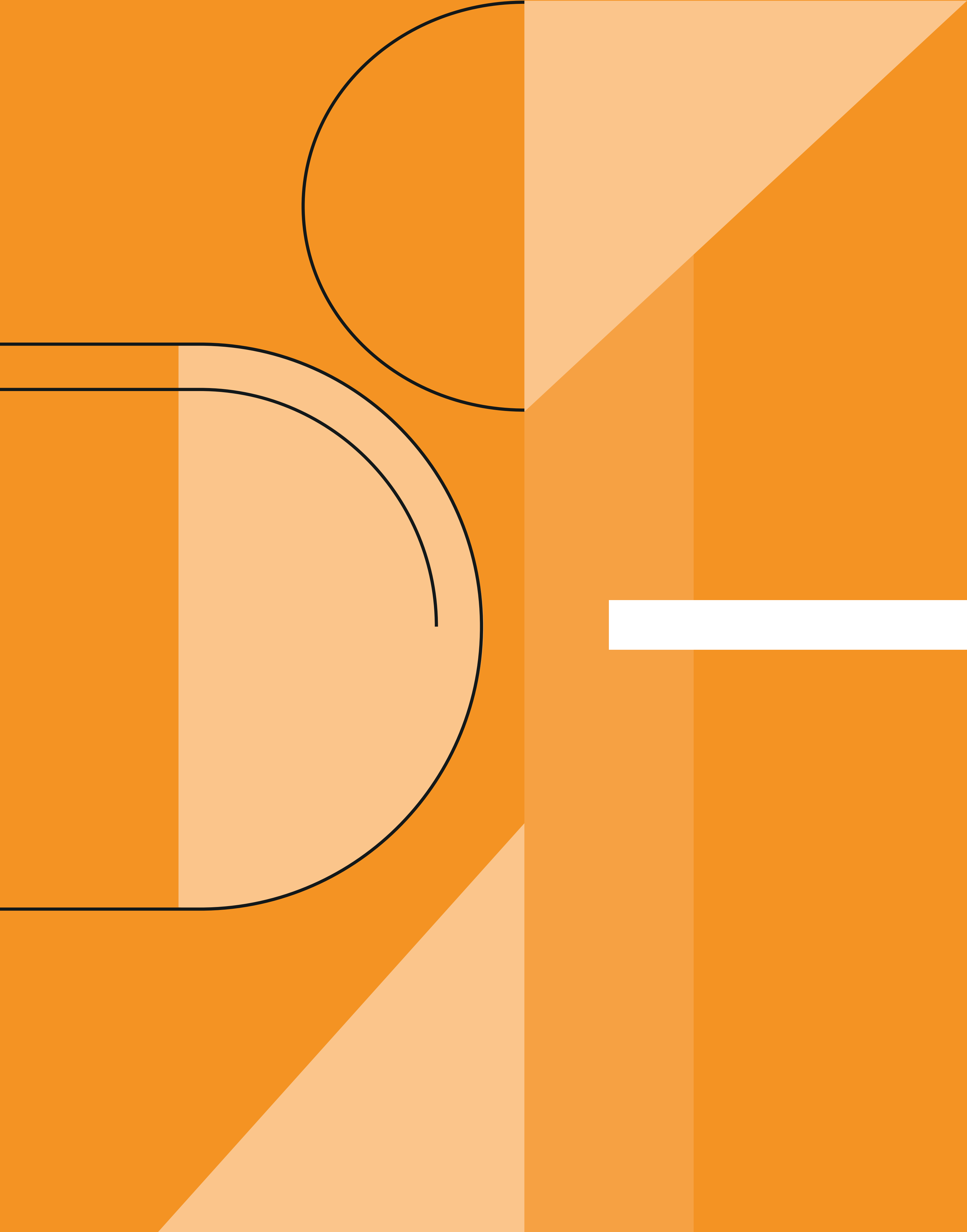
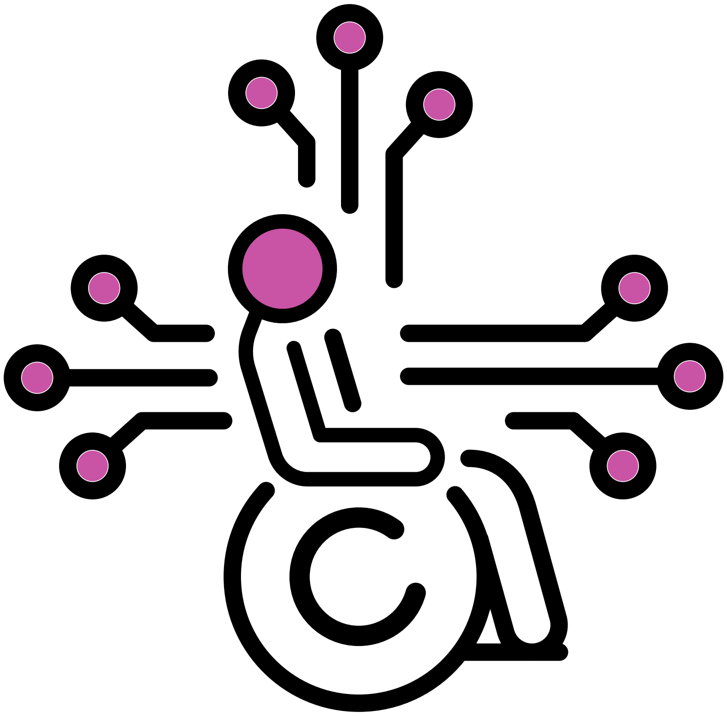
26 Interview 11, field research, February 2022.



INDEPENDENT LIVING FOR CHILDREN AND STUDENTS



PATHOLOGISATION OF DISABLED CHILDHOOD AS AN IMPEDIMENT TO INDEPENDENT LIVING

Rados Keravica

Key messages

1

Disabled adults and children experience similar forms of exclusion based on the perception that their dependencies are natural and inevitable due to the presence of impairment or in the case of children, their age.

2

The findings of the research include:

A. Some participants' understanding of independence as self-sufficiency differs from the meaning of independence promoted by the independent living movement that emphasises interdependence and choice and control over the support that a person receives rather than self-sufficiency;

B. Disability is commonly perceived as a negative difference;

C. Pathologisation of childhood disability incorporates the attachment of negative value to impairment as a bodily difference; and

D. Children are often sidelined in medical encounters and often do not have enough opportunity to express their views or concerns.

3

The risk associated with the pursuit of a medical 'fix' that bears relevance to children's potential for independent living is embodied in four ways:

A. The power of medicine constructs the meaning of independence in terms of self-sufficiency and sets the goals of impairment-related medical interventions in terms of independent functioning;

B. Both children and parents develop an understanding of disability as an individual problem and a negative difference that is best resolved through medical interventions;

C. The pathologisation of impairment leaves little space for disabled children to imagine a fulfilling life and the ability to flourish without pursuing sometimes risky medical interventions; and

D. If children are not allowed and encouraged to express their views, they might miss out on learning that their opinions matter and be less likely to grow up as self-determined individuals.

4

Disabled children need to be provided with the opportunities and support to express their views freely even on sensitive and important issues, such as medical treatment decisions.

Introduction

The independent living philosophy is underpinned by the concepts of autonomy and the self-determination of disabled people [1]. The independent living philosophy, according to Morris, is grounded in three elements: equal opportunity to exercise choice and control, the struggle for an interpretation of the concept of 'independence' that does not imply self-sufficiency and the control of disabled people over the assistance they receive (Morris, 2004, p.427). Disabled people have struggled for a long time to be recognised as adults and fully human and to retain choice and control over their lives (Quinn and Arstein-Kerslake, 2012). The perception of disabled people as dependent has led them to be treated as children and to experience denial of their agency and self-determination (Tisdall, 2012). They are often considered as lacking the capacity to make decisions in their lives and being dependent on the care of others (Arstein-Kerslake and Flynn, 2017). In this regard, disabled adults and children experience similar forms of exclusion on the basis of the perception that their dependency is natural and inevitable due to the presence of impairment or in the case of children, their age (Clark, 2018).

The risk of infantilisation looms large in the lives of disabled people and is embodied in laws and policies, which may promote legal capacity deprivation and the institutionalisation of disabled people, and in family relationships, which may be imbued with paternalism and overprotection (Callus et al., 2019). Frequent infantilisation means disabled people often need to point out that they do not want to be treated as children (Safta-Zecheria, 2018). However, while disabled adults are striving to break away from the status of 'eternal child', the position of disabled children within the disability movement and society as a whole remains unchallenged (Keravica, 2023). While the struggle for the universal right to legal capacity for disabled adults resulted in the codified human rights standards enshrined in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), children are considered as in need of adults' protection and assistance due to their not-fully-evolved capacities (Sandland, 2017). Under the protective paradigm, it is assumed that the adults involved in a child's care are best positioned to determine the best interests of that child (Campoy Cervera, 2017a).

Unlike adults, children cannot exercise their choices freely and may be subjected to paternalism in order to help ensure their full and harmonious development. In the context of healthcare, this paternalism usually takes form in laws and policies that set the age of consent for medical treatment or require children to demonstrate a threshold level of competence, as assessed by a healthcare professional, in order to make autonomous decisions (Alderson, 1990). Children under the age of majority may be the subject of paternalistic interventions undertaken by adults as their legal guardians and in the name of their best interests (Godwin, 2011). Disabled children face the risk of exclusion from decision-making processes in matters important to them due to their age or the presence of an impairment that may lead adults to consider them incompetent (UNICEF, 2013). In the context of these forms of exclusion, what is the relevance of the independent living philosophy for disabled children?

The European Network on Independent Living, a pan-European disabled people's organisation that promotes independent living, makes the following claim in relation to disabled children:

> If disabled people are able to experience independent living from a young age then they are afforded similar opportunities to develop their own life course and personal networks as their non-disabled peers. (European Network on Independent Living, 2014, p.19).

This claim demonstrates that independent living for disabled people does not suddenly start once a person reaches the age of majority. This understanding leads us to think about the ways in which disabled children can be supported and encouraged throughout their childhood to exercise their agency, develop capacities and acquire the experience needed for independent living.

In this paper, I begin by outlining the theoretical framework underpinning my study, drawing on the epistemological framework of the new sociology of childhood and Carol Thomas's work on the socio-relational understanding of disability (Thomas, 2004a; Thomas, 2004b). This section is followed by a consideration of the study design and methodology and related ethical issues. I continue by exploring children's participation through the lens of human rights, analysing how a child's right to be heard is construed from two human rights treaties, namely the UNCRPD and the UNCRC (Convention on the Rights of the Child, 1989). I move then to present emerging findings from my qualitative study that involved disabled children and young people and their parents from England and Serbia. The findings presented relate to the meaning of disability that families develop through encounters with healthcare professionals and the implications of these meanings for disabled children's potential for independent living. Finally, in a discussion section, I reflect on the key lessons learned in terms of the ramifications for disabled children's prospects for independent living.

1. Theoretical framework

The new sociology of childhood, which became prominent in the 1980s and 1990s, espouses the idea that childhood is a social construct rather than a universal phenomenon (James and Prout, 1990). In the new sociology, children's inferiority to adults is not determined solely by their biological development but is also effected through intergenerational subordination to adult knowledge and authority (Mayall, 2002). Moving away from the perception of childhood as inferior to adulthood, the new sociology of childhood had the standpoint that a child is a social actor capable of shaping the world around them while at the same time being influenced by that world (James and Prout, 1990; Qvortrup and European Centre for Social Welfare Policy and Research, 1994; James, 1998; Prout, 2002). It follows from this standpoint that children are not only 'humans in becoming' embarked on a trajectory of socialisation to reach the gold standard of adulthood but are also beings whose views and experiences are worthy of investigation in their own right (Matthews, 2007). Thinking of children as social actors represented an epistemological shift in childhood research and children were no longer regarded as passive research objects. Instead of doing research on children, researchers strived to do research with children and privilege their voices in the knowledge generation process (Mayall, 2000; Christensen and James, 2017).

However, at the time when works in the field of the new sociology of childhood were gaining traction, when it came to disabled children, their voices were still largely absent from childhood research (Wells, 2017). The claim of the new sociology of childhood that children are competent social actors posed a challenge for the inclusion of disabled children. When assessed against the normative standards of biological development, disabled children are likely to be identified as lacking, deficient and incompetent (Davis and Watson, 2000; Curran et al., 2018).

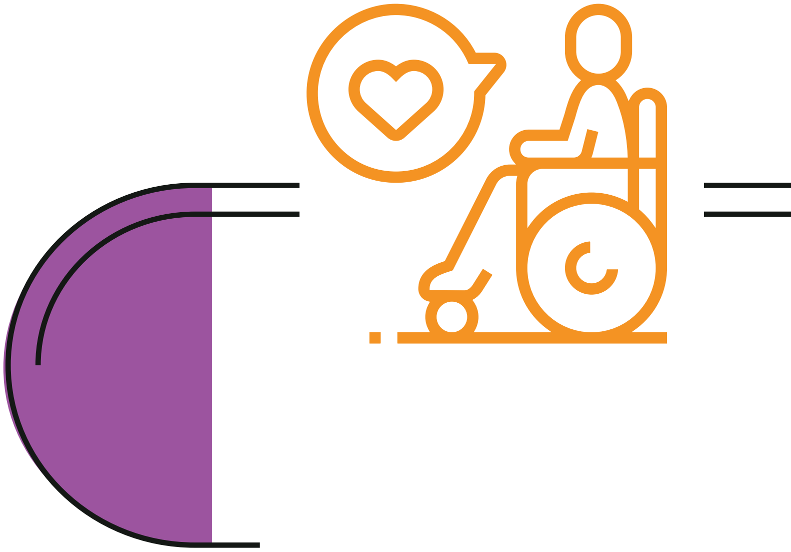
Rather than viewing disabled children's capacities and competence as determined by their age or impairment, my research is underpinned by the view that children's capacities are relational and situational (Coyne and Harder, 2011; McLaughlin, 2020). This view holds that it is possible to enhance children's capacities for participation in decision-making processes or in research through actions undertaken by adults, including age-appropriate or disability-related adaptations of research procedures and decision-making processes (Keravica, 2023).

My research is squarely situated within the growing field of disabled childhood studies that emerged in response to the absence of disabled children from childhood research (Curran and Runswick-Cole, 2013; Runswick-Cole et al., 2018). The scholars writing in this field have attempted to move away from research on children's impairments and toward research that aims to reveal disabling structures that marginalise disabled children. (Shakespeare and Watson, 1998; Priestley et al., 1999; Connors and Stalker, 2007; Stalker et al., 2012). The underlying principles of disabled childhood studies are the positioning of the voices and experiences of disabled children in the centre of inquiry and the challenging of all normalisation practices (Curran et al., 2018, p.45).

Disability studies scholars have warned that the social model of disability may not be enough to account for the experiences of childhood disability, not least because of the impact of impairments on children's lives and the lack of homogeneity and a common identity among disabled children (Connors and Stalker, 2007; Watson, 2012).

In my research, I adopt the socio-relational understanding of disability espoused by Carol Thomas (1999; 2004). According to the socio-relational understanding, disability is a 'product of the social relationships between those with and those without impairments in society' (Thomas, 2004, p.28). In Thomas's view, these social relationships are oppressive and marginalise disabled people into a position of inferiority and powerlessness. Thomas builds on the social model of disability and establishes a distinction between restrictions that stem from a disabling environment and restrictions that are impairment effects related to the nature of the impairment (Thomas, 1999). In other words, the socio-relational understanding of disability elucidated by Thomas helps us to understand that the restrictions on activities that disabled people face may have origins in both people's impairments and socially-produced disablism. This understanding also shows it is helpful to distinguish between impairment effects and disability as a form of social oppression as these are very different causes.

In the ongoing empirical study, I was interested to learn to what extent disabled children participate and have a say in decisions about their medical treatment, focusing on elective orthopaedic surgeries recommended to alleviate impairment effects. The study involves three groups of research participants: disabled children and young people, their parents and healthcare professionals. In this paper, I report the findings from the data collected from disabled children and young people and their parents, focusing on the parts of medical encounters that may have disempowering effects on children and that discursively shape participants' understanding of disability with relevance to independent living.



2. Methodology and research ethics ....

This paper draws on my ongoing socio-legal research study on disabled children's participation in individual healthcare decision-making. Qualitative social inquiry was deployed to explore the views and experiences of disabled children, their parents and healthcare professionals on and with children's involvement in decisions about elective orthopaedic surgeries in England and Serbia.

Both England and Serbia have ratified the UNCRC (England, as part of the United Kingdom, in 1991 and Serbia in 2001) and the UNCRPD (both in 2009) and in that way both agreed to follow the human rights standards enshrined in these two international treaties. The choice of study countries also reflects the intention to offer a comparative analysis of the structural factors that impinge upon disabled children's participation in healthcare decision-making. Some of the factors that form the grounds for comparative analysis include the nature of the national legal system (common law in England and civil law in Serbia), the organisational features of the countries' healthcare systems including the political economy of healthcare and available resources, historical constructions of childhood and disability, and parenting styles.

For example, there are stark differences in the resources available for healthcare between England and Serbia. Government spending for healthcare per capita in 2019 was $4325 in the United Kingdom (OECD, 2021) and only $641 in Serbia (World Bank, 2022). Previous research has documented that material factors, such as healthcare staff shortages, limited time available for appointments with child patients and lack of training for healthcare professionals, adversely affect child participation in healthcare decision-making (Runeson et al., 2001; Beresford and Sloper, 2003; Franklin and Sloper, 2009).

However, the focus of the present paper is not to provide the comparative analysis of the two countries but to point out the common issues that children face in medical settings. The findings presented in this paper represent only a fragment of the wider study and refer only to part of the study conducted with disabled children and their parents. The findings relate to selected themes that bear relevance to how an understanding of disability is construed by parents and children and how that understanding is shaped through encounters with healthcare professionals. I argue that an understanding of disability shaped through the pathologisation of disabled childhood may affect disabled children's potential for independent living.

In total, 15 in-depth semi-structured interviews were conducted online with disabled children and young people aged between 10 and 22 (7 children and young people from England and 8 from Serbia) and 16 similar interviews were conducted with parents (8 from England and 8 from Serbia).

The voices of disabled children and young people were central to the research and were complemented by the views of their parents. This approach is known as 'distributed methodology' and acknowledges the relationality of children's experiences (Mallett and Runswick-Cole, 2014). The data was analysed using reflexive thematic analysis wherein the researcher undertakes interpretive work while continuously reflecting on their own positionality in the research (Braun and Clarke, 2019).

The research received ethics approval from the Research Ethics Committee for the Faculties of Business, Environment and Social Sciences of the University of Leeds [2]. All participants were asked to provide their free and informed consent to take part in the research. For young people under the age of 18, parental consent was also sought. For children who could not explicitly consent due to their communication style or level of maturity, assent was sought along with parental consent. Consent forms and information sheets were provided in a child-friendly version and in a version for young people of higher reading age. All 15 children and young people had physical impairments and 4 had learning difficulties in addition to physical impairment.

3. Children's participation in the matters that affect them

The view of children as social actors has been reinforced by human rights standards. The UNCRC marked the realisation of the need to accord children with a set of rights that go beyond protection and make provision toward empowering them to express their views and take part in decisions about their lives (Fass, 2011). The UNCRC thus aimed to achieve:

> …the balance between viewing the child as the object of caretaking who requires various services and protections from adults and the rights of the child to act fully in his or her capacity as a person (Fass, 2011 p.18).

The repositioning of the child in society and how childhood is seen is reflected in the four key principles of the UNCRC where the participation principle (respecting the views of the child) was introduced alongside three other principles, namely non-discrimination and equality, primary consideration of the child's best interests and the right to survival and development (Committee on the Rights of the Child, 2009). While being heavily focused on child protection and provision in a number of articles, the UNCRC embodies its principle of participation in Article 12. This article is commonly referred to, in abbreviated form, as 'the right to be heard', 'the right to participate' and 'the right to be consulted', however, each of these forms falls short of capturing the entirety of the requirements of the article (Lundy, 2007).

Article 12 of the UNCRC entitles all children to the right to express their views freely and to have those views taken into account when decisions are being made in all matters that affect them. It further requires adults to consider the age and maturity of the child when deciding to what extent the child's views will influence a final decision. The more mature a child is, the higher weight should be placed on their views as a recognition of their 'evolving capacities', another key concept introduced by the UNCRC. Participation in decisions that affect them is not an obligation but a child's choice (Committee on the Rights of the Child, 2009, para. 16). Children should be able to choose whether and to what extent they participate.

Adults charged with the duty to make decisions on behalf of children should be led by the principle of the child's best interests (Committee on the Rights of the Child, 2013). The determination of what constitutes the best interests of a child is not an exercise that should be based entirely on the views of adults. Children's wishes need to be ascertained, made integral to the decision-making process and balanced against other factors, including the need to protect children from harm (Archard and Skivenes, 2009). That a child's views differ from those of adults must never be the sole reason for deeming that child is immature or incompetent. If a decision contrary to the child's wishes needs to be made by the adults, then, at least, the adults should provide feedback to the child, explaining why another course of action was necessary (Committee on the Rights of the Child, 2009).

The UNCRPD includes a standalone article on disabled children (Article 7) which in its third paragraph largely reflects the content of UNCRC Article 12. While space precludes an exploration of the differences between the human rights norms related to child participation enshrined in the UNCRC and in the UNCRPD (see Keravica, 2023 for more information), it is worth mentioning that the UNCRPD introduced an obligation for adults to provide disability- and age-appropriate assistance to children so that they are able to enjoy the right to be heard effectively.

Even though the right to live independently and be included in the community enshrined in UNCRPD Article 19 is commonly associated with the notion of self-determination and the level of autonomy that only adults may be entitled to, the Committee on the Rights of Persons with Disabilities, in its General Comment No. 5, recognised the importance of disabled children's participation stating the following: "Respecting the evolving capacities of children with disabilities and supporting them in having a say in choices that have an impact on them is critical" (Committee on the Rights of Persons with Disabilities, 2017, para. 75). The Committee also emphasised the need to respect children's evolving capacities in its General Comment No. 1 on legal capacity by setting up the obligation for States to "ensure that the will and preferences of children with disabilities are respected on an equal basis with other children" (Committee on the Rights of Persons with Disabilities, 2014, para. 36).

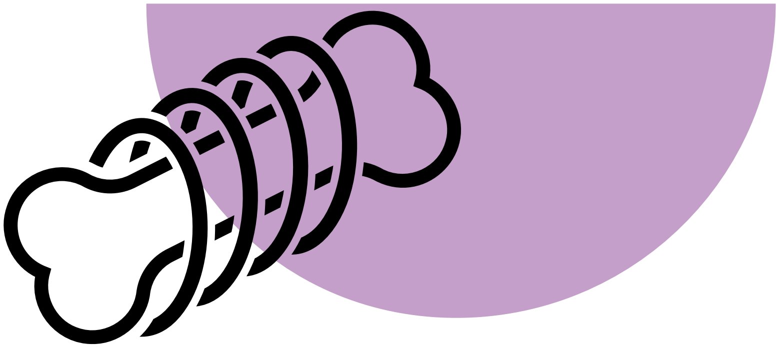
It follows from the General Comments of the Committee that disabled children's right to have their say in decisions that concern them, including in the area of healthcare, is not a game of all or nothing. While they may not be entitled to the same full legal capacity as adults, the right of disabled children to live independently incorporates some degree of choice and control over their lives as guaranteed to them through the 'right to be heard'. In fact, the more children get consulted and involved in important decisions that concern them, the more their capacities evolve and the more experience they accrue (Lansdown, 2005). Opportunities for a child to express their views and to participate actively in the determination of their best interests form the basis of their increasing levels of autonomy. To fully implement the right to live independently, the actions of States parties must be extended beyond those targeted toward disabled adults and due attention must be paid to disabled children's views during their childhood.

The following sections explore disabled children's participation rights in the context of individual healthcare decisions, the focus of the research study.

Disabled children's participation in decisions about their healthcare

Disabled children are more likely than non-disabled children to receive medical attention, including both general and specialised healthcare services, and to spend a substantial amount of time in hospitals and rehabilitation programmes (Bricher and Darbyshire, 2005; Kuper et al., 2014). Due to perceptions of impairments as a problem and disruptive to a child's development, disabled childhood is often marked

> THE LITERAL MEANING OF 'ORTHOPAEDICS' IN GREEK IS 'CHILD CORRECTION' OR 'STRAIGHT CHILD' WHICH ILLUSTRATES THE EXTENT TO WHICH SUCH TREATMENTS ARE INFLUENCED BY THE IDEOLOGY OF NORMALITY



by various forms of remedial treatments, therapies and surgeries that seek to restore bodily functions or ameliorate impairment effects (Priestley et al., 1999; Mclaughlin and Coleman-Fountain, 2014; McLaughlin, 2017).

The social model of disability as a 'big idea' of the disability movement underpins both disability studies and the independent living philosophy (Oliver and Barnes, 2012). The model focuses on the analysis of the disabling environment, squarely locating the problem in society and its treatment of people with impairments. While the social model thinkers have never denied that medical interventions may be useful to stabilise initial conditions (Oliver, 1996, p.36), there is a general tension concerning the idea of using the power of medicine to 'fix' impairments. Oliver contends that "many disabled people experience much medical intervention as, at best, inappropriate, and, at worst, oppressive" (Oliver, 1996, p.36).

Still, the question remains as to what constitutes *appropriate* medical intervention. It is often mentioned that appropriate medical interventions are those to which disabled people have freely consented. However, disabled children are often legally prohibited from making such decisions and it is usually their parents and healthcare professionals who are tasked to decide what is in the child's best interests (Elliston, 2007). Further, if the presence of impairment is unquestioningly considered negative and harmful for a child, then there is very little space to challenge decisions to pursue treatments that promise to 'fix' the impairment (Nelson et al., 2012). Previous research has documented that childhood impairment provokes uneasiness among parents and that their main response is to seek a medical solution to minimise the impairment (Nelson et al., 2012). Even when medicine cannot eradicate an impairment completely, parents may feel an urge or moral duty to 'do something', influenced by social perceptions of 'normality' (Parens, 2006). The strong drive to do everything possible to get their children as close as possible to an ideal of 'normality' may cause parents to pursue elective treatments which pose risks and are imbued with uncertainty (Nelson et al., 2012). Parental sense of moral duty to 'do something' by any means may effectively reduce the space for children to voice their views and to have those views seriously considered.

In my research, I focus on elective impairment-related paediatric orthopaedic surgeries and disabled children's participation in treatment-related decision-making processes. This focus allowed me to recruit children with a range of different impairments who experienced orthopaedic treatments. The literal meaning of 'orthopaedics' in Greek is 'child correction' or 'straight child' which illustrates the extent to which such treatments are influenced by the ideology of normality (Shakespeare and Watson, 1998).

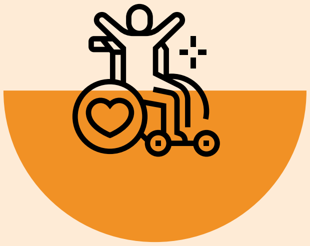
It is not my intention in this paper to question whether the medical interventions experienced by the children and young people who took part in the research were warranted or not. In fact, many of the disabled children and young people interviewed said that they experienced benefits from the orthopaedic surgeries they had, such as alleviated pain, improved gait or posture and greater comfort when participating in their favourite activities.

The experienced benefits notwithstanding, decisions to pursue certain impairment-related medical interventions may have unintended consequences. The power of medicine, by establishing the hegemony of normalcy and pathologising all conditions that deviate from the standards of typical development, may instil in parents and children the understanding of impairment as abnormal (Cooper, 2013). Watson and Shakespeare warn that exposure to frequent hospitalisation and corrective treatments may lead to internalised oppression in children and the development of feelings of self-hate (1998, p.20).

I consider impairment-related orthopaedic surgery to be a material-discursive practice imbued with ethical dilemmas and the values and meanings people attach to disability and life with an impairment. The findings I present in this paper draw on the parts of my interviews with disabled children and young people and their parents that revolved around their understanding of disability and the motivations that led them to opt for medical intervention. I contend that those understandings are largely shaped by encounters with healthcare professionals and the (un)substantiated promises of a cure or medical fix.

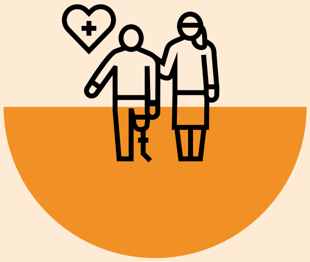
In the following section I present four themes relevant to disabled children's potential for independent living: understanding of independence, perception of disability as a negative difference, pathologisation of impairment and disempowerment of children in encounters with healthcare professionals.

Four themes relevant to disabled children's potential for independent living:



Understanding of independence

Perception of disability as a negative difference



Pathologisation of impairment

Disempowerment of children in encounters with healthcare professionals.

4. Findings

A. Understanding of independence

When discussing what had led them to agree to proposed medical interventions the parents, children and young people interviewed spoke about the hoped-for benefits and discussions revolved around participants' perceptions of the quality of life of disabled people. Parents wanted to provide the best future possible for their children and placed a high value on independence in adult life. However, their understanding of the meaning of independence largely revolved around physical capacity and self-sufficiency.

A mother of an 11-year-old boy with cerebral palsy from England, when I asked her about the outcomes that she is hoping the surgeries would bring said:

> A pain-free life? I mean, I can't imagine that anybody sitting in a wheelchair for the most majority of the day is going to be pain-free. Nobody has said that to me. But I mean, I can't imagine. I want him to be as fit and healthy and active as he can be.

A mother of an 18-year-old young woman with cerebral palsy from Serbia spoke about the attitude of a doctor who felt the urge to do anything possible to prevent her daughter from becoming a wheelchair user. This urge to do something about the young woman's impairment led to multiple surgeries, some of which resulted in decreased functionality of her body. The mother shared the following:

> The doctor absolutely does not like to see children in wheelchairs. She [the doctor] always emphasises it. If a child can, if a child tries hard, she would prefer to prolong it as much as possible, the involvement of the wheelchair, because then a child is static and then there's no progress.... She's always insisted saying that she [the daughter] did not need a wheelchair, yet. She doesn't like to see children in a wheelchair, hence she'd been trying on her [the daughter] everything that's possible…

The narratives from the interviewed parents revealed beliefs and misconceptions related to the quality of life of disabled people, including those using assistive technologies and other sources of support. Independence, in terms of self-sufficiency, ranked highly among the hoped-for benefits of the surgeries. This is consistent with the findings of McLaughlin (2017, p.247) who also reported that medical interventions were seen as something that could provide greater independence. The understanding of independence as self-sufficiency differs starkly from the meaning of independence promoted by the independent living movement which emphasises interdependence and choice and control over the support that a person receives rather than self-sufficiency (Mladenov, 2021).

B. Perception of disability as a negative difference

Oliver (1996, p.5) claimed that disability identity is constituted of three core elements: the presence of impairment, the experience of socially imposed barriers and self-identification as a disabled person. Watson (2002) questioned the existence of disability identity as something that is stable and decontextualised. His study revealed a multiplicity of disabled young people's constructions of their sense of self. Many of them had rejected disability as identity through actions and narratives that help them to blend into the non-disabled category and minimise their differences (Watson, 2002).

This rejection of disability as identity results from an understanding of disability as an inferior state of being and a demeaning label. The data from my study suggests that medicine plays a role in constructing the narrative of disability as an individual problem which is best resolved through medical interventions.

A mother of a 13-year-old disabled boy from England shared her experience of learning about her son's impairment:

Mother: And basically, apart from the skeletal problems, he was a normal, healthy, functioning child. It's just his skeleton that is wrong. And as he [a doctor] said to us, you know, he's a healthy baby, he's just got mechanical problems… And to have somebody say, actually, you know what, your baby is healthy. He's just got mechanical problems, is such a helpful mindset to get into, that you don't have an ill child.

Researcher: So that's framed as something that can be sorted out?

Mother: Yeah, and I think that's the thing, isn't it? He's just got mechanical problems…It sort of reassures you that they're not ill.

This initial construction of an impairment as a 'mechanical problem' formed a core part of the strategy that these parents used to later talk with their son about his condition. For them, to be disabled was to be ill, so they invested effort in avoiding this label:

Mother: And then when we had him, I think one of the things with him was, you know, we've never sort of mentioned the disabled word with him. We just said, you know, you're just different. And I think that's one of the problems that, you know, with labelling, that people do like to label people. And you know, we're all individuals and you can't, you can't make a sweeping comment. So I think I sort of pulled all that into play with him. And I wanted him to feel normal. I wanted him to feel like his friends. I wanted him to know that, you know, he was the same as everybody else.

Researcher: And when you mentioned labels, do you think disabled as a word brings up some negative connotations and negative perception of identity?

Mother: Yeah, 100 per cent I think it does. Yeah, I was reading an article and it was saying that they shouldn't call people disabled, or they should call them diff/abled, because they are differently abled. Because disabled implies that you're less somehow. And well, in my opinion, it implies that you're less somehow and that's not true. You're just different.

It is evident from this example that these parents associated disability with severe illness and a devalued state of being. That their son's impairment was a 'mechanical problem' which might be sorted out through medical interventions gave them hope and helped them to distance themselves from the category of disabled. Even though the multiple surgeries their son experienced did not eradicate his impairment, they invested efforts to help their son not identify as disabled with an aim for him to blend more easily into the category of non-disabled and not think of himself as less valuable.

A 12-year-old disabled girl from Serbia was talking about the conversation between her mother and a doctor that went on in front of her:

Well, I heard him [a doctor] and my mom talking and he said that simply it cannot be done for me, that simply, like…like I am a hopeless case, something like that.

In this case, the doctor, when explaining to the mother that the surgery would not bring any benefits, objectified the young girl referring to her only in terms of her impairment, which was 'beyond repair' in his view. In the witnessed conversation, the girl was not regarded as a human subject but as a passive object or a collection of broken parts that could not be fixed. Such objectification affects children's sense of self, diminishes their confidence and even leads to internalised ableism. Internalisation may begin at early age spurred by the messages about themselves that young people receive from others (Smith and Traustadóttir, 2015).

C. Pathologisation of impairment

To consider the effects of pathologisation of children's impairments it is helpful to briefly discuss a distinction that Sholl draws between medicalisation and pathologisation (Sholl, 2017). In his view, there are overlaps between the two concepts but they are not necessarily the same. He claims that a distinction can be drawn between diagnosing and defining conditions as pathological and treating them through medical interventions. The two processes can be decoupled:

> If pathologization involves the ways in which certain conditions come to be labelled as pathological by medical institutions (definitions), in the clinic (diagnoses), or by self-labeling, then medicalization could be seen as involving various types of medical responses and interventions or treatments that are justified in relation to health concerns (Sholl, 2017, p.268).

Sholl further asserts that medicalisation can occur without pathologising the conditions which are to be medically treated. It follows that a child's impairments do not have to be labelled as 'abnormal' or be assumed to lead to a diminished state of being or suboptimal functioning that deviates from the typical norm to still warrant medical attention to alleviate impairment effects and improve the child's quality of life. Avoiding pathologisation does not imply a rejection of medical treatments but involves rejection of the attachment of negative value to impairment as a bodily difference. Sholl argues that " some conditions can be depathologized while still being medicalized" (Sholl, 2017, p.269).

In practice, a move away from pathologisation requires healthcare professionals to avoid regarding a disabled child as a collection of broken parts that need to be treated by all means because of the underlying pathology but as a child whose conditions may require consideration of the viability and appropriateness of medical interventions and social interventions, such as the provision of aids, personal assistance or an accessible environment. The move would also require posing difficult questions to parents and helping them to consider their attitudes toward disability and understand the limits to the effectiveness of medical interventions, especially when they are imbued with risk and uncertainty (Parens, 2009).

Most of the parents and disabled young people interviewed were able to pinpoint benefits and quality of life improvements that resulted from the chosen surgeries, which implies that medicalisation of impairments may at times be appropriate but should not be conflated with pathologisation. Some of the examples of alleviated impairment effects included improvements in the child's gait and posture, reduced spasticity, alleviated pain, improved ability to stand or walk with or without the support of mobility aids, and more effective participation in favourite activities.

In some cases, the stated motivations to pursue surgical treatments stemmed not only from considerations of quality of life and alleviated impairment effects but from a desire to get closer to an ideal of normalcy. The idea of normalcy was so seductive that in some cases families pursued high risk treatments with uncertain outcomes. Young people placed a high value on the aesthetics of their bodies and favoured surgeries that helped to pass as 'normal'. In a move away from pathologisation, this type of judgement of what the typical norm is should be avoided.

An 18-year-old young disabled man from Serbia with cerebral palsy talked about his experience with his consultant who ignored the symptoms that the young man described but rather insisted on a pathology that in the young man's view was not there at all:

He didn't seem really familiar with the problem I have or maybe he did but he didn't offer a good solution as doctor B [pseudonymized]…something like that. He said he wants to replace my ankle on the right foot or to do surgery on my right arm because he thought that my right arm is also poorly because my right leg was worse than my left one…as my right leg was more affected by cerebral palsy so he assumed that's the case with my right arm as well but it wasn't like that. And then he wanted to perform surgery anyway.

The young man resisted and managed to get a second opinion and get the appropriate treatment at another hospital. He explained the reasons why he thought surgery he received at the second hospital was a good option for him. Although he experienced tangible benefits, he also attached high value to an ideal of 'normalcy':

Well, I was hoping that I could walk normally, as I'm walking now more or less. I mean, people almost can't tell the difference between me and others so I am totally happy. Although that's the least of my problems, whether people can notice the difference or not, what's important for me is that I can move without pain and go swimming without any difficulties so I'm perfectly satisfied with the surgery.

Another disabled boy with cerebral palsy from Serbia who is 17 shared his experiences of being stigmatised and labelled by his peers throughout his adolescence. The social stigma he experienced led him to develop feelings of shame:

Surely, I'd love to walk like everyone else and all of that. It's not easy for me in some situations, and honestly, sometimes I don't like to see myself in the mirror. But ok, that feeling passes quickly. I am aware that I have to fight and that at the end of the day, I don't have any other choice.

Surgery represents a form of work on the body that young people undertake to minimise their difference (Mclaughlin and Coleman-Fountain, 2014; McLaughlin, 2017). Of those interviewed, those whose impairments were such to allow them to get very close to an ideal of normalcy through surgery appreciated the possibility of passing as 'normal'. This passing distanced those children and young people further from the category of disabled as they considered themselves different from 'really' disabled people with more severe impairments. The stories collected show that the discourse of 'normalcy' originates from both the interactions of young disabled people with wider society and the medical encounters in which impairments are diagnosed and labelled as 'abnormalities'.

D. Dis/empowerment of children in encounters with healthcare professionals

As previously mentioned, children have the right to participate in *all* matters that affect them. However, the domain of healthcare is particularly sensitive and one in which the tension between child protection and support for their increasing levels of autonomy comes to the surface most bluntly.

Due to parents' uneasiness related to children's impairments and their desire to try to give their children the best future possible, parents' decisions to pursue medical 'cures' often go unquestioned. However, this does not mean that children should not be given the chance to engage in a dialogue with adults, pose questions and get access to all the information they might need to develop an understanding of what will happen to them. As we can see from the following examples, children are often sidelined in medical encounters and not given enough opportunity to express their views and concerns.

An 18-year-old young disabled woman from Serbia said:

…I think that they [healthcare professionals] should ask a child directly, and not that I have to tell to my mum, and then my mom to ask them, because it has been happening quite often that I had some questions and then I had to tell to my mom: 'Mom, please ask this', because my views did not matter much.

In the following example the 17-year-old young man from Serbia explained how he felt after being examined by a doctor who did not pay sufficient attention to his concerns:

In most of the cases, he [the doctor] ignored me, like he basically had conversations with my mother and father only, and he completely ignored me, so… I was just there like some sort of object for trying out…I don't know…his new ideas.

A disabled teenage girl from England spoke about her experience when she woke up after surgery and the healthcare staff did not take seriously how she felt:

And I was really ill from the morphine. Because I didn't react very well to it. I was really ill. And I think it was the day after I had my surgery. And there was quite a lot of complications with that as well. So I was feeling really ill my face had swollen up, I just, I was being sick. I really wasn't very well. And the physiotherapist came around to try and get me out of bed. But I was having hallucinations. I was just…yeah, I was not very well. And they just kept trying to force me to get out of bed. They were pulling my leg around. And I just…like I could barely speak because I felt so ill. And I just said 'No, just leave me alone'. And they were just so pushy with it. And in the end, my mom told them to just get out and leave me alone. But they really weren't giving up on trying to get me out of bed. But I just wanted to chill. And that's when I felt like I wasn't heard.

In the stories participants in my research shared, the role of parents in medical encounters proved to be significant for how children were treated by healthcare professionals. If parents considered their child's participation important, they encouraged them to ask questions or insisted that healthcare professionals explain to the child what is at stake. Thus, the positioning of children in the three-way relationship of parent-child-healthcare professional strongly depended on the adults' perceptions of the child's competence and maturity and the importance the adults attached to the child's participation. Parents may act as a barrier to children's participation or a source of support (Keravica, 2023).

A 16-year-old disabled girl from England shared a positive experience of being involved in the decision-making process for a proposed treatment. Her parents deemed it important to help her retain a sense of choice and control over what was going to happen to her:

Well, my parents kind of sat me down a few days later, and explained to me what would happen and answered… if I'd like the consequences if I didn't have it, like the pain will get worse. And I would not be able to walk. And they told me exactly what would happen. And the risks, and they just told me everything about it really. And they said it's up to me. It's my decision. So they kind of left it up to me to decide but made sure they were there for me.

This example shows that children and young people do not want to be positioned as passive spectators and objects of adults' concerns during medical treatments. They want to be engaged and have their say in what is happening to them. Children's capacities evolve through experience, need to be understood relationally and constructed through intergenerational relations with adults (Lansdown, 2005).

5. Discussion

Brisenden (1986), in his writing on the negative implications of the medical model of disability on independent living of disabled people, warns against medical treatments and hospitalisations that are recommended for the disabled even when they do not necessarily lead to improvements in the quality of life. According to Brisenden, frequent hospitalisations and medical interventions represent a source of disablement. He explains that this is a consequence of how medicine views and defines disability:

> This has occurred due to a failure of imagination, the result of the medical profession's participation in the construction of a definition of disability which is partial and limited. This definition has portrayed disability as almost entirely a medical problem, and it has led to a situation where doctors and others are trapped in their responses by a definition of their own making (Brisenden, 1986, p.176).

Without the intention to downplay the benefits of the orthopaedic surgeries that the children and young people in the study experienced, I want to highlight the risk associated with the pursuit of a medical 'fix' that bears relevance to children's potential for independent living.

This risk is embodied in at least four different ways. First, the power of medicine constructs the meaning of independence in terms of self-sufficiency and sets the goals of impairment-related medical interventions in terms of independent functioning. Mladenov (2021, p.10), when writing about the independent living movement's struggle for the meaning of independence as choice and control over the support one receives and interdependence with others rather than self-sufficiency, explains that "powerful disability policy actors have perpetuated a one-sided interpretation of independence as self-sufficiency - an interpretation whose reproduction has constituted a hermeneutical injustice inflicted on disabled people".

Second, prompted by the power of medicine, both children and parents develop an understanding of disability as an individual problem and a negative difference which is best resolved through medical interventions. Disabled childhood is often a time of medical interventions. Many young people derive their sense of self from others and gain their first knowledge about disability through narratives of medicine. When I asked study participants to talk about the challenges they face, most young people started with their medical conditions and medical history and were well versed in juggling medical terminology. Griffiths (2018), in his research on disabled young people's involvement in disability activism, showed that the social model of disability as a 'big idea' of the disability movement remains distant to young people, not least because of the narratives constructed by medicine and the preoccupation with fixing impairment during childhood.

Third, the pathologisation of impairment and its denunciation as an 'abnormal' state of being leaves little space for disabled children and young people to imagine a fulfilling life and the ability to flourish without pursuing sometimes risky medical interventions that go beyond the aim of stabilising initial conditions and alleviating impairment effects and are imbued with uncertainty. Such pathologisation further leads disabled young people to distance themselves from other disabled people, especially if the outcomes of the medical interventions get the young person closer to the category of 'normal'. The reward of passing as 'normal' in terms of avoiding being stigmatised by others may be very attractive to young people. However, this 'reward' means the construction of disability as 'abnormality' often goes unchallenged (McLaughlin et al., 2016). This construction can create distance between young people who can 'pass' and those who are 'really disabled'. The independent living philosophy is underpinned by feelings of pride, community belonging and a view of disability as a matter of human diversity (Swain and French, 2000). In the absence of positive role models and peer support, these ideas may seem remote to young disabled people.

Finally, parenting practices that support children to express their views and have a say in important decisions nurture children's evolving capacities and increase their potential for independent living in adulthood. If children are frequently asked for their opinions, they can learn that their opinions matter and will be more likely to become self-determined individuals.

6. Conclusion

The emerging findings presented in this paper do not imply that all impairment-related medical interventions are oppressive or that they are not warranted. In fact, throughout the interviews I conducted with disabled children and young people and their parents, it became clear that in many instances the children and young people experienced alleviation of their impairment effects that, in their view, significantly improved their quality of life.

However, the testimonies of the young people and their parents revealed that there are unintended consequences of frequent hospitalizations and exposure to medical interventions. In the pursuit of a medical 'fix', disabled children and their parents develop an understanding of disability that corresponds to the individual model of disability and may lead to repudiation of disability identity. The ideas of the social model of disability and disability pride, which are central to the independent living movement, may be remote for them. Disabled children need to be provided with opportunities and support to express their views freely, even on sensitive and important issues such as medical treatment decisions. Adults' preoccupation with children's impairments may leave little space for children to take a meaningful part in discussions on their best interests and quality of life. Ignoring children's views on these important matters downplays the importance of nurturing their increasing maturity and autonomy. It is only through ongoing negotiations of their daily lives, including on important matters such as healthcare, that disabled children's capacities evolve.

The independent living philosophy rests on the notions of self-determination and autonomy. It also fosters positive disability identity and a sense of belonging to the disability community. If disabled children are to grow up to be adults in a position to retain choice and control in their lives, then their evolving capacities need to be recognised and nurtured today by the people involved in their care. Pathologisation of children's impairment may convey the message of impairment as a negative difference. However, this need not be the case as medical interventions can be focused on alleviating impairment effects without attaching negative value to life with impairment and speculating what it means to live independently.

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A PROPOSED FUNCTIONAL CURRICULUM FOR HELPING FEMALE STUDENTS WITH MODERATE INTELLECTUAL DISABILITIES ACQUIRE FUNCTIONAL LIFE SKILLS

Ikhlas Sawwaf

Key messages

1

Students with intellectual disabilities in the Kingdom of Saudi Arabia face a number of academic problems due to their inability to adequately benefit from the offered curricula, as the educational services provided in schools are limited to the mild intellectual disability category. The first pillar in devising curricula for pupils with intellectual disabilities is taking their characteristics and needs into account.

2

A functional curriculum contributes to shaping the personality of students with intellectual disabilities, and enhancing their positive personality traits, to be able to adapt socially, be self-reliant, and communicate with society effectively, and hence live independently.

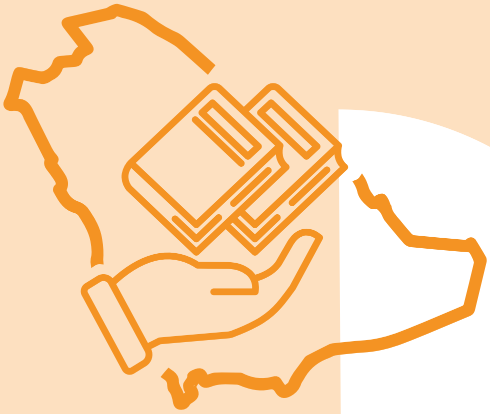
3

The study showed improved independence skills of students who studied the functional curriculum, compared to their levels before studying it, and compared to students who did not study it.

4

The study emphasizes the importance of training special education teachers on the mechanism of using the functional curriculum in teaching and training students with intellectual disabilities. It also stresses the need to ensure applying the family partnership standard in planning, implementing and evaluating these students' curricula.

The researcher recommends applying the functional curriculum more broadly in the Kingdom of Saudi Arabia, and reconsidering the conceptual education curricula currently used for people with different intellectual disabilities. She moreover calls for establishing a functional curriculum electronic database that serves as a reference for special education teachers, and facilitates the implementation of each pupil's individualized education plan.



5

Introduction

Educating students with disabilities is an integral part of the general educational system, as stated in the Education Policy of the Kingdom of Saudi Arabia in its general objectives 54–57 and 188–194 (Ministry of Education, 1432). Regulations and charters stipulate that providing an educational system that takes into account the needs of students with disabilities is one of their rights. The United Nations Convention on the Rights of Persons with Disabilities, adopted in 2006 and signed by most world States, refers in its 24th article to the need to realize this right without discrimination and on the basis of equal opportunities. All States must provide an inclusive educational system that accommodates all pupils, regardless of their condition or circumstances. With the Kingdom of Saudi Arabia signing this Convention in 2008, persons with disabilities, especially those with intellectual disabilities, started receiving more attention. Moreover, an emphasis was placed on the need to devise appropriate curricula to provide students with disabilities in general, and those with intellectual disabilities in particular, with the academic, social, independence, and professional skills that qualify them for public life, knowing that students with disabilities cannot acquire the said skills from the standard educational curricula in their current form.

The process of devising and preparing curricula for students with intellectual disabilities requires in-depth knowledge of their characteristics and needs, as well as an understanding of the educational conditions founded on society's requirements and the learner's needs and interests (بطرس، 2010). The progression, organization and sequencing of the content should be taken into account. Moreover, the general foundations of pupils' physical, mental and social development should be taken into consideration, in addition to developing a general perception of the activities and means of instruction and assessment. Thus, the first pillar of devising curricula for students with intellectual disabilities is having a comprehensive knowledge of the students' characteristics and needs (عبد الحق، 2009). Upon lending attention to the needs of students with intellectual disabilities and focusing on their characteristics, it becomes evident that the lack of adaptive behaviour skills, which impedes the acquisition of functional skills, is due to these students' need for programmes and curricula to develop the skills necessary in their daily lives, and to gradually grow more independent as they develop.

Therefore, there is a need to devise a functional curriculum for students with intellectual disabilities that meets their needs and fills the many gaps in the current curricula.

The following are some definitions of key concepts and terms used in the study.

New definition of intellectual disability (2021)

Intellectual disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behaviour, which impede many daily social and practical skills. This disability manifests before the age of 22.

The researcher procedurally defines study subjects, female students with moderate intellectual disabilities, as students enrolled in intellectual education institutes and programmes affiliated with the Department of Education. These students' IQ score ranges between 40–54 as per the Wechsler Adult Intelligence Scale (WAIS), 36–51 as per the Stanford-Binet test, or the equivalent of either of them as per other standardized individual intelligence tests. Their ages range between six and 21.

Functional curriculum

The Division of Student Support Services of Newfoundland & Labrador, Canada (2008, p.7) defined the functional curriculum as an approach that focuses on the "enhancement of independence though the teaching of functional life skills. The curriculum emphasizes life skills that children and youth [...] require in their current environments and will require in future environments".

The researcher procedurally defines the functional curriculum as a set of procedures and applications related to personal and independence skills that are taught to students with intellectual disabilities at different age and school levels, to train them on the functional life skills necessary for social engagement.

1. Study foundations

A. The problem

Students with intellectual disabilities in the Kingdom of Saudi Arabia face a number of academic problems due to their limited ability to benefit from the curricula currently offered by intellectual education institutes and programmes, especially since the special education regulations stipulate that the educational services provided by schools to students with disabilities be limited to the mild intellectual disability category (1422 AH). A study (2008 ،المعيقل), which evaluated the extent to which life skills are applied in the curricula of students with intellectual disabilities in the Kingdom of Saudi Arabia, confirmed that a number of difficulties face such application, namely: (a) inadequacy of educational environment, (b) unqualified human cadres, (c) lack of life skills, (d) lack of adaptive behaviour or life skill assessment, (e) weakness of family role, and (f) lack of community resources.

In light of this reality, the study in question seeks to design a functional curriculum that accommodates the needs of students with moderate intellectual disabilities, by referring to international functional curricula and adapting them to the requirements of the Saudi environment. The study also seeks to gauge the effectiveness of the proposed curriculum in helping students with moderate intellectual disabilities acquire functional skills, by comparing the performance of a group of female students who are taught the proposed curriculum with the performance of their colleagues who are taught other curricula currently adopted in intellectual education institutes.

B. Questions posed

In her study, the researcher poses the following questions:

How effective is the proposed functional curriculum in providing functional skills for female students with moderate intellectual disabilities?

The following are the pursuant sub-questions:

Are there statistically significant differences at a 0.05 significance level in the performance of the experimental group in terms of acquiring independence skills before and after applying the functional curriculum?

Are there statistically significant differences at a 0.05 significance level between the control group and the experimental group in terms of acquiring independence skills before and after applying the functional curriculum?

C. Study hypotheses

By reviewing previous studies on functional curricula for students with intellectual disabilities, the study hypotheses can be formulated as follows:

1. There are no statistically significant differences at a 0.05 significance level in the score averages of independence skill aspects of the experimental group before and after applying the functional curriculum.
2. There are no statistically significant differences at a 0.05 significance level in the score averages of independence skills between the group that was taught the functional curriculum and the control group after adjusting the pre-assessment differences in independence skills.

D. Study significance

1. Theoretical significance

The theoretical significance of this study is to disseminate modern concepts, such as that of the functional curriculum, among researchers, teachers and learners. Moreover, the study contributes to covering the shortcomings in the educational field with regard to the literature on the application of functional curricula for students with moderate intellectual disabilities.

2. Applied significance

The applied significance of this study is that it may result in producing an applied functional curriculum that accommodates the needs of students in intellectual education institutes. The said curriculum is based on organizing the educational content for students with intellectual disabilities who do not benefit from the adopted curricula. The aim is to facilitate their acquisition of functional life skills, and thus facilitate their access to community-based training and rehabilitation, as well as enhance their independence. Additionally, the functional curriculum seeks to provide teachers and families of students with intellectual disabilities with a reference guide that contributes to training them to identify students' functional needs and the strategy for fulfilling them. This curriculum may also constitute an accompanying or alternative curriculum for students with intellectual disabilities who attend general education schools and do not benefit from their curricula.

E. Study scope

1. Spacial scope

This study was limited to female students with moderate intellectual disabilities enrolled in the Institute of Intellectual Education in Jeddah.

2. Time frame

The study procedures began in the first term of the academic year 1433 AH–1434 AH, and continued for 11 weeks.

3. Human scope

The study included female students with intellectual disabilities, aged nine to 13 years. These students' IQ score ranged between 40–54 as per the Wechsler Adult Intelligence Scale (WAIS), 36–51 as per the Stanford-Binet test, or the equivalent of either of them as per other standardized individual intelligence tests.

F. Study methodology

The researcher used the experimental approach forming equivalent groups (control and experimental), to gauge the effectiveness of the independent variable (the proposed functional curriculum) in achieving the dependent variable (developing the functional skills of students with moderate intellectual disabilities so they achieve independence).

G. Target group

The study targeted female students with moderate intellectual disabilities from the first elementary to the second intermediate grades at the Institute of Intellectual Education in Jeddah, amounting to 169 students according to the Institute's statistics during the study duration.

H. Study sample

The study sample consisted of 30 female students with moderate intellectual disabilities, aged 9 to 13 years, and they were selected according to the following criteria:

1. The student must have been diagnosed by the psychiatric diagnostic team at the Institute of Intellectual Education as suffering from a moderate intellectual disability with an IQ score between 40–54 as per the Wechsler Adult Intelligence Scale (WAIS), 36–51 as per the Stanford-Binet test, or the equivalent of either of them as per other standardized individual intelligence tests.
2. The student must not have been previously enrolled in skills training programmes similar to the one in question.
3. The student must show a clear deficiency in terms of independence skills according to the results of the pre-assessment of these skills.
4. The student must demonstrate psychological, behavioural and health stability that allows her to benefit from the programme provided.

I. Study tool

The tool adopted in the study is the proposed functional curriculum developed by the researcher for the study purposes. The following is an overview of the functional curriculum:

1. Its inception

Brown, Nietupski, and Hamre-Nietupski (1976) challenged the developmental model and instead used the criterion of ultimate functioning of daily life skills in society. In 1979, they introduced a functional term for daily life skills that referred to a new paradigm, which promoted integration into society by targeting skills required in everyday life. They described this curriculum in four functional daily life skill areas: domestic, social, leisure and vocational, which became the new content areas of the curriculum. This new perception of the curriculum spread, with Westling and Fox (2000) presenting 18 papers supporting this change in functional skills. By the end of the eighties, specialists unanimously endorsed the curriculum, noting that it should focus on daily functional skills appropriate to chronological age. The functional curriculum of daily life skills comprises a framework from which we select the priority skills to teach a pupil (Browder, Flowers, Ahlgrim-Delzell, Karvonen, Spooner & Algozzine, 2004).

2. Overall objective

The functional curriculum is aimed at shaping the personality of students with intellectual disabilities and enhancing their positive personality traits, to be able to adapt socially and rely on themselves. This is achieved through training these students to perform several functional skills, implement them in their daily lives, and integrate into society.

3. Sub-objectives

1. Providing functional life skills to students

with intellectual disabilities to enhance their independence and self-reliance.

2. Enabling students with intellectual disabilities to make decisions, solve problems, and communicate effectively with their peers and community.

3. Qualifying students personally, professionally and socially.

4. Making students self-confident by choosing activities and objectives appropriate to their abilities and potential, and compatible with their needs.

4. Standards

The proposed functional curriculum is based on a number of pillars and standards aimed at developing the functional skills of students with intellectual disabilities by specifying:

1. What do pupils learn? Objectives are determined based on their strengths and needs identified in their individualized education plan, and based on the results of the skill pre-assessment. This standard is the first in the functional curriculum standards.

2. Where do pupils learn? Pupils should have access to primary and subsidiary learning environments that are as safe, stimulating, diverse and as natural as possible, such that these environments meet the standards of community-based training and real-life training whenever possible.

3. How do pupils learn? By providing:

    - Diverse, active and social teaching methods.

    - Aids, strategies and assistive techniques appropriate to each skill and each pupil individually.

    - Training to teachers in charge of implementing the curriculum, and ensuring they understand the curriculum objectives and application mechanisms, in addition to achieving the family partnership standard.

Through studying the relevant literature, special curricula and functional curricula standards, the researcher concluded a set of standards for the current curriculum:

1. Developing an individualized education programme for each pupil: The pupil's functional skills are determined through an individualized education programme specifically devised for him/her.

2. Applying family partnership: Whenever possible, it is necessary to ensure the family's involvement in all the preparation stages of the student programme.

3. Enriching the practical experience and applying exercises in daily life activities. Practical experience is divided into two parts:

    a. The academic practical experience through simulating reality.

    b. The community practical experience through community-based and real-life trainings.

4. Continuous planning and evaluation of training programmes within the curriculum.

5. Comprehensiveness and integration in the skills training, and linking activities to one another by organizing the educational content.

6. Taking into account the chronological age, and regulating amounts of learning material in the functional skills training.

7. Linking general and functional curricula whenever possible.

5. Sections

The proposed functional curriculum is composed of three main sections:

First: The theoretical framework that includes:

1. Defining the functional curriculum.

2. Determining its pillars and foundations.

3. Determining its standards for students with intellectual disabilities.

4. Distributing the strands of the functional domains among the proposed main and subsidiary training environments.

5. Providing teachers with the implementation mechanism of the daily programme.

Second: The functional independence domain, which includes:

1. Defining independence skills.

2. Showcasing teacher directions for implementing the independence domain.

3. Identifying the strands and skills of the independence domain, namely:

- Personal care:
  - Using the toilet.
  - Personal hygiene and overall appearance.
  - Clothing.
  - Eating.
  - Health care and nutrition.
  - Sex education.

- Domestic skills:
  - Housekeeping.
  - Kitchening unit.
  - Food preparation.
  - My food unit.
  - Storing food.
  - Clothing care.

- Telephone skills.

- First aid.

- Security and safety:
  - Physical safety.
  - Personal safety.

- Shopping (supermarket and others).

- Personal finances:
  - Purchasing.
  - Budget planning.

- Orientation, mobility and travel.

2. Preparing a teaching programme for functional skills under the independence domain's various strands

A. Implementation

In preparing the teaching programme, the researcher took the following measures:

- Measuring the level of performance in functional skills under the independence domain, and randomly dividing the sample into a control group and an experimental one, such that each group goes through the following procedure:
  - Experimental group (n=15): pre-assessment –> intervention using the functional curriculum –> post-assessment.
  - Control group (n=15): pre-assessment –> studying the adopted intellectual education curricula –> post-assessment.
- Devising a list of needs and strengths for each student and including them in her individualized education programme.
- Focusing on the common goals among students, and having teachers and mothers choose the goals they deem a high priority for students. Accordingly, 15 general goals were selected, of which specific goals were assigned to the participating students. Moreover, the main and subsidiary training environments were identified, in addition to specifying the teaching aids and the appropriate teaching strategies to be employed.
- Re-dividing the experimental sample into three groups instead of two, based on the educational method used with each group, as well as the students' common goals and behaviours, provided that each group is trained on each skill at a rate of three sessions per week, and a duration of two minutes for each session.
- Preparing a weekly skills schedule defining the sessions and training groups.
- Determining the expected number of training sessions, which is seven training sessions for each skill, provided that the students who have not achieved the success criterion continue training on the same skill, while the rest of the students move on to acquire new skills.
- Developing an attendance sheet to ensure that all students receive the skills training sessions.
- Preparing a mastery form for each skill subject of the training session, so that the trainer and the external observer -the assistant teacher- fill out the form on the spot.
- Devising a lesson preparation model that includes the overall objective of the lesson, analysis of the training skill, teaching aids, teaching strategies and skill training procedures.
- Determining the types of incentives based on the behavioural observation results and the interviews with students' mothers, as per the following:

1. Material incentive using the selection board: the pupil chooses the incentive she wants to receive at the end of the week after obtaining the incentive points for all the skills on which she had trained.

2. Symbolic incentive using the individual incentive board: the student upgrades her performance in the skill at the end of the session, in addition to continuous verbal reinforcement throughout the skill training.

3. Preparing teaching aids for each goal according to the chosen educational strategies.

B. Programme duration

The programme was implemented over an 11-week period, of which the first three weeks were allocated for the pre-assessment of functional skills and the development of individualized education programmes. After that, an intervention period of eight weeks took place. During these eight weeks, the students received 20 lessons per week, amounting to 45 minutes. In total, they received 160 lessons. After the intervention period, the students in the experimental and control samples were re-evaluated using the functional skills assessment forms used in the pre-assessment. The overall scores were calculated for each independence domain strand. Additionally, the overall score for independence skills in all strands was calculated for each student in the experimental and control groups.

C. Selected skills

The table below shows the skills that were selected for the training, based on the pre-assessment results, and as per the priorities defined by the teachers and mothers.

Skills selected for training based on the pre-assessment results, and as per the priorities defined by the teachers and mothers

Skill	Strand	General skill	Goal	Teaching strategy	Teaching aids	Training environment	Concepts and skills developed through skill training
1	Personal care	Overall appearance	Trimming nails	• Skill analysis Modelling • Gradually decreasing assistance • Acting and drama	Nail clipper – hand cream – soap – tissue papers – litter bin	• Classroom • Toilet	• Cleanliness, abiding by the Sunnah • Applying and distributing cream and washing hands
2	Personal care	Overall appearance	Using a sanitary pad (changing the pad)	• Skill analysis Modelling • Gradually decreasing assistance • Acting and drama	Various sanitary pads – tissue papers – cards stating the application steps – litter bin	• Classroom • Toilet	• Menstrual hygiene routine • Practices to relieve menstrual pain • Privacy during the menstrual cycle • Mental preparation for the menstrual cycle
3	Personal care	Overall appearance	Folding an abaya	• Modelling • Gradually decreasing assistance • Gradually increasing assistance	An abaya for each student	• Classroom – Outdoor yard while students enter or exit the school	• Organization and tidiness • Paying attention to personal belongings • Independence

Skill	Strand	General skill	Goal	Teaching strategy	Teaching aids	Training environment	Concepts and skills developed through skill training
4	First aid	First aid	Performing first aid	• Skill analysis • Story • Modelling • Gradually decreasing assistance • Acting and drama	First-aid kit – Picture cards for matching – Bulletin board of story representing the characters	• Classroom • School clinic	• Caution when playing and applying security and safety skills, staying away from risks, steps to report an injury, ability to solve problems and make decisions
5	Domestic skills	Housekeeping	Washing dinnerware	• Skill analysis – Modelling • Gradually decreasing assistance	Utensil set – strainer inside the sink –strainer for soapy utensils – apron – sponge	• Domestic skills room	• Cooperating at home • Helping mother • Independence • Following security and safety skills in the kitchen
6	Domestic skills	Housekeeping	Sweeping floors using broom and dustpan	• Skill analysis –Modelling • Gradually decreasing assistance	Broom and dustpan for each student	• Classroom – Domestic skills room – Home simulation environment	• Cooperating at home • Helping mother • Visual-motor coordination • Precision • Speed in completing a task
7	Domestic skills	Housekeeping	Changing garbage bag	• Skill analysis – Modelling • Gradually decreasing assistance	One litter bin for each student – garbage bags	• In the main classroom – inner courtyard of the school – classroom – domestic skills room	• Finances and saving • Hygiene • Cooperating at home • Helping mother • Fine motor skills
8		Kitchening	Packaging using cellophane wrapping and tin foil	• Skill analysis – Modelling • Gradually decreasing assistance	Several cellophane and tin foils – plates – boxes with lids – real food and nuts	• Domestic skills room • Classroom	• Fine motor skills • Collaborating at home and helping mother
9			Preparing a picnic basket	• Skill analysis – Modelling • Gradually decreasing assistance • Role playing in simulated environment	Realistic simulated environment of a beach – four picnic baskets – picnic supplies (plastic plates, spoons, nuts, candy, potatoes, juice, coolers, coffee, tea…)	• Domestic skills room • Classroom • Simulated medium (beach)	• Cooperation • Problem-solving • Decision-making • Following rules on trips • Keeping environment and beach clean • Sharing food • Learning about the beach and what is found there
10	Domestic skills	Kitchening	Pouring hot liquids (tea & coffee)	• Skill analysis • Modelling • Gradually decreasing assistance	Coolers (coffee – tea) – cups (coffee – tea)	• Domestic skills room • Classroom	• Following security and safety skills in the kitchen Caution Precision Receiving and welcoming guests

Skill	Strand	General skill	Goal	Teaching strategy	Teaching aids	Training environment	Concepts and skills developed through skill training
11	Domestic skills	Clothing care	Washing clothes by hand	• Skill analysis • Modelling • Gradually decreasing assistance	Large washing pot – laundry detergent – underwear for each student	• Domestic skills room	• Personal hygiene • Hanging clothes on clothesline • Saving on water Washing underwear privately • Precision Developing fine motor skills
12	Telephone use	Telephone use	Making a phone call	• Skill analysis • Instruction • Modelling • Role playing • Story	Game composed of two phones connected by a wire to communicate the sound – bulletin board – puppets	• Classroom	• Social communication • Training on communication skills and clear pronunciation Developing receptive language • Asking for permission before using the phone Types of phones social events • Mentioning the neighbourhood where the student lives
13	Orientation and mobility	Orientation and mobility	Mentioning the neighbourhood where the student lives	• Skill analysis • Modellin • Role playing	Game composed of two phones connected by a wire to communicate the sound – bulletin board – puppets – cards – map of city	• Classroom	• Improving pronunciation • Social communication
14	Personal finances	Personal finances	Saving in piggy bank	• Modelling • Role playing	Picture cards of real toys and various supplies that are attractive to the students – piggy banks bearing students' names and pictures – selling stand – Cashier – Actual toys and supplies similar to ones in picture cards –Money	• Classroom	• Making choices • Decision-making • Charity • Spending wisely • Paving the way to the buying and selling process (shopping)
15	Shopping	Purchasing	Buying from a specific list	• Skill analysis • Modelling • Gradually decreasing assistance • Field visits • Presentation • Video • Simulated environment	Actual shopping cart – actual shopping basket – cashier –shopping lists – simulated supermarket model (HyperPanda) – money	• Model of simulated environment • HyperPanda Supermarket (real-life setting)	• Spending wisely • Purchasing sensibly • Getting to know the names of some grocery items • Matching words to images • Following shopping rules • Bus rules • Decision-making and making choices • Saving money to make purchases • Selling • Preserving public property

Source: Author

Picture showing one of the students performing first aid.

Picture showing students being trained on the skill of saving money in the piggy bank.

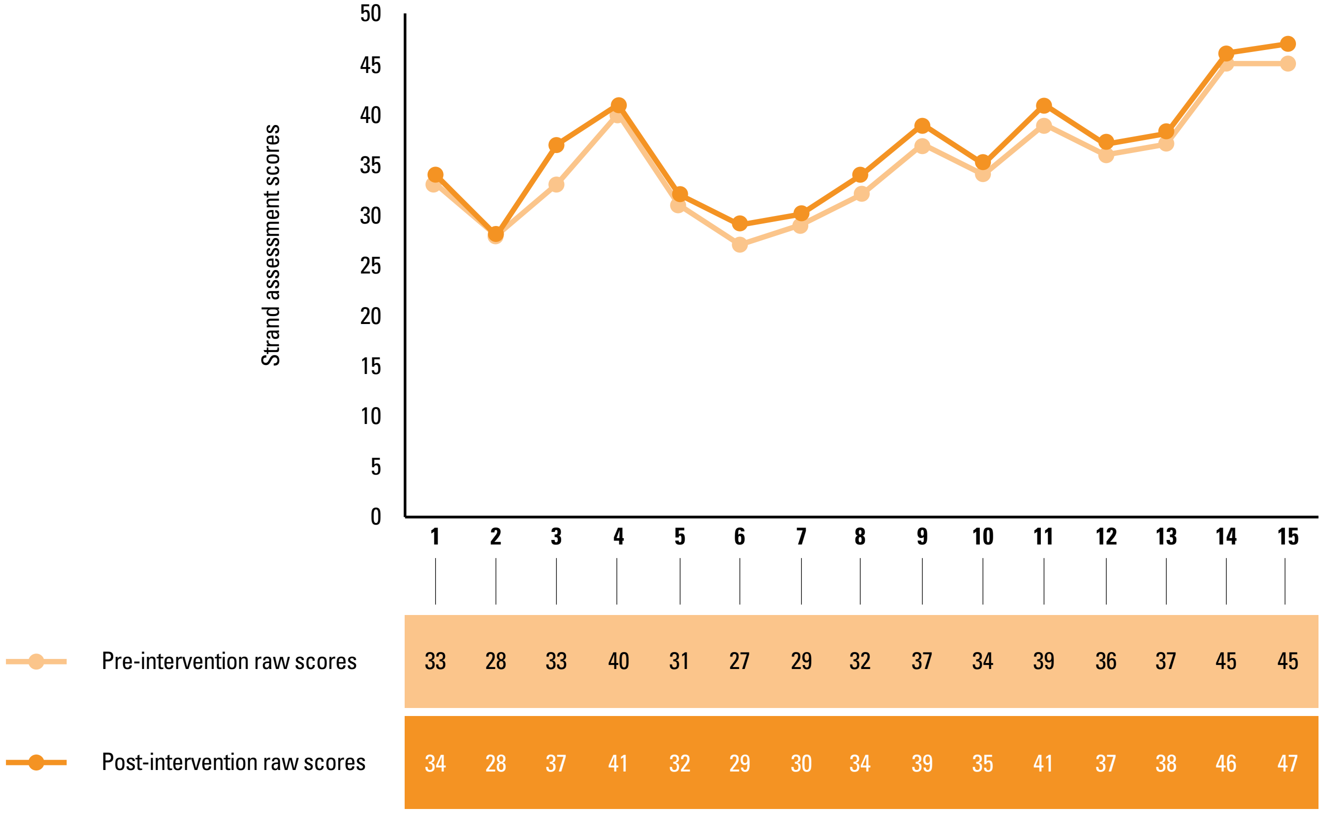
Picture showing a student applying the shopping skill in a real-life setting.

3. Study findings

A. Study findings related to the first hypothesis

1. The study revealed statistically significant differences at &=0.01 significance level between the pre- and post-assessment scores attained by the students in the experimental group in the overall level of independence skills, in favour of the post-assessment scores.
2. The study showed statistically significant differences between pre- and post-assessment scores attained by students in the strands of self-care, domestic skills, first aid, telephone use, shopping, personal finances, and movement and orientation, but not in the fifth strand, security and safety. The skills under the shopping strand improved significantly by 600 per cent after introducing the functional curriculum.

Figure 1. Pre- and post-assessment scores of experimental group members in the self-care strand

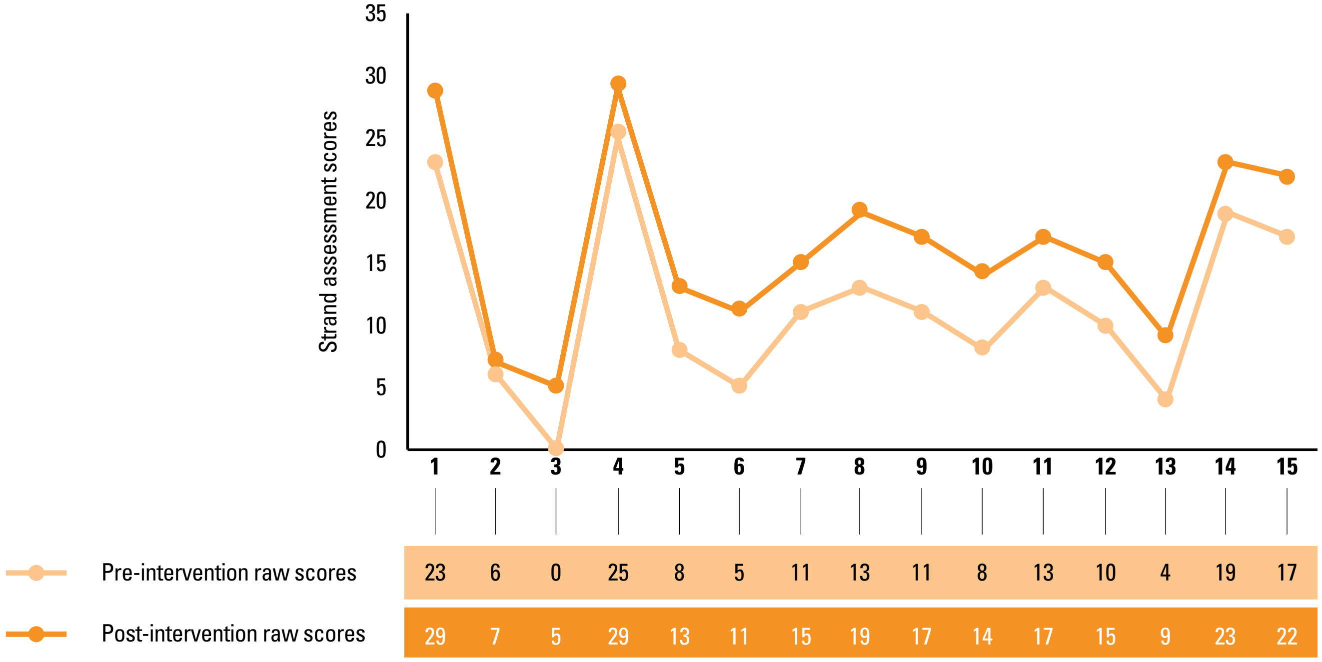


	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	33	28	33	40	31	27	29	32	37	34	39	36	37	45	45
Post-intervention raw scores	34	28	37	41	32	29	30	34	39	35	41	37	38	46	47

Source: Author.

The graph in figure 1 shows a slight improvement in the performance of the study sample students in the self-care strand, except for student 2, who did not show any improvement in this strand after the intervention period using the functional curriculum.

Figure 2. Pre- and post-assessment scores of experimental group members in the domestic skills strand

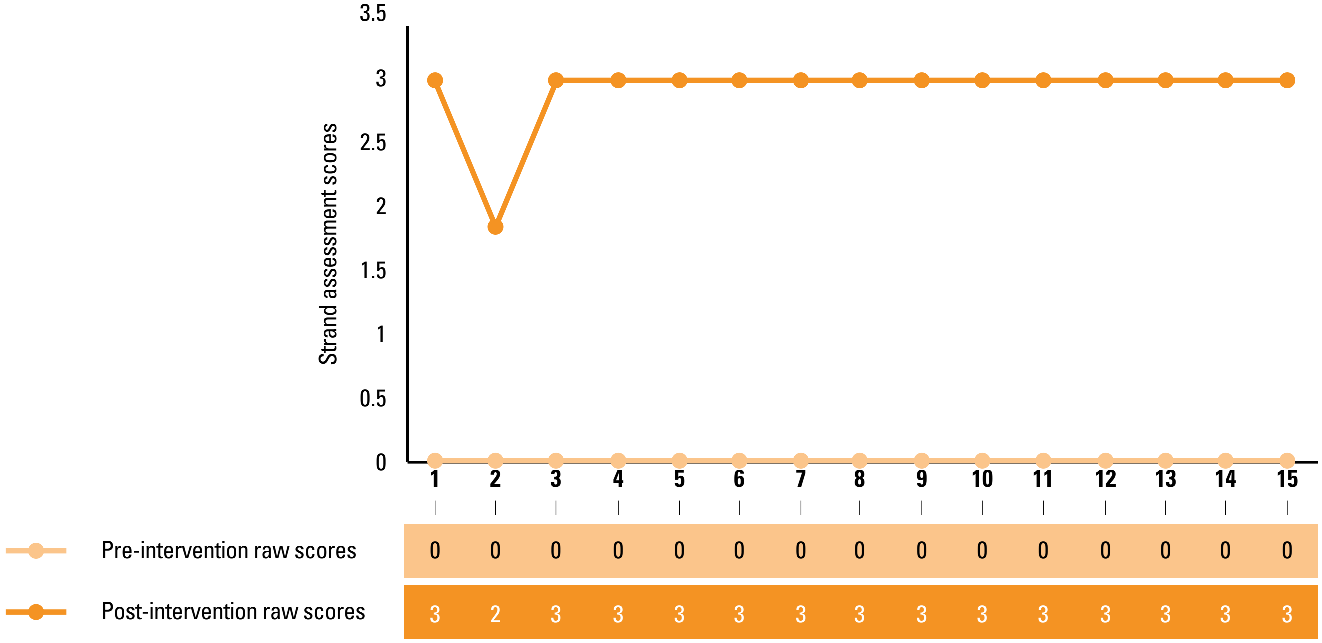


	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	23	6	0	25	8	5	11	13	11	8	13	10	4	19	17
Post-intervention raw scores	29	7	5	29	13	11	15	19	17	14	17	15	9	23	22

Source: Author.

The graph in figure 2 shows an improvement in the performance of all students in the domestic skills strand.

Figure 3. Pre- and post-assessment scores of experimental group members in the first-aid strand

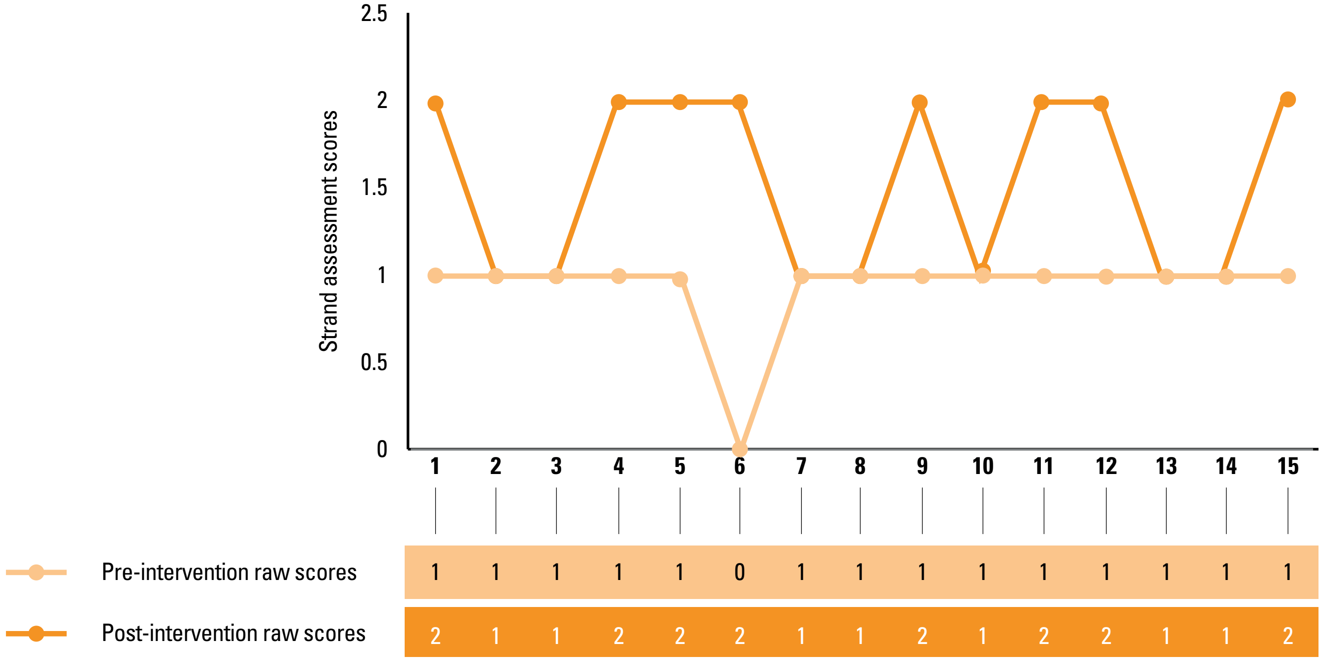


	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Post-intervention raw scores	3	2	3	3	3	3	3	3	3	3	3	3	3	3	3

Source: Author.

The graph in figure 3 shows a significant improvement in the performance of all students. It is noteworthy that this strand is completely new for them. They had not learned any first-aid skills before the intervention period.

Figure 4. Pre- and post-assessment scores of experimental group members in the telephone use strand



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1
Post-intervention raw scores	2	1	1	2	2	2	1	1	2	1	2	2	1	1	2

Source: Author.

The graph in figure 4 reflects a varied performance by students in the telephone use strand. Students 1, 4, 5, 6, 9, 11, 12 and 15 showed an improvement, while students 2, 3, 7, 8, 10, 13 and 14 did not. This disparity is due to the fact that students who performed better had received training on telephone use objectives, while the group that did not improve had not. The fact that some students received training while others did not is because the curriculum adopted in this study is founded on applying an individualized education programme for each student, based on her needs and abilities. Therefore, students who could have a telephone conversation were trained, while students with severe speech problems that completely prevented them from using the phone were not. However, they were allowed to move forward even without receiving training on the goal.

The graph in figure 5 shows no change in students' performance in the security and safety strand, and there are no significant differences between the score averages before and after the programme implementation. This is due to the fact that this strand was not included in the students' individualized programmes that were based on the current performance level of each student, for the following reasons:

3. Training depends on achieving several goals beforehand that the students had not yet mastered. For example, the goal of calling emergency numbers is linked to students knowing the numbers in Arabic or English, a skill the students did not have. Training on this skill may face criticism due to the students' inability to perform part of the

task, which is dialling the phone number, similar to the criticism received by Drysdale et al. (2008) when students were trained on the telephone use skill before they had acquired the skill of knowing numbers, which prevented them from mastering the telephone use skill completely.

4. Training on some goals takes a long time exceeding the study period, given its pertinence to other skills, such as personal safety skills, especially those related to recognizing strangers, proper conduct in the event of getting lost in a public place, and other similar goals.

5. The students' mothers opted against choosing a goal under this strand for several reasons:

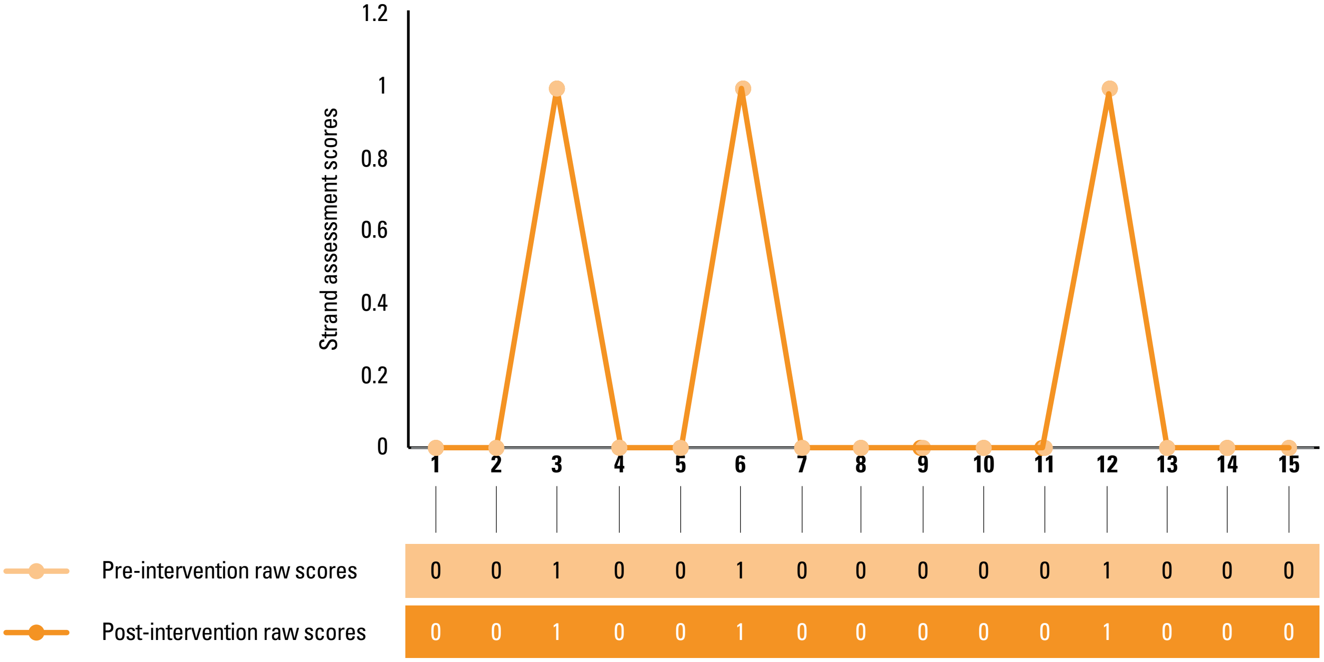
    - The students were trained on first-aid skills, which the mothers considered to be an important and sufficient part of security and safety skills.

    - The mothers did not want to train their daughters to recognize hazardous materials at home and follow pedestrian safety rules, for fear of putting them at risk if they tried to experience the training unattended.

    - Mothers considered that the students had a greater need for housekeeping and shopping skills at the time, preferring to prioritize the said skills.

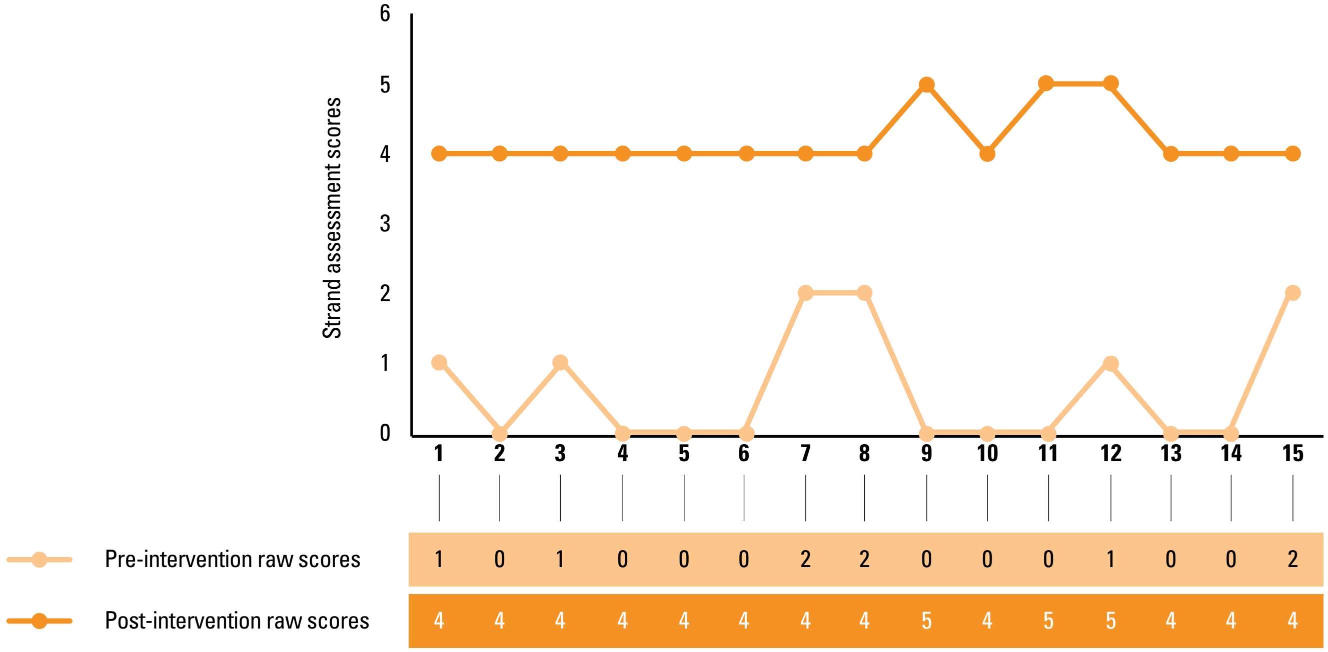
Browder et al. (2004) justify this selective process by considering that the functional curriculum constitutes a framework within which the student's priority skills can be selected.

Figure 5. Pre- and post-assessment scores of experimental group members in the security and safety strand



Source: Author.

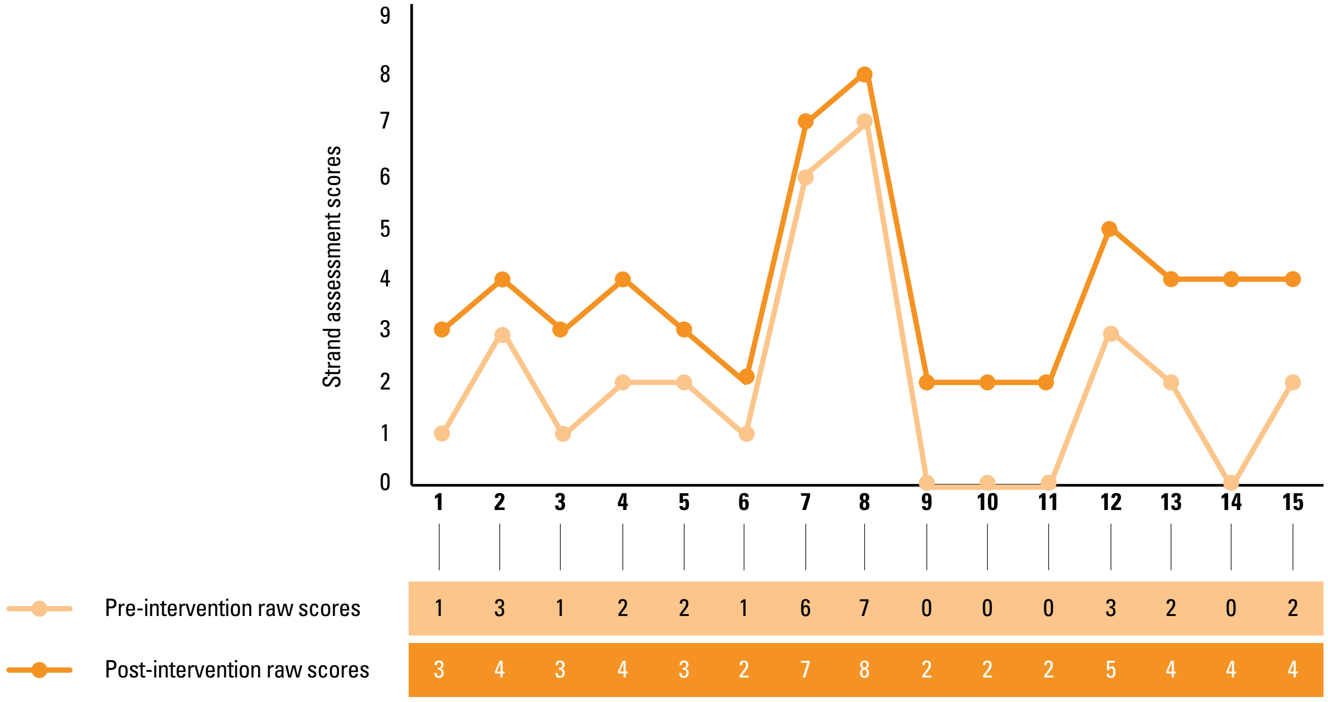
Figure 6. Pre- and post-assessment scores of experimental group members in the shopping strand



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	1	0	1	0	0	0	2	2	0	0	0	1	0	0	2
Post-intervention raw scores	4	4	4	4	4	4	4	4	5	4	5	5	4	4	4

Source: Author.

Figure 7. Pre- and post-assessment scores of experimental group members in the personal finances strand

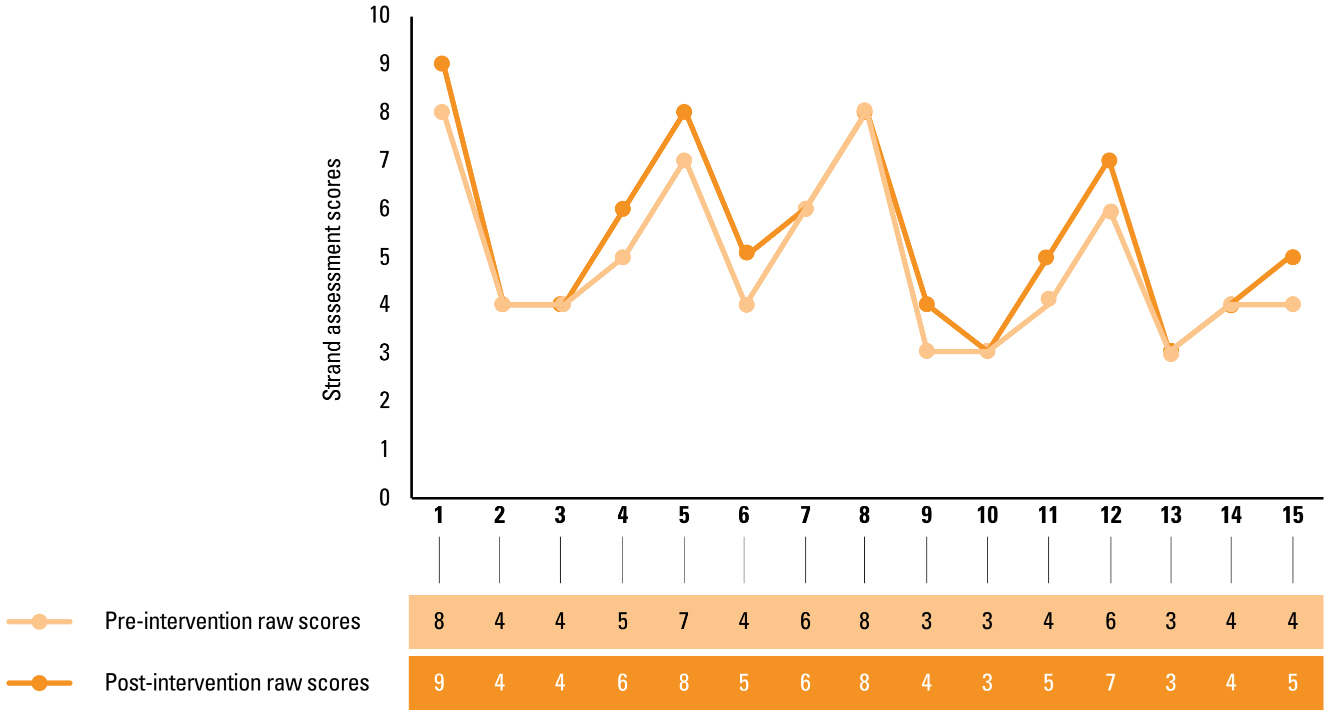


	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	1	3	1	2	2	1	6	7	0	0	0	3	2	0	2
Post-intervention raw scores	3	4	3	4	3	2	7	8	2	2	2	5	4	4	4

Source: Author.

The graphs in figures 6 and 7 indicate a clear improvement in the students' performance in the shopping and personal finances strands after receiving the pertinent training.

Figure 8. Pre- and post-assessment scores of experimental group members in the orientation and movement in society strand



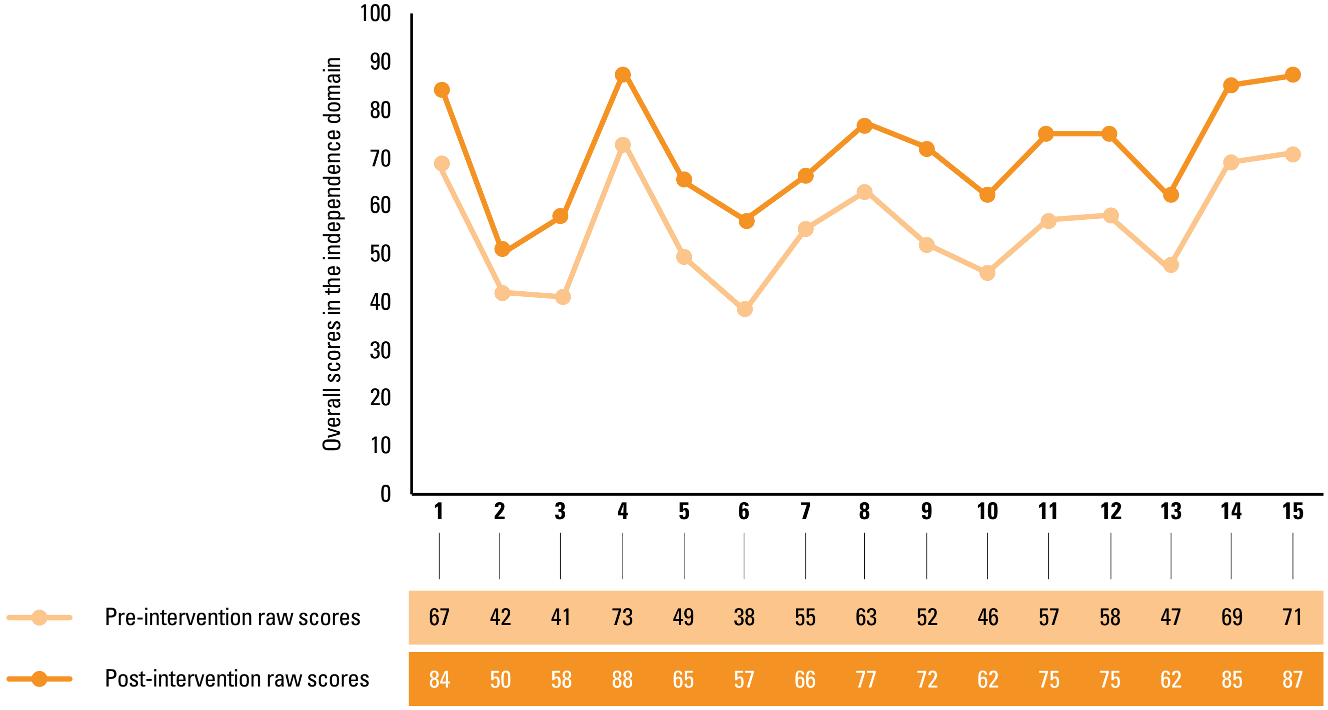
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	8	4	4	5	7	4	6	8	3	3	4	6	3	4	4
Post-intervention raw scores	9	4	4	6	8	5	6	8	4	3	5	7	3	4	5

Source: Author.

The graph in figure 8 shows an improvement in the performance of students 1, 4, 5, 6, 9, 11, 12 and 15, whereas the performance of students 2, 3, 7, 8, 10, 13 and 14 showed no change. The students who showed improvement had received training on the objectives related to this strand, given that the curriculum adopted in this study was founded on applying an individualized education programme for each student, based on her needs and abilities. In this strand, the training included practicing mentioning the name of the neighbourhood in which the student lives and linking it to the skill of conducting a telephone conversation. The students who showed a need for this goal and the ability to achieve it received the training, whereas students with deep speech problems that prevented them from achieving that goal did not. Therefore, the outputs of students in the experimental group were different in this strand.

> “The students who showed improvement had received training on the objectives related to this strand”

Figure 9. Pre- and post-assessment overall scores of experimental group members in the independence domain



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pre-intervention raw scores	67	42	41	73	49	38	55	63	52	46	57	58	47	69	71
Post-intervention raw scores	84	50	58	88	65	57	66	77	72	62	75	75	62	85	87

Source: Author.

The graph in figure 9 shows differences between the average overall scores attained by the experimental group members in the pre- and post-assessments in the independence domain, in favour of the post-assessment scores. Moreover, the students' performance recorded statistically significant differences between the pre- and post-assessments in strands 1, 2, 3, 4, 6, 7 and 8, while not in the fifth strand (security and safety). These results indicate a noticeable improvement in the performance of students in the experimental sample after teaching them the functional curriculum. This proves the effectiveness of the functional curriculum in helping students acquire independence skills, especially in the first, second, seventh, and eighth strands, as results show a statistically significant correlation between the difference in the experimental group's pre- and post-assessment scores on the one hand, and applying the functional curriculum on the other.

> …the **effectiveness** of the **functional curriculum** in helping students acquire independence skills, especially in the **first**, **second**, **seventh**, and **eighth** strands, as results show a statistically **significant correlation** between the difference in the experimental group's **pre-** and **post-assessment scores** on the one hand, and applying the **functional curriculum** on the other.…

B. Study findings related to the second hypothesis

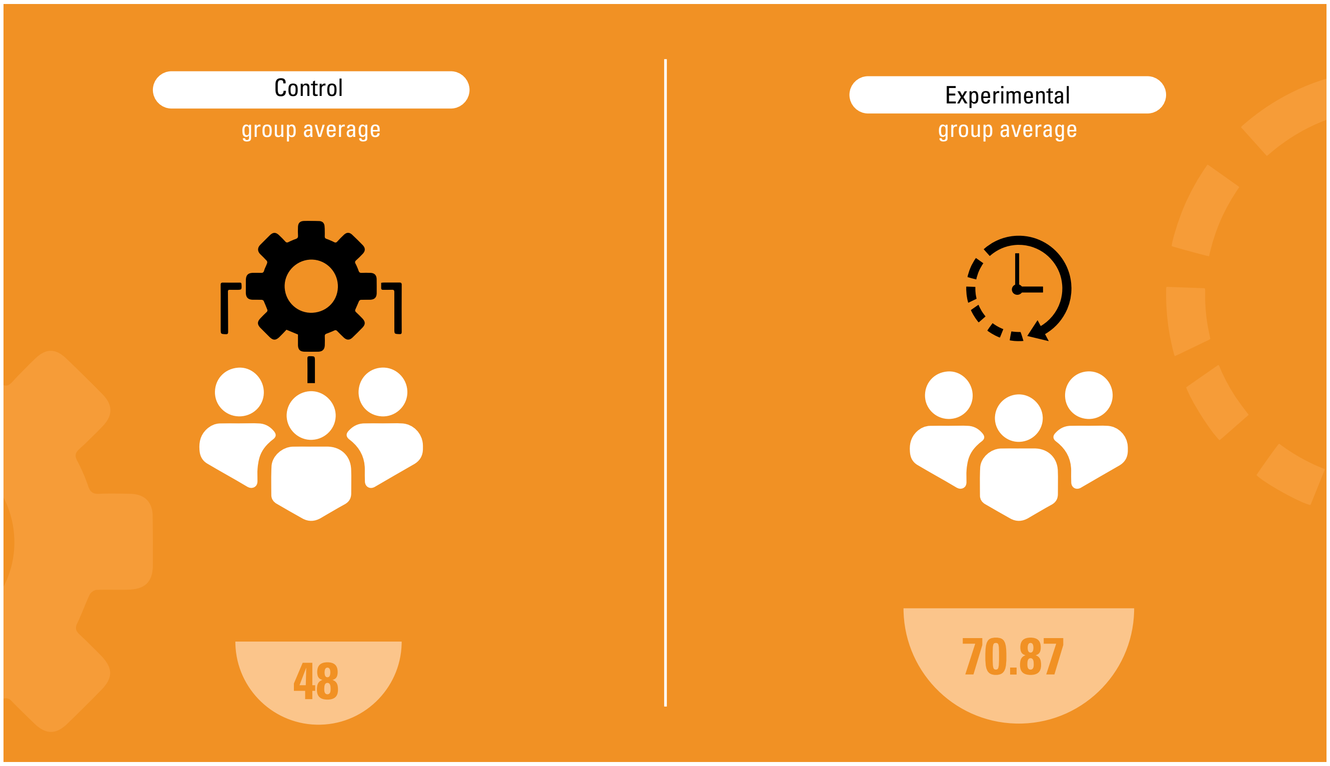
1. The study showed that there were statistically significant differences at &=0.01 significance level between the experimental and control groups' independence skills averages in the post-assessment, i.e. after applying the functional curriculum in teaching the experimental group.

2. The study showed that there were statistically significant differences at a 0.01 significance level, between the average independence skills scores of the experimental group that was taught the functional curriculum, and those of the control group after isolating the effect of the experimental group's pre-assessment scores. Therefore, the proposed functional curriculum is effective in helping students with moderate intellectual disabilities acquire functional skills.

3. The results of the associated variance analysis revealed that there were statistically significant differences at a 0.01 significance level, between the experimental group and the control group in favour of the former, in strands 1, 2, 3, 4, 6, 7 and 8, after isolating the effect of the associated variable (experimental group pre-assessment scores).

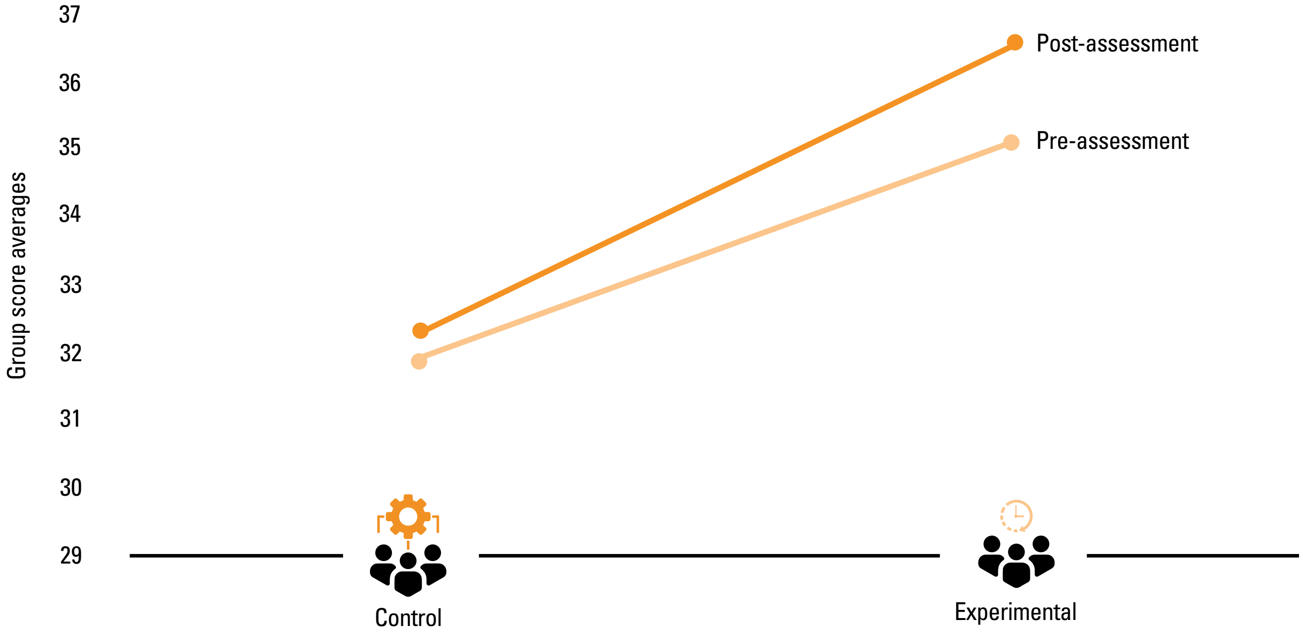
4. The study showed that there were no statistically significant differences at a 0.05 significance level between the experimental group and the control group in the post-assessment score in the security and safety strand, even after teaching the former the functional curriculum.

Figure 10. Averages of control and experimental group members in post-assessment



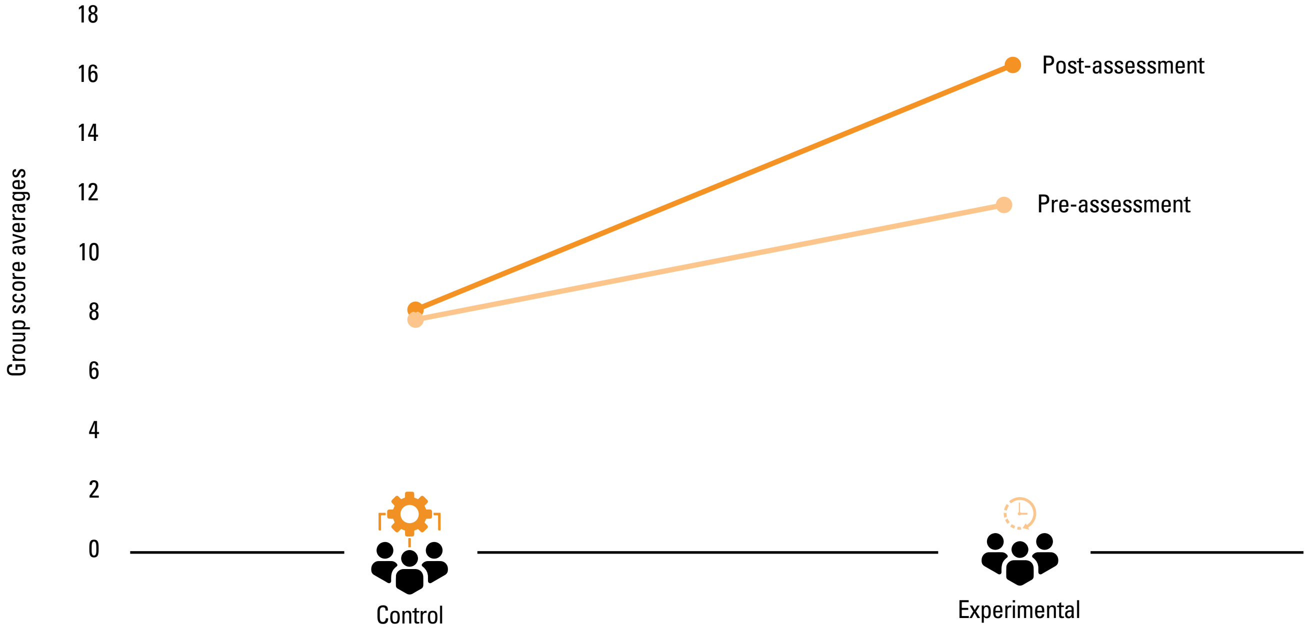
Source: Author.

Figure 11. Differences between the calculated averages of the experimental and control groups in the pre- and post-assessment in the self-care strand



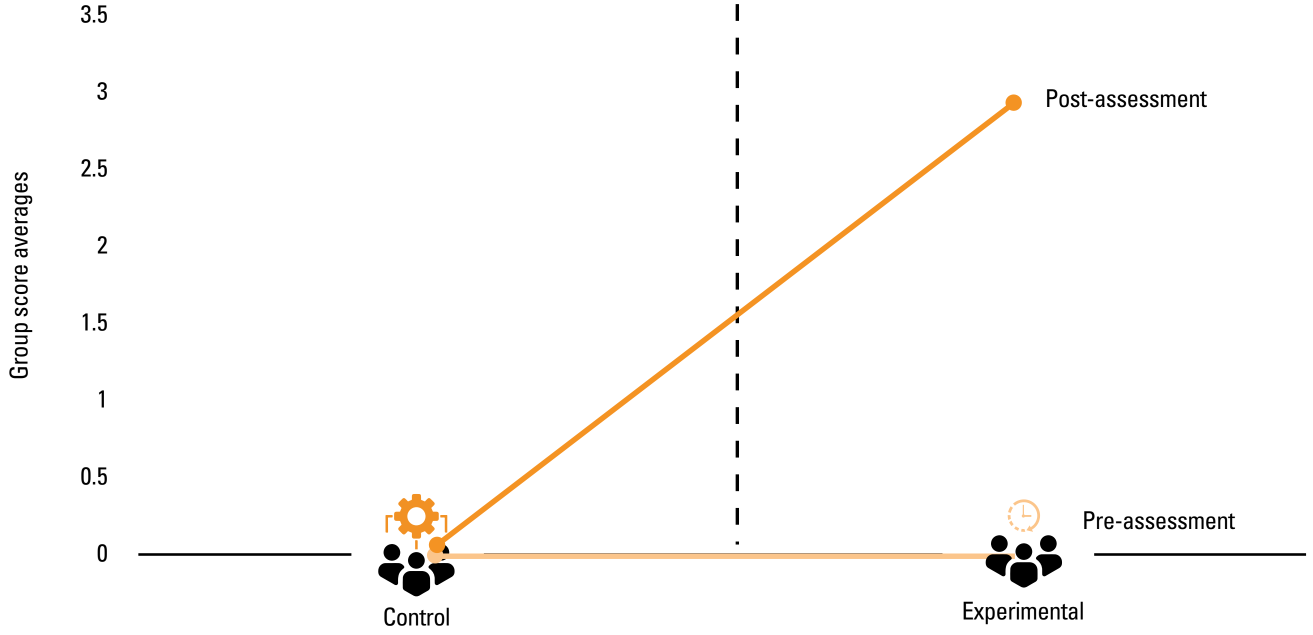
Source: Author.

Figure 12. Differences between the calculated averages of the experimental and control groups in the pre- and post-assessment in the domestic skills strand



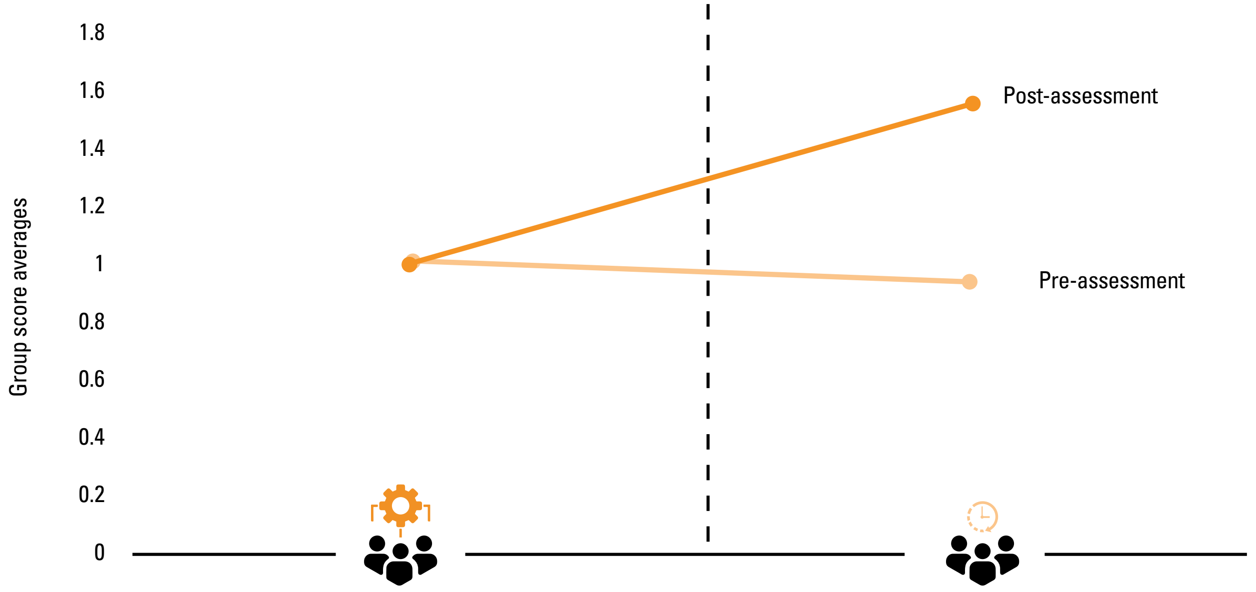
Source: Author.

Figure 13. Differences between the calculated averages of the experimental and control groups in the pre- and post-assessment in the first-aid strand



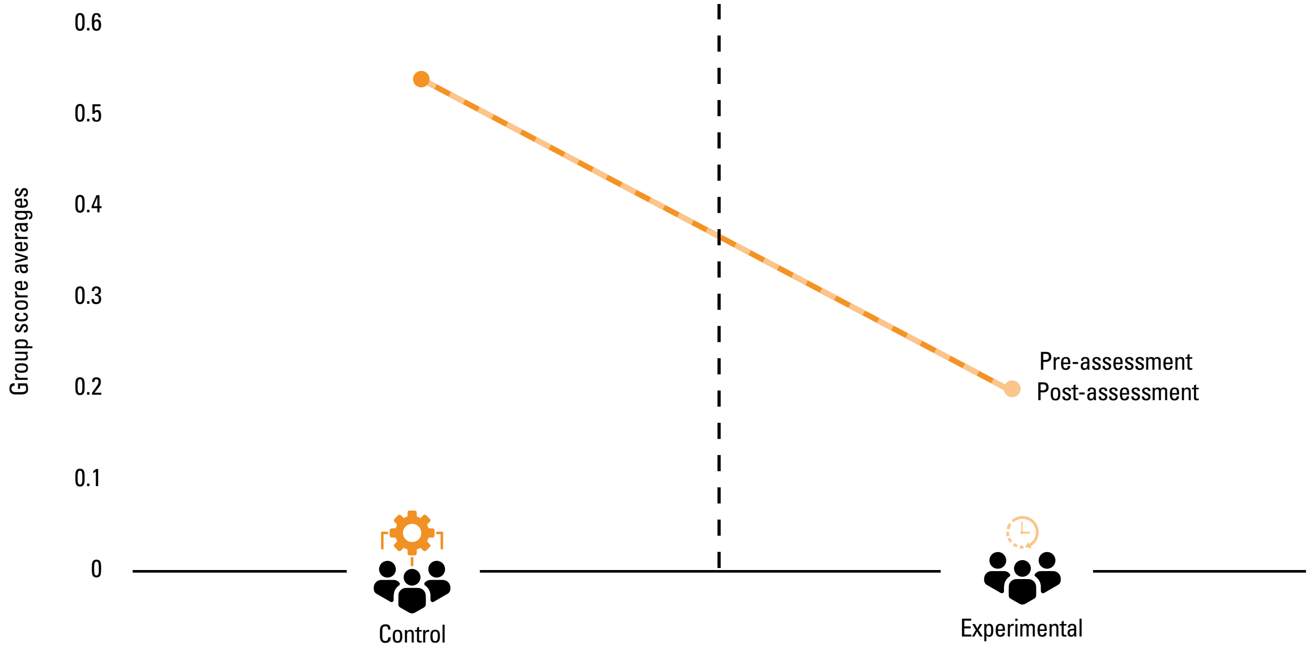
Source: Author.

Figure 14. Differences between the calculated averages of the experimental and control groups in the pre- and post-assessment in the telephone use strand



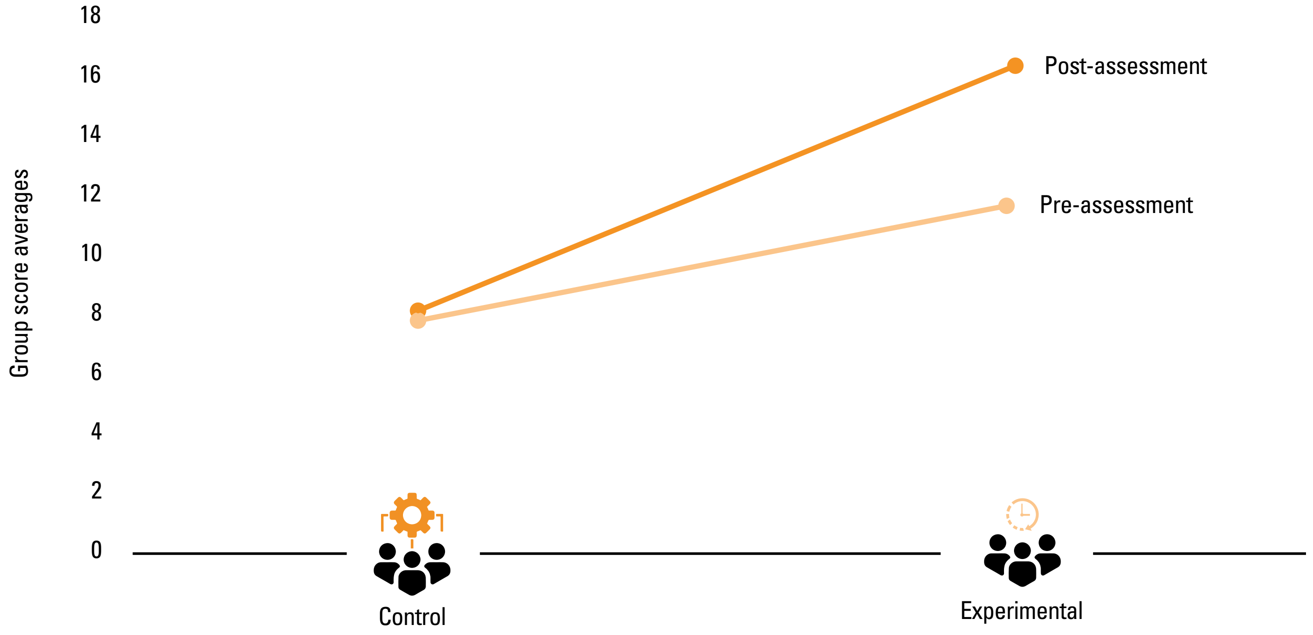
Source: Author.

Figure 15. Differences between the calculated averages of the experimental and control groups in the pre- and post-assessment in the security and safety strand



Source: Author.

Figure 16. Differences between the calculated averages of the experimental and control groups in the pre- and post-assessment in the shopping strand



Source: Author.

4. Recommendations

In light of the study findings, the researcher reached the following recommendations:

1. Given its positive results in helping students with moderate intellectual disabilities acquire functional skills, the proposed functional curriculum must be applied in intellectual education institutes and comprehensive rehabilitation centres in the Kingdom of Saudi Arabia, for both male and female students.

2. It is necessary to review the intellectual education curricula currently adopted in the institutes and programmes for the different intellectual disability categories. It is also necessary to include functional skills in all domains (academic, independent, social and professional), and not to limit them to students with moderate intellectual disabilities.

3. Persons in charge of intellectual education programmes need to capitalize on the skills and instructions in the proposed functional curriculum and apply them in integration programmes for persons with intellectual disabilities.

4. Special education teachers must be trained on how to use the functional curriculum in teaching and training students with intellectual disabilities.

5. The family partnership standard must be actively applied in planning, implementing and evaluating the curricula of students with intellectual disabilities.

6. It is important to apply community-based training and rehabilitation in intellectual education institutes, through forming partnerships between the Ministry of Education institutions and private companies in various fields. These partnerships serve the training of students in real-life settings and facilitate their transition to the work environment.

7. It is important to dedicate workshops to train students with intellectual disabilities on job skills, such as secretarial work, flower arrangement and gift wrapping, hairdressing, carpentry work...

8. A computer programme and an electronic database for the functional curriculum can be developed to serve as a reference for special education teachers, so as to facilitate the implementation of each student's individualized education plan.

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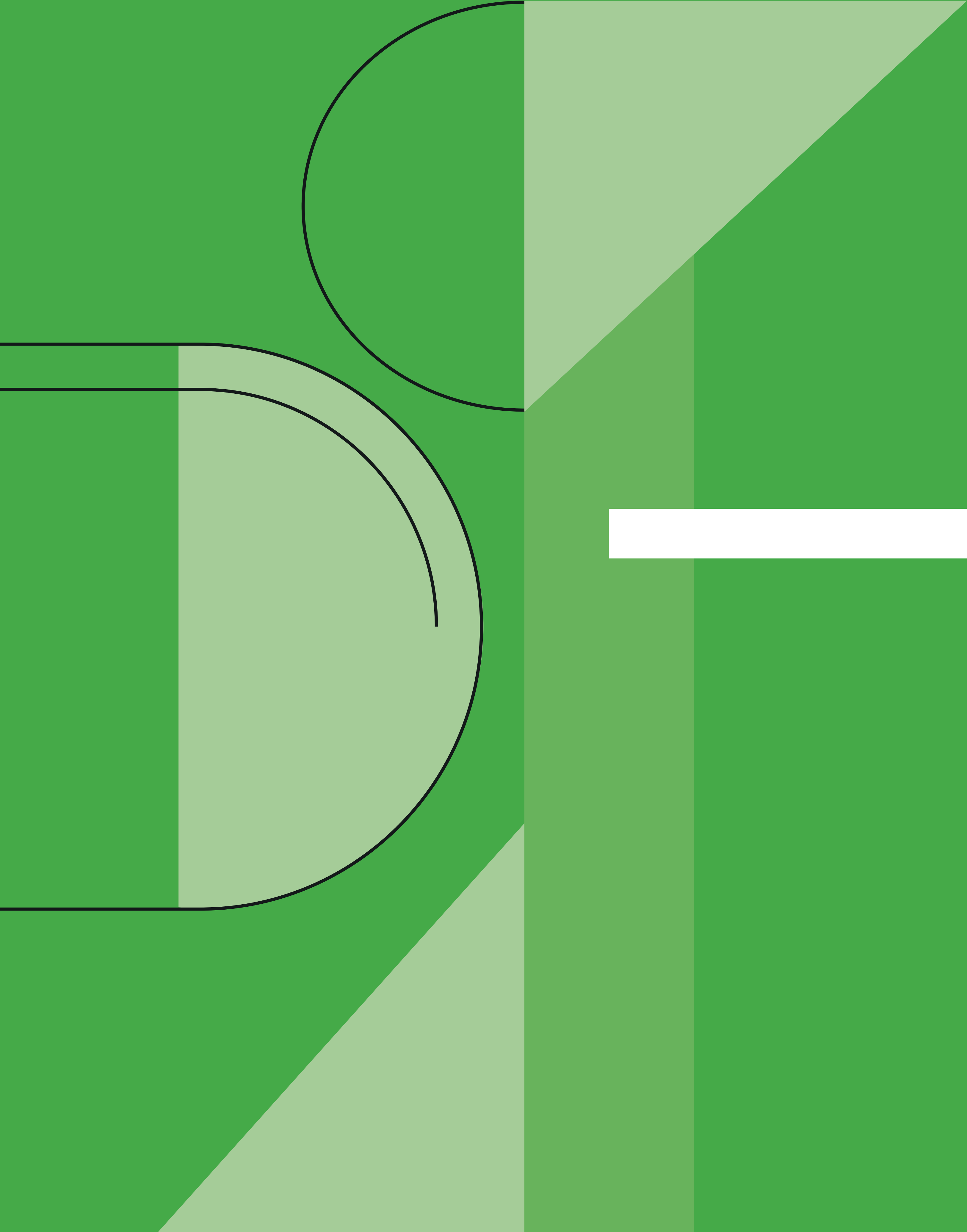


TRANSITION AFTER UNIVERSITY AND FINDING WORK

DOES DISABILITY AFFECT LABOUR MARKET OUTCOMES?

APPLICATION OF THE CASE OF EGYPT

Aida Ramadan
Racha Ramadan

Key messages

1

Despite the legal and institutional reforms and initiatives undertaken in Egypt, persons with disabilities experience many barriers in accessing the labour market.

2

Using the Egypt Labor Market Panel Survey (ELMPS) 2018, this study shows that disability is associated with a lower probability of participation and employment in the Egyptian labour market.

3

When employed, persons with disabilities are typically found in low-level, low-paid jobs, precarious employment, or segregated from the mainstream labour market.

4

Enhancing employment of persons with disabilities requires a holistic approach to promote their employment, entrepreneurship and micro-enterprises, to enhance international cooperation and technology transfer, and to improve the collection of high-quality data on disability.

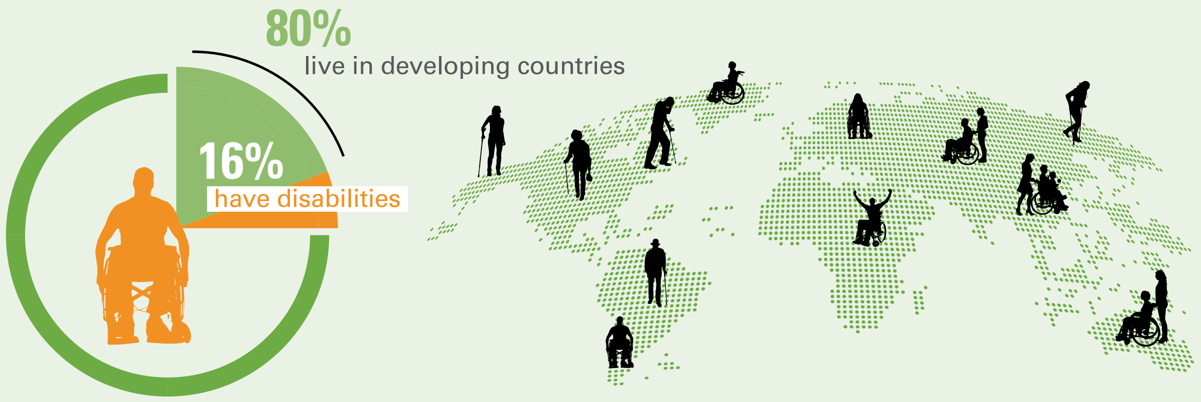
Introduction

Disability is one of the most pressing issues that can affect the development process of all countries across the globe (El Refaei, 2016). People with disabilities are more likely than their peers without disabilities to have worse socioeconomic outcomes since they experience enormous obstacles in accessing health care, education, training, employment and social services (such as housing and transport), in addition to facing exclusion from day-to-day activities (WHO, 2011). These disadvantages are exacerbated in developing countries (WHO, 2015). According to WHO (2022), more than one billion people or about 16 per cent of the global population have a disability, of whom nearly 80 per cent live in developing countries. Furthermore, it is anticipated that disability prevalence will continue to increase in the coming years, owing to ageing populations with the related higher risk of disability, and the global rise of chronic health conditions (WHO, 2011). For these reasons, the inclusion of people with disabilities warrants attention.

Specifically, the understanding of the relationship between disability and employment has gained momentum during recent decades (DESA, 2019). In addition to being a matter of fundamental human rights, persons with disabilities having access to work is also a means of gaining economic advantages. The socioeconomic position of any individual in the community depends largely on their employment and corresponding earnings in the labour market. The labour market appears to be a place where many persons with disabilities experience various barriers. There are significant differences in employment-to-population ratios between persons with disabilities, and persons without disabilities across the globe. In many

According to WHO (2022)

More than **1 billion people or about 16%** of the global population **have a disability**



cases, the employment-to-population ratio of people with disabilities is half or even one-third of that of the general population (ESCWA, 2014; DESA, 2019). Even when people with disabilities are employed, they are typically found in low-level, low-paid jobs, precarious employment or segregated from the mainstream labour market (DESA, 2019).

Egypt is no exception, where at least 10.6 per cent of the population has a disability (CAPMAS, 2017).[1] Although Egypt signed the Convention on the Rights of Persons with Disabilities in 2007, and ratified it in 2008, persons with disabilities in Egypt have long been marginalized, stigmatized and disadvantaged in almost all dimensions of life (Hagrass, 2012). Like elsewhere in the world, persons with disabilities in Egypt are more likely to be deprived of training and employment; hence, they frequently depend on their families or government social security programmes. As a result, they are highly at risk of poverty, abuse, exploitation, exclusion and isolation (El Refaei, 2016).

On the national level, for decades, Egypt has been eager to address the rights and needs of people with disabilities and their socioeconomic position. Egyptian efforts to include them in society have been apparent and are intended to achieve long-lasting and better development strategies. This commitment lies at the heart of the Sustainable Development Strategy in Egypt Vision 2030, guided by the global Sustainable Development Goals (SDGs). It is also reflected in the Disability Rights Law, adopted in 2018. Despite the legal and institutional reforms and initiatives aiming to enhance the employment of persons with disabilities in the Egyptian labour market, disability has still been associated with substantial employment disadvantages (Sieverding and Hassan, 2019). The few empirical studies concerning employment of persons with disabilities that have been conducted are also relatively limited in Egypt. Even descriptive studies on the relationship between disability and economic outcomes are lacking. This deficiency may be due to the lack of accurate data on disability, which in turn hinders the decision makers from developing appropriate policies to integrate persons with disabilities into the Egyptian labour market. Meanwhile, assessing the employment situation of persons with disabilities becomes even more urgent within the framework of the SDGs and Sustainable Development Strategy, and with the associated pledges of equitable and inclusive development for all.

In 2017, the government of Egypt began to measure disability, using new and accurate measures developed by the Washington Group on Disability Statistics (WG). Collection of such data makes it possible to assess the employment situation of persons with disabilities. Therefore, the main objective of this paper is to use these measures, introduced in the Egypt Labor Market Panel Survey (ELMPS) 2018, to contribute to the existing literature and fill the gap in Egyptian empirical research on employment of people with disabilities in Egypt in two ways. First, using descriptive analysis, the paper seeks to develop a detailed profile of persons with disabilities in Egypt according to levels of severity, the most prevalent types and patterns of disability by socioeconomic factors (gender, age, region of residence, wealth and education). Second, the paper aims to assess the extent to which disability is associated with a lower probability of employment in Egypt. The impact of disability on entering the labour force is a preliminary step, a baseline model is estimated using logistic regression with “being in the labour force” as the dependent variable. The study then evaluates the effect of disability on the probability of employment and working in the public sector once the individual has entered the labour market. Since the dependent variable in this case is only observed for those already in the labour force, it may represent a non-random sample. Accordingly, probit models with selection are applied to account for this potential selection bias.

The paper is organized as follows: Section 1 reviews the existing literature; Section 2 tackles the disability-related legal evolution in Egypt; and Section 3 presents a detailed profile of persons with disabilities in Egypt using the ELMPS 2018. The methodology and results of the study are discussed in Sections 4 and 5. Section 6 includes the conclusion and policy recommendations.

`1. Literature review

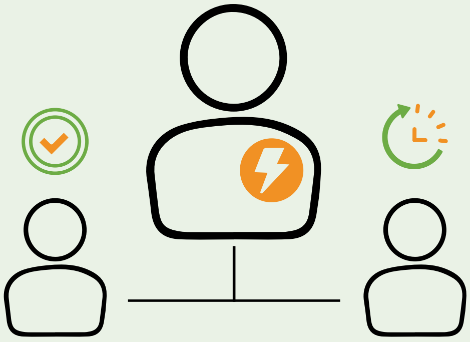
Despite the differences in the definition of disability, time periods or the source of data across countries, it is almost agreed upon that disability has significant negative effects on both employment and earnings (Baldwin and Johnson, 1994; Kidd et al., 2000). Theoretically, the employment rate of people with disabilities is lower than that of people without disabilities due to reasons of both supply and demand (WHO, 2011). On the supply side, more effort and time may be required to get to the workplace or perform tasks (Barnes and Mercer, 2005). Hence, persons with disabilities usually face a higher cost of working. Accordingly, the reservation wage of a person with disabilities (namely the lowest wage a person is willing to work for) is more likely to be higher than that of a person without a disability. On the demand side, a person with a disability may be offered a lower wage due to discrimination, which occurs because of employer prejudice (that is, unfavourable attitude), asymmetric information or exploitation of persons with disabilities (WHO, 2011). Thus, a higher reservation wage combined with a lower offer wage may result in persons with disabilities to be less likely to be employed than persons without disabilities. Moreover, employers may be reluctant to hire persons with disabilities, as they may need workplace accommodations, which may affect the company's costs and the company's main objective of profit maximization (Schartz et al., 2006).

On the other hand, multiple empirical studies have indicated many benefits of employing persons with disabilities. These studies have found that most accommodations cost little or even nothing compared with the benefits gained from employing people with disabilities (Schartz et al., 2006). With the correct accommodations and preparation, persons with disabilities can thrive and become as, or even more, productive and qualified for a certain job than their peers without disabilities (ILO, 2015). In addition, the theoretical framework introduced by Barney (1991) provides a human capital–based approach to understanding the importance of hiring people from minority groups. According to Barney, employing persons with disabilities can provide a competitive advantage to companies in the form of a skilled and loyal source of workers. In addition, by employing persons with disabilities, companies can benefit from diversity,[2] tax benefits, and a larger talent pool, improve their company's image and avoid legal issues resulting from not employing persons with disabilities. Furthermore, not employing persons with disabilities may result in such macroeconomic costs as disability benefits, losses in human potential and productivity, losses in tax revenue and the resultant inhibiting impact on consumer spending. The positive effect of employment on people with disabilities themselves, economically, socially, and psychologically, is another benefit of increasing employment of people with disabilities.

Within this context, a worldwide movement has started to empower, support and integrate people with disabilities into their societies by removing the barriers they face and providing equal opportunities, generally, and in employment, in particular. For example, the Convention on the Rights of Persons with Disabilities affirms the right to work equally for all people with disabilities, as a basic and natural means to safeguard human dignity (CRPD, Art. 27). Moreover, the employment of people with disabilities also has received explicit attention through the 2030 Agenda, more commonly known as the Sustainable Development Goals (SDGs). The SDGs include various goals related not only to employment and decent work, but also to education, inequality, accessibility, data collection and monitoring of the SDGs. Thus, progress towards integrating persons with disabilities into the labour market, and ultimately mainstream society, can be used, by itself, as a gauge for achieving the SDGs.

Studies that deeply examine the position of people with disabilities in labour markets are plentiful in developed countries, but not in developing countries. In the Middle East and North Africa (MENA) region, in particular, there appears to be a wide gap in the literature. Even the limited literature that exists depends primarily on qualitative techniques. In Lebanon, for example, Wehbi and El-Lahib (2007) discussed the obstacles persons with disabilities faced in finding and keeping jobs, and provided recommendations for change through surveying a sample of people with disabilities in a rural region. In Saudi Arabia, Mansour (2009) investigated the attitudes and concerns of employers about hiring persons with disabilities through a questionnaire distributed to different employers in the country. He found that productivity, work performance and lack of skills were the primary reasons employers chose not to employ persons with disabilities.

Chronic diseases



%25-

reduction of the probability of being employed

-22 HRS/WEEK

reduction of the number of working hours

In Egypt, the literature concerning persons with disabilities is very limited as well. Most of this limited research is medical, cultural or social. The empirical studies, if any, are only qualitative. These studies aimed mainly to identify medical and social reasons for disability (Hagrass, 2005), its consequences on the quality of life for both persons with disabilities and their families (El-Saadani and Metwally, 2019), societal attitudes toward persons with disabilities, the Egyptian disability laws (Zidan, 2012) and rehabilitation services available to them (El Refaei, 2016). Other studies focused on specific groups of persons with disabilities, such as blind people (Sharaf, 2015) and people with intellectual disabilities (Abdelhameed, 2010). To date, the relationship between disability and education is the most frequently discussed research question in Egyptian literature (Sharaf, 2015; Lord and Stein, 2018; El-Saadani and Metwally, 2019).

To date, there is one quantitative study on chronic diseases in Egypt, but that study is not limited to people with disabilities. Rocco et al. (2011) used the 2002 Egypt Household Health Utilization and Expenditure Survey to investigate the effect of chronic diseases on the probability of employment through fitting a linear probability model to examine the impact of chronic diseases on the number of working hours per week and wage rates among the employed. They found that chronic diseases reduced the probability of being employed by approximately 25 per cent, and the number of working hours by about 22 hours per week, but had no impact on wages. Based on their data, these researchers concluded that since chronic diseases could significantly reduce employment and labour supply, the labour endowment might not be fully utilized.

Other relevant studies were qualitative, and more likely to be associated with a specific disability type or employment sector. For instance, Sharaf (2015) evaluated the role of local NGOs in empowering persons with disabilities to access education and employment in Egypt, with a focus on those with vision impairments. By conducting interviews with five local NGOs, the authors found that the strategies employed to empower visually impaired people in the labour market were somewhat restricted to providing "soft" skills and developmental training. Othman and Sorial (2017) focused on integrating persons with disabilities in the engineering sector, specifically architectural design firms in Egypt. The study conducted six case studies of architects with disabilities, in addition to a survey with a sample of architectural design firms. They found that architects with disabilities were not only able to do what other architects did, but they could also excel and outperform the latter's achievements. Furthermore, companies that hired architects with disabilities were able to achieve competitiveness through diversity, incorporating a broader pool of experiences, avoiding legal concerns and improving their image.

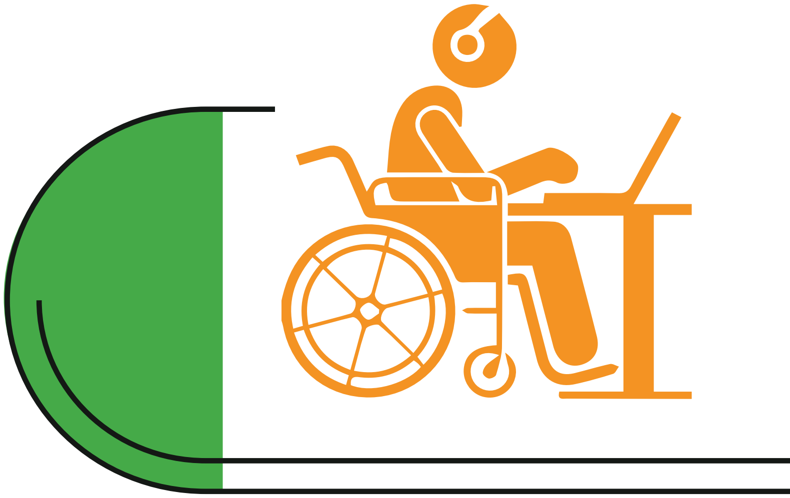
This dearth of quantitative research on the experience of people with disabilities in employment was likely due to the lack of accurate and adequate data on persons with disabilities up to 2017. Such lack of data significantly hampered conducting studies aiming to develop a detailed profile of people with disabilities in Egypt and their employment status.

In 2017, Egypt started to measure disability status using new accurate measures developed by the WG. These measures have been used in quantitatively assessing the influence of disability on education (El-Saadani and Metwally, 2019). Sieverding and Hassan (2019) also used these measures when investigating the relationship between aspects of economic vulnerability and health measures. This study provided a descriptive analysis of employment as being one of the economic vulnerability aspects and disability as being one of the health measures. However, the present study can be considered as the first quantitative study to explore the impact of disability on participation and employment using the measures developed by the WG.

2. The legal framework of disability in Egypt ....

In Egypt, disability has frequently been viewed within the medical model framework, in which disability is defined as a biological disease, disorder, injury or other health problem. Hence, when forming disability law and policies, the focus is on how to prevent, treat and manage the individual's impairment, and not on the physical and social barriers in the environment that prevent people with disabilities from being integrated into society. Whereas the focus of the medical model is to correct the impairments experienced by persons with disabilities and attempt to bring them back to the norm, by providing medical care and rehabilitation, (Mitra, 2006), the focus of the alternative social model is to address social, environmental, economic and cultural barriers they encounter in the health system, education, training, employment, working environments, transportation and housing.

The adoption of the medical approach is reflected in the first-ever Egyptian law related to disability, the Rehabilitation Law for persons with disabilities (Law No. 39 of 1975). This law focused primarily on the individual's physical and functional deficiencies as the only cause of disability-related problems, ignoring the environmental, economic, social and cultural barriers. Concerning employment of people with disabilities, the law and its subsequent amendment (Law No. 49 of 1982), imposed an employment quota on all public and private sector companies with 50 workers or more, requiring



that 5 per cent of their workforce be made up of persons with disabilities. An employer found in violation of this law would be subject to financial penalties (a paltry 100 LE fine) or imprisonment.

Although the Rehabilitation Law for persons with disabilities could be considered a significant step forward in promoting employment for persons with disabilities, quotas support the classical belief that persons with disabilities need particular provisions because they have medical impairments. Furthermore, although the quota guaranteed some jobs for persons with disabilities, it was restrictive in the sense of hindering them from participating and competing in the open labour market (Hagrass, 2005). Moreover, the provisions in this law specified only certain low-grade and menial jobs. These factors demonstrate that discrimination against people with disabilities inherently existed even in the law supposed to protect them. In addition, because the penalty fee was so low, employers could easily forgo hiring workers with disabilities, preferring to pay the penalty, with no risk of imprisonment. There are no records of actual imprisonment for employers found in violation of this law (Hagrass, 2012). Moreover, the procedures of recruiting persons with disabilities were limited to documenting papers rather than actual employment of those persons. In this way, persons with disabilities were asked to stay home and receive a minimum wage (Al Gazzaz, 2021). It is noteworthy that employment of people with disabilities was covered by the Rehabilitation Law of 1975 but not considered within Employment Law No. 137 of 1981; this indicates that persons with disabilities were not considered as a part of the labour market, and hence disability was a rehabilitation issue. This further confirmed the legal adoption of the medical model and the related exclusion of persons with disabilities from employment and society as a whole (Hagrass, 2005).

In 2007, when Egypt signed the Convention on the Rights of Persons with Disabilities, a new era began with respect to treatment of people with disabilities, which seeks to go beyond the medical approach towards recognizing the principal rights of persons with disabilities to live independently and be included in the community (CRPD, Art. 19). This change is reflected in the amendments to the Egyptian constitution in 2014, which could carry new hopes for persons with disabilities. In the new constitution, people with disabilities are mentioned for the first time as equal citizens, in nine different clauses, ensuring their rights in all aspects of life and prohibiting disability-based discrimination. Furthermore, the core principles of the Sustainable Development Strategy, adopted in 2016, include the empowerment of people with disabilities. To achieve this goal, Egypt is committed to enhancing their rehabilitation, protection, inclusion and participation in all aspects of life. This commitment was highlighted in the president's declaration of the year 2018 as the year of people with disabilities. It was also reflected in the Disability Rights Law, Law No. 10 of 2018 on the rights of persons with disabilities, which replaced the Rehabilitation Law for persons with disabilities of 1975.

The new Disability Rights Law is currently the main national legal framework for the rights of persons with disabilities, addressing the purpose and articles of the Convention on the Rights of Persons with Disabilities. Accordingly, this new law asserts the responsibility of the Egyptian government towards the inclusion and social protection of persons with disabilities.

With respect to employment, under the new law, the government must guarantee the right of people with disabilities to acquire equal job opportunities without discrimination, and in accordance with their capacities, academic credentials and vocational training (Art. 20). Although the new law also imposes an employment quota of 5 per cent as in the previous law, it applies to employers with at least 20 employees (Art. 22), rather than 50 employees under the prior law. The employer who does not comply with the quota under the new law is also subjected to a financial penalty of not less than 10,000 and up to 30,000 LE and/or imprisonment for a period not exceeding one year (Art. 54).

Additionally, the law considers the needs of persons with disabilities within the workplace. It provides a paid one-hour work time reduction daily for workers with disabilities and for relatives (up to the second degree) who take care of an employee with disabilities. Furthermore, the new law stipulates punishments related to discriminatory behaviour, violence and isolation in the workplace. It also encourages employers to hire persons with disabilities by providing a 5 per cent reduction on income taxes for the employment of every person with a disability above the legal quota (Art. 23).

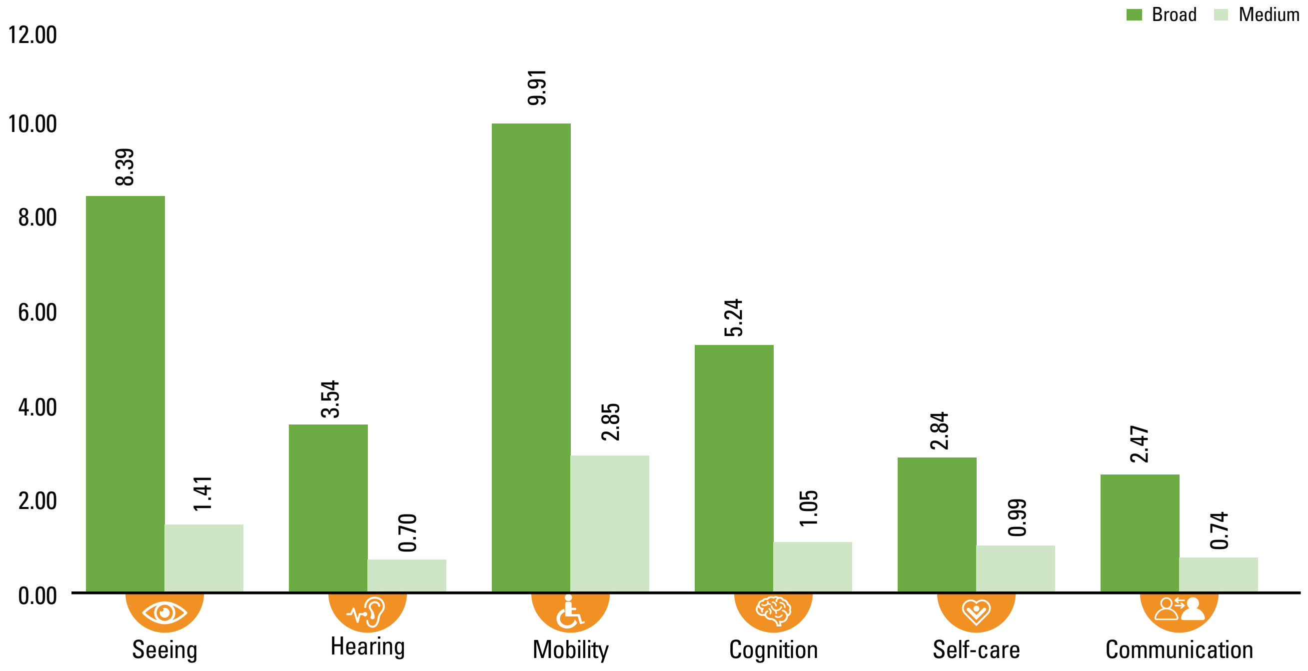
> “… the government must guarantee the right of people with disabilities to acquire equal job opportunities without discrimination, and in accordance with their capacities, academic credentials and vocational training”

3. Profile of people with disabilities in Egypt ....

The research analysis draws on the WG disability measures introduced in the nationally representative data of ELMPS 2018,[3] executed by the Economic Research Forum (ERF) in cooperation with the Central Agency for Public Mobilization and Statistics of Egypt. Such measures are composed of six questions designed mainly to address different levels of difficulty in performing in six core functional domains. These domains are seeing, hearing, mobility, cognition (remembering and concentrating), self-care and communication. For each of these domains, the response difficulty categories are “No, no difficulty,” “some difficulty,” “a lot of difficulty,” and “cannot do it at all.” Difficulties in these domains within an inappropriate environment may be correlated with a greater risk of participation limitations. It is worth noting that this set of questions is currently the most used measure of disability worldwide (ESCWA, 2018). With a response rate of 82.7 per cent, the developed profile of people with disabilities depends on a sample of 50,634 individuals.

Following the WG (2020) guidance, three severity thresholds of disability are constructed. The first one is the “broad/any disability” threshold, in which any individual is considered to have a disability if he/she has at least a score of “some difficulty” in at least one of the six domains. The second measure is the “medium/severe disability” threshold, in which any individual is considered to have a disability if he/she has at least a score of “a lot of difficulty” in at least one of the six domains. Finally, the “narrow/complete disability” definition is the one in which any individual is considered to have a disability if he/she has a score “cannot do it at all” in at least one of the six domains. According to these three severity levels, the prevalence rate of disability is 16.6 per cent,

Figure 1. Prevalence rates of disability by domains and levels of severity (percentage)



Source: Based on authors' calculations using ELMPS (2018)

4.6 per cent and 0.9 per cent using the broad, medium and narrow definitions, respectively. Given the limited size of the sample falling within the narrow definition, most of the coming analysis is restricted to the broad and medium definitions.

Figure 1 displays the prevalence rates of disability according to the six disability domains alongside the severity thresholds. As the figure shows, disability pertaining to mobility is the most prevalent type (9.91 per cent and 2.9 per cent), followed by seeing (8.38 per cent and 1.41 per cent) and then cognition (5.24 per cent and 1.05 per cent), using both broad and medium definitions, respectively. Communication is the least stated domain by the broad definition (2.47 per cent), while both hearing and communication are the least reported domains by the medium definition with very close rates (0.7 per cent and 0.74 per cent, respectively).

It is widely agreed that disability intersects with many other socioeconomic dimensions that deepen and aggravate its influence on the quality of life. Such dimensions may include gender, age, region of residence, wealth and education. Accordingly, table 1 displays the prevalence rates of disability by the broad and medium definitions alongside those socioeconomic factors. Following in the strides made by El-Saadani and Metwally (2019), the associated odds ratios are further calculated to compare between different groups.

Starting with gender, the disability rates among females are higher than those among males under both definitions. Using the odds ratios, results show that females are significantly more likely to be persons with disabilities than males by the broad definition. However, this difference is insignificant under the medium definition.[4] Such a pattern may be due to what is called the health-survival paradox. This paradox states that females are more likely to live longer but have poorer health compared with males. Hence, they are more likely to acquire an impairment.

Moreover, the older the person, the greater likelihood of becoming a person with a disability, reflecting an accumulation of health risks across the lifetime. Disability rates rise remarkably with age and peak in the oldest age cohort (65+) under both definitions. Accordingly, the odds of having any or a severe disability increase while moving from the youngest cohort to the oldest one, and all are statistically significant.

As table 1 reveals, disability is greater in urban areas than rural ones under both definitions. Hence, compared with rural areas, the odds of having any and severe disabilities in urban areas are higher and statistically significant. One possible reason for such a difference is the older age profile of residents in urban areas (Krafft et al., 2019). Other possible reasons may be that persons with disabilities are more easily found and counted in urban than in rural areas. The analysis shows that such a higher rate of any and severe disability in urban areas stems predominantly from the main urban regions, namely Greater Cairo, Alexandria and the Suez Canal cities. Meanwhile, the disability rates in the urban lower and urban upper regions are very close to their corresponding rates in the rural lower and rural upper by both definitions.

The poverty-disability nexus is well established and confirmed throughout literature. Table 1 reveals that the rate of any and severe disabilities is the highest among individuals in the poorest quintile (Q1). Compared with this poorest group, being in the richest one significantly decreases the odds of having any and severe disabilities by 27 per cent and 48 per cent, respectively. These high rates of disability among the poor are expected since both poverty and disability reinforce each other.

Turning to education, the disability rate reaches its peak among the illiterate group by both definitions. The likelihood of having any or a severe disability decreases by 68 per cent and 78 per cent, respectively, in the tertiary education group compared with the illiterate one. What is especially striking is the slight increase in disability rate when moving from the secondary to tertiary category. Although this is a surprising result that requires more investigation, it was confirmed in the Egyptian literature, as in Sieverding and Hassan (2019).

The likelihood of having any or a severe disability decreases by

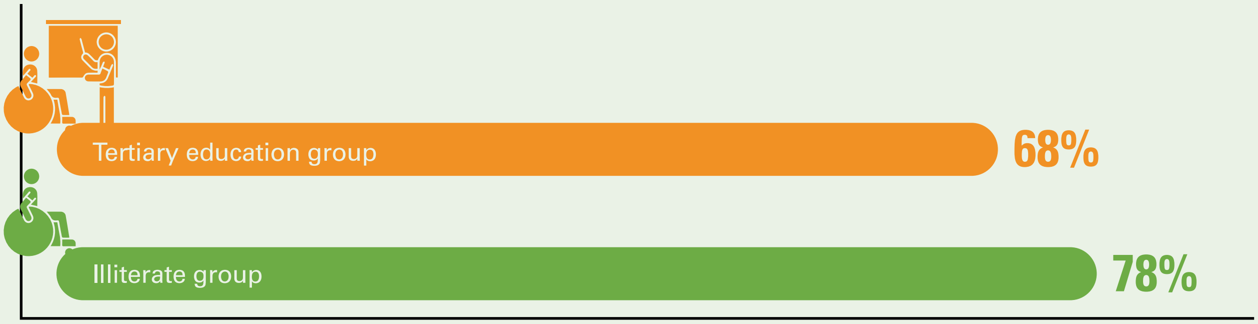


Table 1. Prevalence rates of disability by the broad and medium definitions according to demographic and socioeconomic factors, ELMPS 2018

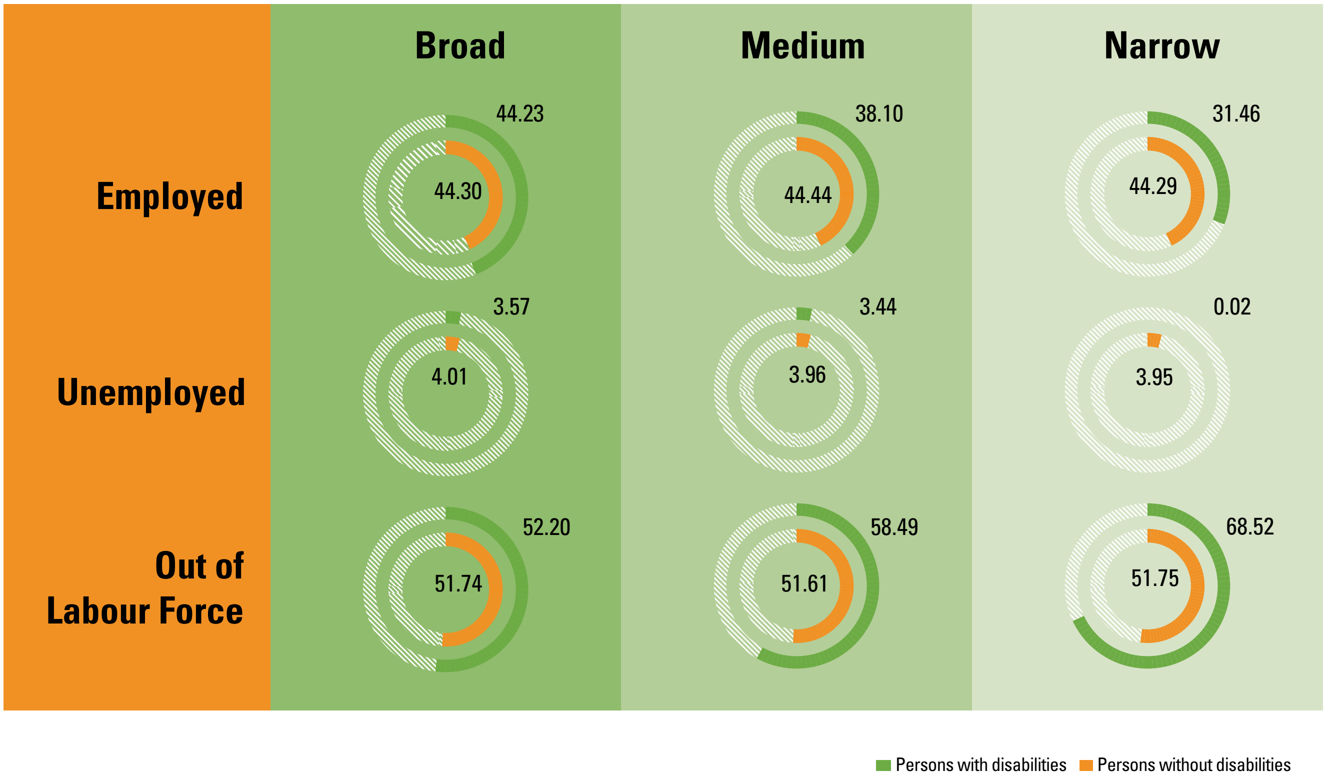
		Broad definition		Medium definition	
	Demographic and socioeconomic factors	Percentage of persons with disabilities (Percentage)	Odds ratios	Percentage of persons with disabilities (Percentage)	Odds ratios
	Overall	16.6	--	4.6	--
Gender	Female	17.58	(RG)	5.04	(RG)
	Male	15.6	0.9*	4.15	0.93
Age groups	0–11	5.97	0.036*	1.2	0.046*
	12–19	6.59	0.038*	1.43	0.041*
	20–29	7.39	0.043*	1.77	0.049*
	30–39	11.57	0.073*	2.27	0.075*
	40–49	19.74	0.142*	4.38	0.14*
	50–59	31.89	0.29*	7.97	0.26*
	60–64	42.86	0.472*	11.7	0.38*
	65+	62.15	(RG)	25.3	(RG)
Geographical location	Urban	19.51	1.29*	5.25	1.19*
	Rural	14.61	(RG)	4.16	(RG)
Education	Illiterate	32.96	(RG)	11.77	(RG)
	Reads and writes	13.84	0.32*	3.37	0.29*
	Primary	13.1	0.31*	3.22	0.25*
	Preparatory	13.2	0.27*	3.53	0.25*
	General secondary	11.2	0.24*	2.7	0.18*
	Vocational secondary	13.75	0.3*	2.7	0.2*
	Tertiary	15.2	0.32*	3.3	0.22*

Source: Calculated by the authors using ELMPS (2018).

Moving to the situation of people with disabilities in the labour market, the sample is restricted to the working-age group (15–64) consisting of 35,401 individuals. For the employment status, we use the market definition of employment stated in the Nineteenth International Conference of Labour Statisticians (ILO, 2013), following Krafft et al. (2019). Within such a definition, search for an employment opportunity is required for the labour force and unemployment variables.[5]

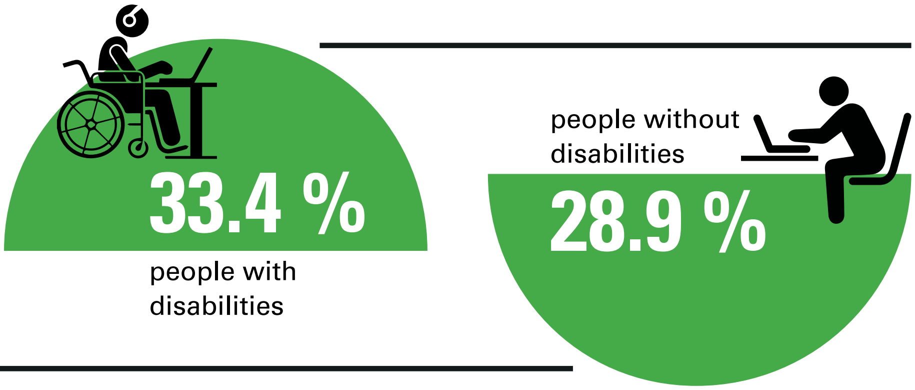
The prevalence rates of disability for the working-age population are 15.6 per cent, 3.7 per cent and 0.7 per cent by the broad, medium and narrow definitions, respectively. Starting with labour force participation and following the strides made by United Nations Department of Economic and Social Affairs (DESA) (2019) and Sieverding and Hassan (2019), figure 2 displays the percentages of employed, unemployed and out of labour force among persons with and without disabilities, using the broad, medium and narrow definitions. As the figure displays, persons with disabilities across all severity levels tend to be out of the labour force. Generally, results reveal that while the overall employment-to-population ratio for persons without disabilities (44.3 per cent) is slightly higher than that of persons with disabilities (44.2 per cent) using the broad definition,[6] the employment gap between both groups is wider using the medium definition (44.4 per cent versus 38.1 per cent, respectively) and the narrow one (44.3 per cent versus 31.5 per cent, respectively).[7] The same patterns hold according to different socioeconomic factors, except in some cases that should be deeply elaborated, as shown in table 2.

Figure 2. Employed, unemployed and out of labour force by disability status and levels of severity (percentage)



Source: Based on authors' calculations using ELMPS (2018)

The employment-to-population ratio in the two younger cohorts jointly by the broad definition



Disaggregating these rates by gender shows that the employment-to-population ratio of males without disabilities is higher than that of males with disabilities by the broad definition and considerably much higher by the medium one. One plausible explanation may be that having a disability is more likely to result in a disadvantage in finding employment, especially for males with severe disabilities. Interestingly, table 2 shows that the employment-to-population ratio of females with disabilities, as compared with males, is higher than that of those without disability using both definitions. This finding can be interpreted through their age profile in the Egyptian labour market. Employed females tend to be of older age (Krafft et al., 2019). Hence, they are more likely to be exposed to a disability if compared with the unemployed or out of labour force individuals, who tend to be younger. Such a result was further confirmed in the Egyptian literature, as in Sieverding and Hassan (2019). Examining these findings jointly reveals that being a male without disabilities guarantees a greater chance of employment. By contrast, females both with and without disabilities are less likely to be employed than males.

Regarding age, the employment-to-population ratio of people with disabilities (33.4 per cent) is higher than that of their peers without disabilities (28.9 per cent), in the two younger cohorts jointly by the broad definition. However, it is not the case for older cohorts. This result becomes clear if the association between disability and education is considered. In the two younger cohorts, approximately 19.3 per cent of persons with disabilities can at most read and write, compared with 11.2 per cent of persons without disabilities. On the other hand, around 43.8 per cent of persons with disabilities in these two younger cohorts are in secondary education or above, compared with 52.3 per cent of persons without disabilities. Accordingly, youth without disabilities in the younger cohorts tend to be in education, while their peers with disabilities are most probably out of education and engaged in some form of employment.

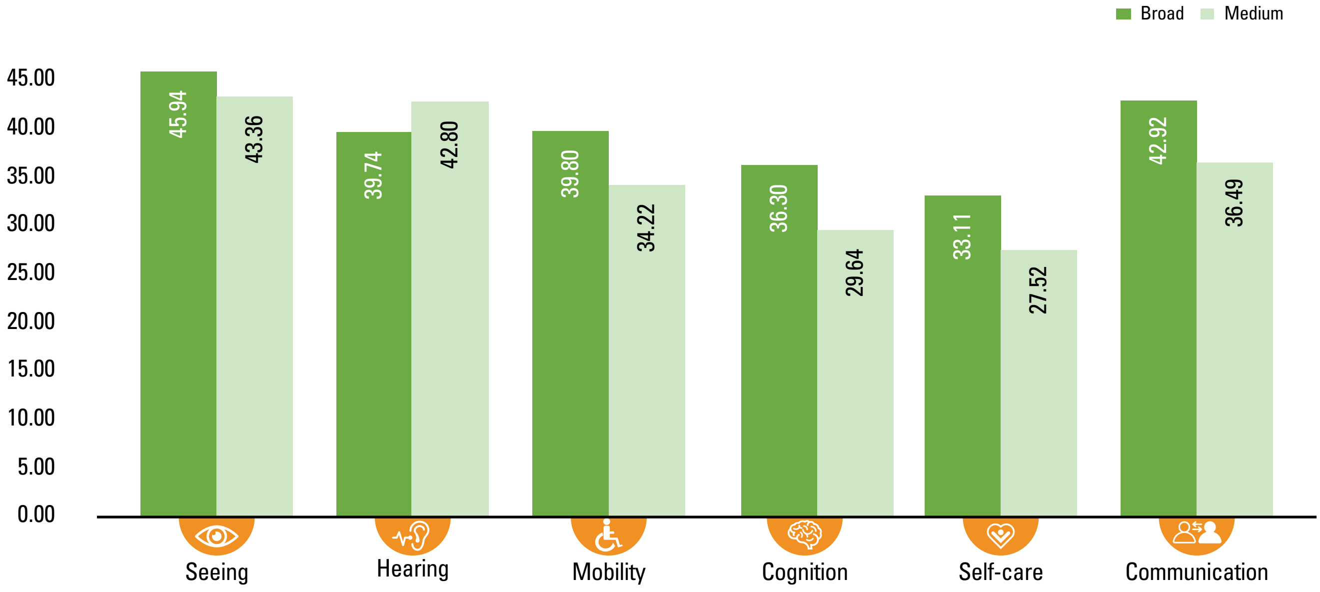
Notably, the employment-to-population ratio of persons with disabilities is higher than that of persons without disabilities in rural areas. Focusing on persons with disabilities, their employment-to-population ratio in rural areas is also higher than that of urban ones, using both definitions. These findings may be due to the fact that approximately 23 per cent of employees with disabilities work as unpaid family workers or are self-employed workers in agriculture. As for wealth quintiles, the employment-to-population ratio of individuals with any disability is the highest in the richest quintile. This result can be attributed to the fact that rich persons with disabilities can afford some kinds of employment (such as self-employment) compared with their poor counterparts.

The educational level of the individual with a disability plays a significant role in the employment of persons with disabilities. The employment-to-population ratio for persons with disabilities is the highest among people with tertiary education. Such a result highlights the importance of education on the likelihood of being employed. However, the fact that older people, who are highly concentrated in the lowest education categories, are more likely to be employed than younger people, makes the employment-to-population ratio higher within the first two categories than in the middle three ones. On the other hand, the employment-to-population ratio of persons with disabilities who have intermediate education or above is somewhat higher than that of their peers without disabilities. One explanation may be that once persons without disabilities are enrolled in education, they are more likely than persons with disabilities to continue education rather than engage in employment.

By looking closely at the results of severe disability across all socioeconomic characteristics, it can be noted that the deterrent impact of disability on employment becomes stronger as the degree of severity increases. Importantly, the employment-to-population ratios, according to disability domains, are considered. Figure 3 reveals a remarkable heterogeneity among persons with disabilities in employment according to disability domains. The employment-to-population ratio is the highest among individuals with any or a severe disability in vision (45.9 per cent and 43.4 per cent, respectively). Then, the next highest is among those who have any disability in communication (42.9 per cent), and those who have a severe disability in hearing (42.8 per cent). The lowest is among those with any or a severe disability in self-care (33.1 per cent and 27.5 per cent, respectively).

For those who are employed, the study found that 18 per cent of the public sector workforce are persons with disabilities. Such a remarkably high percentage of persons with disabilities in this sector is likely the result of the older age profile of workers, since those who have acquired jobs in this sector are more likely to retain their jobs until retirement. These findings also may highlight the commitment by the public sector to employing people with disabilities.

Figure 3. Persons with disabilities who are employed, by domain and level of severity (percentage)



Source: Based on authors' calculations using ELMPS (2018)

Table 2. The employment-to-population ratios by disability status and demographic and socioeconomic factors among the working-age sample population (15–64); ELMPS 2018

		Broad definition		Medium definition	
	Demographic and socioeconomic factors	Persons without disabilities (Percentage)	Persons with disabilities (Percentage)	Persons without disabilities (Percentage)	Persons with disabilities (Percentage)
	Overall	44.3	44.2	44.4	38.1
Gender	Female	16.46	20.36	17.1	17.2
	Male	72.6	71	72.6	63.1
Age groups	15 – 19	14	14	14.2	7.9
	20 – 29	37.6	43.8	38	37.6
	30 – 39	55.2	51.4	54.7	59.3
	40 – 49	61.6	58.5	61.3	54
	50 – 59	58.9	48	56.9	37.9
	60 – 64	26.4	19.9	25	12.3
Geographical location	Urban	44.2	42.9	44.3	35.4
	Rural	44.3	45.4	44.5	40.6
Wealth quintiles	Q1	45	43.5	44.9	41.4
	Q2	44.9	41	44.7	34.6
	Q3	43	45.1	43.4	38.1
	Q4	44.6	44.7	44.9	36.7
	Q5	43.9	46.5	44.4	39.4
Education	Illiterate	39.6	32.4	38.7	25
	Reads and writes	55.9	47.8	54.2	56
	Primary	37.3	39.2	37.5	38.8
	Preparatory	24.7	36.3	25.8	33.2
	General secondary	17.9	28.6	18.9	23.7
	Vocational secondary	52.4	54.4	52.7	47
	Tertiary	60.7	64.1	61.2	60.5

Source: Calculated by the authors using ELMPS (2018).

4. Methodology

Several models are estimated to fully assess the deterrent effect of disability status on the likelihood of employment, controlling for other variables hypothesized to affect employment. The broad definition of disability is adopted to preserve the sample size of persons with disabilities. Again, employment is defined according to International Labour Organization (ILO) criteria (ILO, 2013).

First, a logistic model is estimated to tackle the impact of having any disability on the likelihood of labour force participation (model 1). The dependent variable in this case is a binary variable equals one if the individual is in the labour market (employed or unemployed) and zero otherwise. Two other versions of model 1 are estimated: one model controlling for the interactions between disability and gender, and disability and status of the individual in the household (model 2), and another model assessing the effect of disability types on the probability of labour force participation (model 3). Thus, the probability of participating in the labour market is given by:

$$Pr(LF_i^*>0) = Pr(u_i> - X_i\beta) = \Lambda(X_i\beta);$$

where Λ (.) is the standardized logistic distribution, X_i is the vector of regressors and β is the associated parameter vector. Following the literature, other control variables are included in the models. These variables include factors that determine worker productivity (such as age and education) and factors that determine the relative value of personal time (such as marital status and wealth) (Baldwin, 1999). Moreover, it is believed that women and men often have different incentives and face different barriers to participating in the labour force; hence, a gender binary variable is included in the models. A variable that reflects the level of urbanization is also included since urban and rural areas have different structures of labour markets. Furthermore, the status in the household (head or non-head), household size and unemployment rate at the governorate level[8] are included as well (Fadayomi and Olurinola, 2014).[9]

Once in the labour market, would persons with disabilities be employed or unemployed, and if employed, would they be more likely to work in the public sector? To answer these questions, other models are estimated with different dependent variables. One model is estimated where the dependent binary variable equals one if the individual is employed and zero if unemployed (model 4). Another version of model 4 is estimated to assess the effect of disability types on the probability of employment. Finally, model 5 tackles the impact of being a person with a disability on the likelihood of being employed in public sector. Yet, the dependent variable in these cases is only observed for those already in the labour force. Hence, to control for selection bias, probit models with selection[10] are applied, following Hotchkiss (2004), and Jones and Latreille (2011).

At the first stage of this model, a labour force participation equation is estimated where the propensity to be in the labour force (LF_i*) is given by:

$$Pr(LF_i^*>0) = Pr(u_i > -X_i\beta) = \Phi(X_i\beta);$$

where Φ (.) is the standardized normal distribution.

Then, at the second stage, the outcome equation can be estimated conditional on labour force participation being observed ($LF_i = 1$). This outcome equation is given by:

$$E_i^* = T_i \gamma + v_i;$$

where the variable E_i, which is only observed if $LF_i = 1$, is related to the latent variable E_i^* as follows: $E_i = 1$ if $E_i^* > 0$ and $Ei = 0$ otherwise. $E_i = 1$ indicates the presence of an employed person or public sector worker, based on the specified model. It is assumed that ui and vi are normally distributed with zero means and unit variances, and the correlation between them is given by ρ. If there are unobservable factors affecting both equations, the correlation may be non-zero ($\rho \neq 0$). In this case, the results of a simple probit model of the outcome equation are biased. Yet, if the correlation turns out to be insignificant, we can depend on the results from the simple probit model.

Finally, to identify these models, at least one variable is included in the selection equation (labour force participation equation) that is not included in the outcome equation. Yet, in our case, the variables that determine the dependent variables are roughly the same as those determining labour force participation. Thus, it is difficult to find a suitable identifying variable. Nonetheless, a number of studies attempted to solve this identification problem by inserting variables as the unemployment rate at the governorate level, status in the household and household size in the selection equation (Hotchkiss, 2004; Jones, 2011). These variables may affect the probability of labour force participation, but not employment. On the other hand, an additional explanatory variable, economic activity, observed only for the employed, is included in the last model.

5. Estimated results ....

First, we explore the results of the logit models by investigating the effect of disability on the probability of labour force participation. Second, we analyse the results of the probit models with selection by examining the disability impact on the likelihood of being employed and being employed in the public sector. All models are statistically significant (p-value=0.000).

A. Estimated results of the labour force participation models

For model 1, the percentage correctly predicted by this model is approximately 83 per cent, and the area under the receiver operating characteristic curve[11] is 0.9, indicating an excellent, powerful and accurate performance of the model.

Results of this model are displayed in the first two columns of table 3. The results are substantially in accordance with expectations in the economic theory. All coefficients are statistically significant at a 99 or 95 per cent confidence level, except that of the married category, urban/rural variable, second education category and unemployment rate at the governorate level. In other words, being married results in being no more nor less likely to be in the labour force than never marrying. Moreover, living in urban or rural areas has no statistical effect on the probability of being in the labour market.[12] As for education, a person who has a primary degree does not differ from an illiterate one in the probability of participation. It is worth noting that these variables were insignificant in all estimated logit models.

As long as the coefficients of logit models are not readily interpretable, the discussion depends on the reported odds ratios. Regarding the key question of this paper, the results show that being a person with a disability significantly decreases the odds of being in the labour force by 13 per cent, holding all other factors constant.

As for the other variables, not surprisingly, being a female is associated with lower probabilities of participation (the odds ratio is 0.053). This may highlight the conventional household roles or the existing barriers that can impede female labour force participation, confirmed throughout the related literature on the gender gap in labour market. For age, there is an increasing pattern in the odds ratios along the first three categories compared with the age cohort (15–19), then a decreasing pattern appears. Hence, as individuals are getting older, the probability of participation increases until they reach the age cohort (40–49), at which point it starts to decline.[13]

Concerning marital status, individuals who are divorced/widowed are approximately 17 per cent less likely to be in the labour force, compared with the control group "never married". As for wealth, there is a decreasing pattern in the corresponding odds of participation along the richer wealth quintiles compared with the poorest one. For example, going from the poorest quantile to the richest one is associated with a decrease in the odds of being in the labour market by approximately 31 per cent.

Education is especially noteworthy since it is a powerful factor affecting the probability of participation in the labour market. As results reveal, there is an increase in the odds ratios at higher levels of education, implying that a higher education level corresponds significantly with a higher probability of participation in the labour market. The likelihood of being in the labour force among individuals with tertiary education is approximately multiplied by 5 compared with individuals who are illiterate. On the other hand, being in preparatory or general secondary education significantly reduces the likelihood of being in the labour force compared with being illiterate. This may be due to the fact that once children enrol in school, they are more likely to continue education rather than enter the labour market. In sum, investment in education seems to have a positive influence on the individual's participation in the labour market.

Furthermore, the results reveal that individuals who are the heads of households are three times more likely to participate in the labour market than those who are non-heads of households. Moreover, the greater the household size, the higher the probability of the person entering the labour market.

According to the literature, the influence of disability on the probability of participation may depend on the magnitude of other socioeconomic factors. Therefore, to investigate how disability interacts with these variables, interaction terms are constructed between disability status and each of the other socioeconomic variables, following El-Saadani and Metwally (2019). The results of model 2 show that only the interactions between disability and gender, and disability and status of the individual in the household, are statistically significant at p-value<0.01. Moreover, the likelihood ratio test (p-value=0.0000) indicates that the model with one or both interaction terms fitted significantly better than the baseline model. This means that the relationship between participation and disability probably depends on gender and household status of the individual. For both persons with and without disabilities, being a female reduces the odds of participation in the labour market (the odds ratios are 0.1 and 0.05, respectively). On the other hand, among males, disability significantly decreases the likelihood of participation in the labour market by approximately 43 per cent. However, being a woman with disabilities significantly increases the odds of participation by approximately 20 per cent compared with women without disabilities. These estimates indicate that the penalty for disability is substantial for males compared with females. Such a result is not surprising since it is even confirmed by the raw data, which indicate that the participation rate of females in the labour market with disabilities (23.7 per cent) is higher than that of their peers without disabilities (20.7 per cent). It is also confirmed by the descriptive analysis conducted by Sieverding and Hassan (2019).

When we insert the other interaction term, the results reveal that being the head of household increases the odds of participation in the labour market for the person with a disability (the odds ratios are 2.2) and more for the person without a disability (the odds ratios are 3.3). On the other hand, among males who are non-heads of households, disability significantly decreases the probability of their participation by 27 per cent.

The result that disability reduces the likelihood of participation entails a question concerning the impact of disability types on the odds of participating in the labour market. Hence, rather than using one dummy variable denoting the presence of a disability, four dummies are created for disability in mobility, hearing, seeing and, for the final dummy, in cognition, self-care, or communication.

The results of model 3, presented in table 3, show that having a disability in mobility, cognition, self-care or communication significantly reduces the likelihood of participation. Having a mobility disability is associated with a decrease in the likelihood of participation by approximately 28 per cent, compared with other persons with disabilities or persons without disabilities. Furthermore, disability in cognition, self-care or communication tends to decrease the odds of being in the labour force by approximately 13 per cent. Of note is the fact that the variables denoting a disability in hearing and seeing are not statistically significant. This means that these types of disability do not have a statistical impact on the probability of participation in the labour market. It is worth noting that the results of the other variables are generally robust since they remain substantially unchanged over different models.

Table 3. Estimated coefficients and odds ratios of logit models; ELMPS 2018

Independent variables	Model 1		Model 2		Model 3	
	β	OR	β	OR	β	OR
Any disability (reference: no disability) With a disability Disability types (reference: another disability or no disability)	0.13***	0.87***	-0.32***	0.73***	-	-
Disability-mobility	-	-	-	-	-0.33***	0.72***
Disability-seeing	-	-	-	-	0.07	1.07
Disability-hearing	-	-	-	-	-0.01	0.99
Disability-other	-	-	-	-	-0.14*	0.87*

Independent variables	Model 1		Model 2		Model 3	
	β	OR	β	OR	β	OR
Gender (reference: male)						
Female	-2.9***	0.053***	-3.02***	0.049***	-2.9***	0.053***
Age groups (reference: 15–19)						
20–29	1.4***	3.88***	1.4***	3.9***	1.4***	3.9***
30–39	2***	7.1***	2***	7.1***	2***	7.1***
40–49	2.1***	7.8***	2.05***	7.7***	2.1***	7.9***
50–59	1.8***	6.2***	1.8***	6.1***	1.9***	6.4***
60–64	-0.8***	0.45***	-0.73***	0.48***	-0.77***	0.46***
Marital status (reference: never married)						
Married	0.08	1.07	0.09	1.1	0.08	1.08
Divorced/widowed	-0.18*	0.83*	-0.18*	0.83*	-0.17*	0.84*
Urban/rural (reference: urban)						
Rural	0.005	1	-0.001	1	0.005	1
Wealth quintiles (reference: Q1)						
Q2	0.13***	0.88***	-0.13***	0.88**	-0.13***	0.88***
Q3	0.16***	0.85***	-0.16***	0.85***	-0.16***	0.85***
Q4	0.21***	0.81***	-0.21***	0.81***	-0.21***	0.81***
Q5	0.37***	0.69***	-0.38***	0.69***	-0.37***	0.69***
Education (reference: illiterate)						
Reads and writes	0.17**	1.2**	0.19**	1.2**	0.17**	1.2**
Primary	-0.03	0.97	-0.02	0.98	-0.03	0.97
Preparatory	0.38***	0.68***	-0.38***	0.69***	-0.39***	0.68***
General secondary	1.17***	0.31***	-1.16***	0.31***	-1.18***	0.31***
Vocational secondary	0.47***	1.6***	0.48***	1.6***	0.47***	1.6***
Tertiary education	1.55***	4.7***	1.57***	4.8***	1.54***	4.7***

Independent variables	Model 1		Model 2		Model 3	
	β	OR	β	OR	β	OR
Head/non-head (reference: non-head)						
Head	1.1***	3***	1.18***	3.3***	1.1***	3***
HH-size	0.04***	1.04***	0.04***	1.04***	0.04***	1.04***
Unemployment rate at the governorate level	0.007	1	0.007	1	007	1
Disability*gender:						
With a disability# female	-	-	0.59***	1.8***	-	-
Disability*head:						
With a disability# head	-	-	-0.4***	0.67***	-	-
Constant	-0.69***	0.5***	-0.69***	0.5***	-0.69***	0.5***
Pseudo R2	0.4274		0.4292		0.4279	
N	35,327					

Source: Calculated by the authors using ELMPS (2018).

B. Estimated results of the employment models

The probit models with selection are estimated to investigate the effect of disability on the probability of being employed (model 4) and being employed in the public sector (model 5). The correlation (ρ) between the errors of the two equations, labour force participation equation and the outcome equation, is significant, so we depend on the results from the probit models with selection.

The results in table 4 indicate that disability has a significant negative impact on the probability of being employed (model 4). In another version of this model containing the different types of disability, mobility and vision impairments tend to decrease the likelihood of being employed. In other words, vision impairments have no significant impact on labour force participation; however, once a person has entered the labour market (that is, attempts to enter the workforce), she/he is less likely to be employed. Moreover, disability has no significant impact on the likelihood of being employed in the public sector. In other words, persons with disabilities are less likely to enter the labour force and be employed, but once they are employed, disability is no longer a significant determinant concerning employment in the public sector (model 5).

As for the other variables, table 4 indicates that once females are in the labour force, they are less likely to be employed compared with males.

If employed, they are more likely to work in the public sector. This latter result corresponds to what was found in the literature as the public sector is considered family friendly.

Concerning age, the older cohorts starting from ages 30 to 39 are more likely to be employed if compared with the youngest group. Once employed, they are more likely to be in the public sector. Moving to marital status (ages 15 to 64), the results show that being married or divorced/widowed has a significant positive impact on the probability of being employed compared with the never-married category. When employed, married people are more likely to work in the public sector.

Living in a rural area increases the likelihood of being employed and working in the public sector. As for the wealth quintiles, the results show that any level of wealth, except for the third quintile, increases the likelihood of being employed once in the labour market. If an individual is employed, wealth increases the probability of working in the public sector compared with the poorest quantile.

Surprisingly, once an individual is in the labour force, any education level decreases the likelihood of being employed versus unemployed, compared with being illiterate. This surprising result may require more investigation. Once employed, having any higher educational level significantly increases the probability of working in the public sector. Turning to economic activity, results show that any economic activity increases the likelihood of working in the public sector if compared with the agriculture sector.

Table 4. Estimated coefficient of the probit models with selection; ELMPS 2018

Independent variables	Employment models		
	Model 4 Being employed		Model 5 Working in public sector
	β's		
Any disability (reference: persons without disabilities)			
With disabilities	-0.17***	-	0.01
Disability types (reference: another disability or no disability)		-	-
Disability-mobility	-	-0.13*	-
Disability-seeing	-	-0.22***	-
Disability-hearing	-	0.09	-
Disability-other	-	-0.04	-
Gender (reference: male)			
Female	-1.29***	-1.29***	0.33***
Age groups (reference: 15–19)			
20–29	0.14	0.13	0.33*
30–39	0.44***	0.44***	0.65***
40–49	0.7***	0.7***	0.98***

Independent variables	Employment models		
	Model 4 Being employed		Model 5 Working in public sector
	β's		
50–59	1.1***	1.1***	1.6***
60-64	0.5***	0.5***	0.61***
Marital status (reference: never married)			
Married	0.47***	0.47***	0.26***
Divorced/widowed	0.46***	0.46***	0.15
Urban/rural (reference: urban)			
Rural	0.1***	0.1***	0.13***
Wealth quintiles (reference: Q1)			
Q2	0.13***	0.14***	0.07
Q3	0.06	0.06	0.18***
Q4	0.18***	0.18***	0.26***
Q5	0.21***	0.21***	0.37***
Education (reference: illiterate)			
Reads and writes	-0.38***	-0.38***	0.46***
Primary	-0.15**	-0.15**	0.38***
Preparatory	-0.16**	-0.16**	0.56***
General secondary	-0.39***	-0.39***	0.92***
Voluntary secondary	-0.36***	-0.37***	0.86***
Tertiary	-0.37***	-0.37***	1.04***
Economic activity (reference: agriculture)			
Manufacturing	-	-	0.99***
Electricity, water, food, ICT, and insurance	-	-	1.6***
Construction and real estate activities	-	-	0.65***
Wholesale and retail trade	-	-	0.15*
Transportation	-	-	0.9***
Professional, scientific and technical activities	-	-	1.7***
Public administration and education	-	-	2.9***
Constant	0.99***	0.99***	-4***
N	35,327		33,519

Source: Calculated by the authors using ELMPS (2018).

6. Concluding remarks and policy recommendations

In light of the current commitment and efforts of the government of Egypt to integrate persons with disabilities into the labour market and into society generally, together with its decision to ratify the Convention on the Rights of Persons with Disabilities and enact its own domestic disability law, the question arises to what extent are people with disabilities being included in the labour market. This paper aims to assess the employment of people with disabilities in the Egyptian labour market using the ELMPS 2018. This study is the first to use the ELMPS 2018 to quantitatively assess the employment of people with disabilities in Egypt. Such assessment can identify their opportunities and challenges, bridging the current empirical gap and paving the way for more effective policies.

Results indicate that being a person with disabilities significantly reduces the odds of entering the labour market by approximately 13 per cent. Among males, disability status tends to reduce the likelihood of participation by about 43 per cent. However, being a female with disabilities significantly increases the odds of participation by approximately 20 per cent, compared with females without disabilities. Among males who are non-heads of households, disability significantly decreases the probability of participation by 27 per cent. Focusing on disability types, the study found that having a mobility impairment is associated with a decrease in the likelihood of participation in the labour market by approximately 28 per cent. Furthermore, having cognitive impairments, or limitations in self-care or communication, tends to decrease the odds of entering the labour market by approximately 13 per cent. Once persons with disabilities decide to participate in the labour force and attempts to find work, they are also less likely to be employed. So, they remain unemployed. In addition, individuals with mobility impairments are less likely to be employed. However, disability has no significant impact on the likelihood of employees with disabilities to work in the public sector.

Given these findings, a sizeable portion of the Egyptian workforce is underutilized. Although the related policy initiatives and reforms undertaken appear to be useful in fostering inclusion of people with disabilities, it seems too early to conclude that such policies and reforms are having their intended impact. Indeed, more work needs to be done to fully promote people with all types of disabilities in the Egyptian labour market.

In this regard, several policy recommendations, to enhance employment opportunities for persons with disabilities, are summarized below. These recommendations may be valuable to policymakers as they work towards promoting an inclusive society:

- First and foremost, policymakers should pursue a holistic approach to promote the employment of persons with disabilities, unlock their potential and improve their access to decent work. The government should work on enforcing and monitoring the recently enacted Egyptian domestic laws to ensure that public policies are harmonized, and aligned with international conventions and policies.

- It is critical to raise public awareness on disability, as recognized in Article 8 of the Convention on the Rights of Persons with Disabilities. Such awareness campaigns challenge negative stereotypes and seek to change societal attitudes about disability within society. These changes can be accomplished by improving the current curricula and educational textbooks of undergraduate students to include relevant education on disability and human rights principles. Furthermore, governmental bodies, NGOs, organizations of persons with disabilities and other stakeholders should launch disability-based campaigns to raise awareness and programmes targeting social attitudes. Media campaigns have a significant role in this regard as well.

- There is a need for promoting and encouraging entrepreneurship, micro-enterprises and self-employment among people with disabilities. Laws and regulations should facilitate the ability of people with disabilities to obtain loans with simple conditions, advisory services and start-up monitoring. These suggestions can be implemented through a special programme improving access of people with disabilities to microfinance, as has been done in other countries. Such a programme should target raising awareness among people with disabilities about their potential for obtaining a loan and launching a company, combating stereotypes about their financial and entrepreneurial abilities and providing accessible information, training and technical assistance.

- International cooperation and technology transfer are needed to share cost-effective policies and practices, exchange information and experiences, and obtain technical assistance and training for people with disabilities. Such efforts may be accomplished through fostering partnerships with key international and regional stakeholders, including United Nations agencies, international NGOs, donors and others.

- Continuing to promote and improve the collection of high-quality data on disability is vitally important. Such data collection can be accomplished by applying the WG extended set of questions, which expands the WG short set of questions by incorporating more functional domains, and asking more questions within each domain. More evidence-based research is also needed to bridge the present knowledge gap on disability, its influence on social and economic development, the challenges faced by persons with disabilities and their needs. Moreover, further studies regarding the effectiveness of the policies and programmes undertaken are required to assist policymakers in deciding whether to scale up, revise or abandon the existing policies, and develop new ones within the framework of the 2030 Agenda for persons with disabilities.

These recommendations and reforms are expected to enhance the employment of persons with disabilities, paving the way towards greater inclusion and participation of people with disabilities in Egyptian society. Yet, given the substantial financial budgets needed, appropriate public and political support are required to ensure that these reforms are implemented effectively, and successfully.

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Appendices

Appendix A. Table of regressors

Table A1. Regressors

Disability	• A dummy where 1 denotes the presence of persons with disabilities and zero otherwise.
Other factors	• One dummy for gender (female and male). • Five dummies for age groups (15–19, 20–29, 30–39, 40–49, 50–59 and 60–64). • Two dummies for marital status (never married, married, divorced/widowed). • One dummy for geographical location (urban and rural). • Four dummies for household wealth quintiles (Q1, Q2, Q3, Q4 and Q5). • Six dummies for education (illiterate, reads and writes, primary, preparatory, general secondary, vocational secondary, tertiary education). • One dummy for the status in the household. • The household size (continuous variable). • The unemployment rate at the governorate level (continuous variable).
The additional explanatory variable in the last model	• Seven dummies for economic activity: ○ Agriculture, forestry and fishing. ○ Manufacturing, mining and quarrying. ○ Electricity, gas, water supply, sewage, accommodation and food service activities, ICT, financial and insurance activities. ○ Construction and real estate activities. ○ Wholesale and retail trade, repair of motor vehicles and motorcycles. ○ Transportation and storage. ○ Professional, scientific and technical activities, arts, entertainment and recreation, activities of households as employers, human health and social work activities. ○ Public administration and defence, compulsory social security, education.

Appendix B: The WG short set of questions

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Response scales to the questions:

- No — no difficulty.
- Yes — some difficulty.
- Yes — a lot of difficulty.
- Cannot do at all.

Endnotes

1 Although WHO estimates a disability rate of about 20 to 25 per cent in most countries, the research shows disability is significantly underreported everywhere due to the widespread stigma related to disability that might push families to hide their members with disabilities. Also, while gathering information on disability, the use of a single question technique, and the wording of said question as "Do you have any kind of mental or physical disability?", resulted in significantly underestimating of actual disability rates.

2 Diversity can pave the way for new ideas and effective problem-solving techniques to appear, hence better adapting to changes and challenges. Additionally, this diversity can enhance decision-making, motivate competition between workers, and eventually promote productivity and the company's competitiveness and market share.

3 The ELMPS (2018) is the fourth wave which is publicly available upon request on the ERF website through the following link: http://www.erfdataportal.com/index.php/catalog/157.

4 The differences were also tested using the chi-square test and the same results were obtained.

5 According to this definition, if an individual worked in the last week for at least one hour as a wage worker, self-employed worker, employer or unpaid family worker, then he/she is considered employed. On the other hand, if an individual was willing to work, actively searched for an employment opportunity in the previous three months and was ready to start working in the next two weeks but could not work for an hour over the last week, then he/she is considered unemployed. An individual is in the labour force if he/she is employed or unemployed.

6 The gap is not a sizeable one bearing in mind that other factors which can affect these ratios are not considered here.

7 The sample size of the working-age individuals with complete disabilities is small (236), and this difference is not statistically significant using the chi-square test. So, we should be careful while interpreting its results.

8 The unemployment rate at the governorate level is obtained from the annual bulletin of the labour force survey (CAPMAS, 2018).

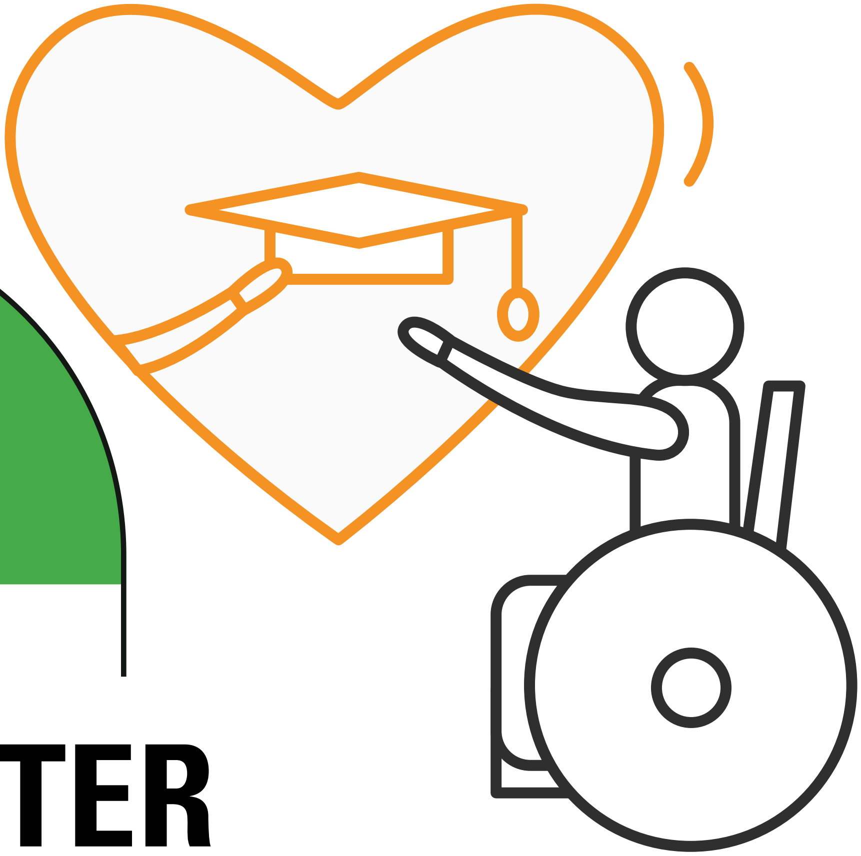
9 For more details about the variables, check table A1 in appendix A.

10 Estimates are computed using Stata's 'checkpoint' command.

11 The receiver operating characteristic is a graphical plot that assesses the performance of a classification model. The area under the curve measures the power and usefulness of the model, where a wider area implies a more powerful model.

12 A model containing five dummies for the region of residence was estimated, but only the rural lower region was statistically significant at a 95 per cent confidence level.

13 A different specification of the model containing a quadratic term of age, rather than age cohorts, was estimated. This non-linear concave pattern was confirmed through the negative sign.



LIFE AFTER UNIVERSITY AND INDEPENDENT LIVING

FIELD STUDY ON A GROUP OF PERSONS WITH DISABILITIES IN OMAN

Rahma Said Al Kalbani

Key messages

1

The extent to which the concept of independent living has been applied from the perspective of a number of persons with disabilities in Omani society is determined by identifying the measures taken by the public services sector to enable them to work and start a family after their university studies, as well as by exploring these individuals' experiences, the challenges they face, and recommendations that can be adopted as part of future policies.

2

Applying the concept of independent living for persons with disabilities depends on their level of access to opportunities for basic schooling and university education, and following that, to work and start a family, regardless of their means and abilities. Prevailing attitudes and perceptions within society prevent persons with disabilities from becoming self-reliant, exercising self-determination and fully integrating into society.

3

There is a positive relationship between persons with disabilities being able to access public and social services and the extent to which they make use of them, which could contribute to increasing their ability to adapt socially. Differences on this point between this study and previous studies can be attributed to differing concepts of social adaptation and independent living.

Key messages

4

There is a lack of studies on the independent living of persons with disabilities in Omani society, although there are previous studies on the ability of persons with disabilities to adapt to different environments.

5

There is a need to stimulate scientific research on independent living, as well as to involve persons with disabilities, especially women, in the preparation, formulation, implementation and evaluation of policies related to independent living and self-determination at the local and global levels. Efforts should be consolidated to promote the concepts of independent living, self-reliance and self-determination among persons with disabilities and their families through awareness-raising, education and training programmes as part of a national strategic framework.

Introduction

Persons with disabilities are an integral part of society, regardless of the causes and effects of their disability. Global interest in and awareness of disability issues have increased with the issuance of documents such as the Universal Declaration of Human Rights, the Declaration of the Rights of the Child and the 1975 Convention on the Rights of Persons with Disabilities, which incorporate the principles of social inclusion, participation and equal opportunities and constitute an international roadmap guiding all plans and strategies aimed at improving the lives of persons with disabilities and ensuring their access to public services such as education and health care. Concerted efforts are needed to devise non-traditional methods of social rehabilitation, including independent living programmes.[1]

Independent living can only be achieved through social protection, social inclusion and social empowerment that leads to the independence of persons with disabilities in society while minimizing risk and maximizing the accessibility and affordability of public services so that they are able to make decisions on matters that concern them and their lives.

Whatever form social inclusion and rehabilitation services take, they must include helping persons with disabilities to become independent in their daily lives by teaching them self-reliance, training them in mobility, and providing them with devices and equipment that support their independence, such as wheelchairs and hearing aids. There must also be a focus on training the families concerned and society on how to engage with persons with disabilities, as well as on the use of the media to promote this.[2]

Social empowerment is at the core of the rights of persons with disabilities. It involves building their social, educational and economic capabilities and helping them acquire skills, knowledge and abilities that will enable them to participate positively and effectively in various activities and life events. Empowerment must include changing societal attitudes towards this group and refraining from describing the group as "helpless, alone or deficient" or pitying them.[3]

Oman has paid considerable attention to this issue, both in terms of securing legal protection through a range of legislation and in terms of care services, with the Ministry of Social Development in particular working to achieve social inclusion by offering a package of rehabilitation programmes and special services to help this group adapt socially.

However, legal provisions and legislation on independent living come up against a societal obstacle in the form of the prevailing perception that these persons are unable to rely on themselves. However, the relevant authorities, civil society institutions, international institutions and community-based initiatives are continuing their efforts to promote the concept of independent living in supportive communities that facilitate the integration process.

Independent living can only be achieved through

1. The concept of independent living

Independent living is one of the main goals that international conventions and institutions concerned with matters relating to persons with disabilities seek to achieve. Any social policy targeted at persons with disabilities starts with the premise that they are an integral part of society, enjoy all the rights available to others – including the right to work and social security – and participate effectively in and contribute to community-building.[4] This relies on equipping them with the skills to be able to take on a degree of social responsibility. National social policy creates opportunities for protection through legislation that ensures that persons with disabilities have access to public services, such as education, health care and employment, as well as the opportunity to start family and raise children with the greatest independence.

Independent living is not a new concept; it has its roots in the Smith-Fess Civilian Rehabilitation Act of 1920. The concept establishes the importance of persons with disabilities being aware that they can manage their lives by accessing special services and removing potential difficulties and limitations.[5] This concept is therefore based on the right to choose and the ability to make decisions based on how these persons see themselves.

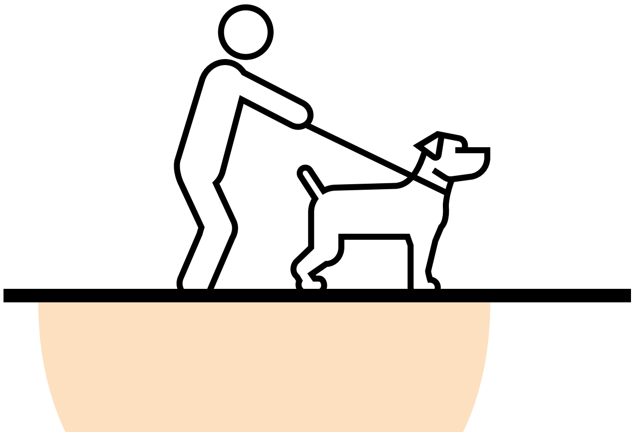
The philosophy of independent living is a social approach in which persons with disabilities enjoy all civil rights, and their basic needs for health care, rehabilitation and social services are met. This means that they have the same rights to freedom, self-management and self-determination as others.[6]

Technology plays a key role in supporting the independence of persons with disabilities and allowing them to communicate and accomplish tasks without the need for physical mobility. This means it must be reflected in the strategies and financial resources supporting independent living.

The concept of independent living goes hand in hand with the concept of social inclusion, which is the desired goal, and which requires equal opportunities and persons with disabilities taking up key roles in society.[7] The Convention on the Rights of Persons with Disabilities was based on the social model of disability, which emphasizes society's responsibility to remove behavioural and physical barriers that lead to the exclusion of persons on the basis of their mental and physical condition.[8]

When appropriate legislation and adequate financial resources are in place and a consistent and clear philosophy is adopted in the formulation and implementation of strategies and plans for achieving independent living, any society, regardless of its culture and means, can support persons with disabilities. This support enables them to fully rely on themselves and make life decisions. Furthermore, supportive policies can be continuously developed to ensure the ability of these persons to live independently with limited intervention from society.

The aim of supporting independent living is to encourage persons with disabilities to integrate into society by positively exercising societal roles and, in so doing, give them the ability to be psychologically and socially independent and gradually attain greater autonomy from parental and social authority.



2. Persons with disabilities in Oman............................

A. Figures and statistics

Persons with disabilities make up 1.5 per cent of the total population in Oman. The statistical bulletin issued by the National Centre for Statistics and Information shows that hearing impairments are the most prevalent form of disability in the country. These cases appear at birth and are mostly caused by marriage between relatives or between persons with disabilities. In terms of education, uneducated persons with disabilities primarily fall in the age group of 60 years and above. In terms of employment, 33 per cent of persons with disabilities work, with 82 per cent of them working in the public and private sectors. The percentage of persons with disabilities who are in employment is 84.6 per cent among males and 15.4 per cent among females. Of these, 20.1 per cent are in clerical roles. A total of 3,341 persons with disabilities are retired. With regard to marital status, 42 per cent of persons with disabilities are married, most of them being male.[9]

Data from the Ministry of Social Development show that disability cards have been issued to 46 students enrolled in university, 30 of whom are male and 16 are female students. The data showed that four individuals are undertaking postgraduate studies, three of whom are male and only one is female. Only one person made use of residential development services in 2021, as persons with disabilities rarely reside in a separate dwelling from that of their parents, which would previously have been adapted for them.[10] Furthermore, where they do live in separate dwellings, it is the family that arranges for the necessary adjustments to accommodate their needs. Statistics indicate that few families have been unable to do so financially.

B. Conventions and legislation

The importance of the Convention on the Rights of Persons with Disabilities undoubtedly lies in its ability to significantly transform the approach towards persons with disabilities from simply recognizing their rights to enacting laws and formulating domestic policies that achieve tangible results. The challenge for states is to adopt inclusive practices that bring tangible advances in the promotion of social inclusion for persons with disabilities.[11]

Oman has sought to ensure the greatest degree of legal protection for persons with disabilities, ratifying the International Convention on the Rights of Persons with Disabilities through Royal Decree No. 121 of 2008. Under Article 19 of the Convention, State parties are obliged to facilitate the independent living and social inclusion of persons with disabilities, which includes choice of residence and access to the public services available to others. The State issued the Care and Rehabilitation of Disabled Persons Act[12] of 2008 by Royal Decree No. 63 of the same year to ensure the greatest degree of independence, social inclusion and benefit from all available facilities. For example, among other provisions, Chapter II of the Act addresses the right of such persons to education, health care, work, independent living and public services, as well as social, cultural, sporting and other activities.[13]

Other measures include regulations for the establishment of rehabilitation centres for persons with disabilities issued through Ministerial Decision No. 124/2008, regulations on issuing disability cards through Ministerial Decision No. 94/2008, and the formation of the National Committee for Disabled Care in accordance with Ministerial Decision No. 1/2009.

A comparative study on several States indicated that the Care and Rehabilitation of Disabled Persons Act of 2008 enshrined the right of persons with disabilities to preventive and curative health care provided by the State, including rehabilitative and prosthetic devices to help with mobility. Government entities are thereby committed to taking the necessary measures to ensure that persons with disabilities benefit from public services, and authorities concerned with social, cultural and sporting activities are working to ensure their effective participation in society.[14]

C. Historical developments

According to a field study on interaction and communication skills development for persons with hearing impairments, there have been three stages in the historical development of care for persons with disabilities in Oman.[15] The first phase (1970–1980) was characterized by the provision of primary care services, the improvement of living conditions, the establishment of rehabilitation centres and schools for persons with disabilities, and the raising of awareness around disability with a focus on prevention. The second phase (1980–1990) represented a milestone in service provision for persons with disabilities as it saw the establishment of further rehabilitation and education centres, increased focus on the provision of rehabilitative and prosthetic devices, a reduction in fees for public services and the abolishment of some of these fees, and the establishment of a national committee on policies for persons with disabilities. The third phase (1990–present) focused on the enactment of laws and the provision of new services, as well as the improvement of existing services. It also involved the establishment of civil society organizations and a focus on activities.

In addition to basic services, the Ministry of Social Development currently provides rehabilitation services that help persons with disabilities in their daily lives, including by providing them with medical devices, such as regular and electric wheelchairs, medical beds, prescription glasses, medical hearing aids, various respirators and driving devices, so that they can live their lives independently. These services are based on the regulations for assistance issued by Ministerial Decision No. 54/90.

Article 12 of the Care and Rehabilitation of Disabled Persons Act of 2008 grants persons with disabilities the right to obtain a card that gives them access to various facilities, rights and privileges, such as exemption from some transport and communications costs and the right to obtain parking permits.

Concerted national efforts are currently being made to generate employment opportunities in institutions for persons with disabilities in coordination with the relevant government departments and companies. Such opportunities depend on their qualifications, as well as their physical and mental abilities. Vocational training centres have also opened their doors to persons with disabilities. These measures include assigning a social worker to monitor vacancies and direct persons with disabilities to them, as well as carrying out studies that assess the extent to which private sector enterprises adhere to the employment ratio specified in Omani Labour Law and the Care and Rehabilitation of Disabled Persons Act of 2008. With regard to self-employment, the Ministry of Social Development grants interest-free loans to persons with disabilities who are able to manage their own businesses and projects, as well as several privileges for successful projects, to enable them to raise their income and increase their financial independence.

In conclusion, the provision and development of services is a continuous process that requires local measures to be integrated with global trends. It directs efforts towards achieving full independence – in terms of health, as well as psychologically and socially – for persons with disabilities, increasing societal awareness of disability, and promoting collective contributions to caring for persons with disabilities and meeting their needs, and continuously improving public care, rehabilitation and education services.[16]

3. Independent living for persons with disabilities in Oman: a social approach

A. Problem statement

Significant attention is given to persons with disabilities in Oman, and the relevant stakeholders strive to safeguard their right to live independently and have their needs met. Independent living is a requirement for persons with disabilities to fulfill their aspirations for themselves and participate effectively in community-building. Independent living for persons with disabilities is a multi-layered concept that goes beyond a separate home; it includes mobility and access to space and requires equal opportunities in work and education.[17]

In the absence of local studies on independent living statistics and the concept of independent living, the present study examines the extent to which this concept has been applied in Omani society from the perspective of a number of persons with disabilities.

B. Objectives and themes

The present study addresses independent living, one of the most prominent challenges facing persons with disabilities, by:

- Identifying the measures taken by the public services sector to enable persons with disabilities to work and start a family after their university studies.
- Exploring the experiences of persons with disabilities and the challenges they face.
- Presenting best practice and recommendations that can form part of future policies to support persons with disabilities to work and start a family.

To achieve these goals, the study seeks to answer the following key questions:

- To what extent are persons with disabilities able to choose their place of residence and the persons residing with them without coercion?
- To what extent do persons with disabilities have access to services in their place of residence, have access to social services, receive protection and are not socially isolated?
- To what extent do persons with disabilities make use of public social services and facilities? How responsive are these services to their needs?
- To what extent is it possible to raise the level of service provision and propose policies that support the independence of persons with disabilities and contribute to their inclusion in society?

C. Theoretical and practical significance

The present study discusses the concept of independent living, its reality, challenges and aspirations, in an effort to implement the ideas and proposals of persons with disabilities that would contribute to the development and improvement of the services provided to them.

D. Methodology

The present study adopted a descriptive and analytical approach, and data collection was based on a focus group comprising 15 people with disabilities who completed their university studies and transitioned to independent living in order to work or start a family. Data were also collected from a number of people who have been involved in providing public services and formulating support and assistance policies in Omani society over the past two years, in light of the changing global circumstances.

The study focused on a sample of 15 members of the focus group, all residents of Muscat Governorate and working in the public sector. The study sample was distributed as follows:

15 MEMBERS

Focus Group

15 PUBLIC SECTOR WORKERS

Muscat

Gender

8 Male

7 Female

Marital Status

7 Married

8 Single

Educational attainment

14 with bachelor's degrees

3 with general education certificates

Type of disability

8 with visual impairments

5 with mobility impairments

2 with hearing impairments

E. The concept

The subject of the present study is the concept of independent living for persons with disabilities, which was defined by the United Nations Committee on the Rights of Persons with Disabilities in 2008 as follows: Independent living means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives.

F. Previous studies

There are no studies directly related to the independent living of persons with disabilities in Omani society, but there have been several studies that address the ability of these persons to adapt to different environments. Despite the difference between these two topics, such studies can be used to analyse the social status of persons with disabilities and provide a basis for the present study, as they include the same age group and social conditions.

- The aim of one study[18] was to identify the extent to which students with disabilities were able to adapt to university life independently, considering administrative facilities, available technologies and societal awareness. The study found that students had a high ability to make life decisions and were more self-reliant following separation from their families.

- The aim of another study[19] was to identify the level of anxiety among students with hearing impairments about the future beyond their studies. The findings revealed greater anxiety among males compared to females with the same social variables.

- A further study[20] examined the legislative context of independent living for persons with disabilities in Ireland and the requirements for achieving it. It found that many had concerns about their ability to make life decisions, despite the many facilities available to them. The study stressed the need to develop a clear policy that would contribute to the effective involvement of persons with disabilities in everything that could improve their day-to-day quality of life.

Although earlier Arab and national studies differ in content from the present one, they can be used due to the similarities in samples and communities. Earlier studies have shed light on persons with disabilities and the extent to which legislative and institutional contexts accommodate their needs for independent living. They have focused on these individuals' perceptions of themselves, which are important factors in their ability to work and start a family independently.

However, previous studies have not discussed the practices persons with disabilities can follow to achieve independent living, which is what the present study focuses on, by identifying challenges and attitudes for persons with disabilities to be more self-reliant and able to make life decisions.

G. Study findings

Theme 1: The extent to which persons with disabilities are able to choose their place of residence and the persons residing with them without coercion.

In relation to whether they are free to choose their place of residence, 60 per cent of respondents selected a “neutral” answer, with the remaining respondents split equally between “agree” (20 per cent) and “disagree” (20 per cent). It is worth noting that the 60 per cent figure related to people with visual impairments. When discussing the findings with the study sample, the following was revealed:

- Although people with disabilities have implicit freedom to choose where to stay, they often choose places close to their family, if not the family home itself.

- Participants were not always able to choose their place of work due to the limited opportunities and fields available to persons with disabilities. The nature of the work is predetermined, limited to clerical occupations, office jobs and data entry, regardless of the area of specialization of these individuals.

The nature of the work discussed in this study is limited to the public sector, as the members of the study sample work in the public services sector.

Theme 2: The extent to which persons with disabilities have access to services in their place of residence, have access to social services and are protected from social isolation.

The study found that 40 per cent of the respondents received no assistance to adapt their place of residence, while 33.3 per cent did receive assistance and 26.7 per cent chose a neutral answer. Again, the proportion who did not receive assistance comprised those with visual impairments. When asked to provide a reason for this, the study sample indicated that they had no need to make housing modifications. Those with hearing impairments received assistance from civil society organizations dealing with this type of disability. Those with mobility impairments chose a neutral response without providing any explanation.

Theme 3: The extent to which persons with disabilities make use of public social services and facilities and how responsive the services are to their needs.

The study found that 40 per cent of the study sample had made use of social services, especially after graduating from university, while 26.7 per cent were unable to access these services easily. The remaining 33.3 per cent responded with a neutral answer.

The findings demonstrated a lack of understanding among the study sample of the concept of public services and the criteria for evaluating them.

Theme 4: The extent to which the level of service provision can be raised and policies can be proposed that would support the independence of persons with disabilities and contribute to their inclusion in society.

Respondents differed on the scope for policies to be developed that would support the independent living of persons with disabilities, and discussion of the findings revealed that:

- Independent living can be supported by raising awareness among community members, decision makers in the field of public services and representatives of persons with disabilities in institutions and organizations.

- Independent living cannot be achieved if people with disabilities are considered “dependent” and “incapable” of self-reliance.

- Independent living is not a concept that people with disabilities strive to achieve; rather, they seek a safe environment and supportive tools such as laws and technology.

> Independent living cannot be achieved if people with disabilities are considered “dependent” and “incapable” of self-reliance.

4. Analysis of the study findings

The study findings reveal key indicators on issues relating to independent living, state policies, the responsiveness of various sectors to the needs of persons with disabilities, these individuals' perceptions of themselves and the important impact these perceptions have on their self-reliance and ability to make life decisions.

The findings are consistent with another study,[21] which revealed statistically significant differences in the level of role conflict among mothers of children with disabilities owing to the age variable. Thus, the ability of children with disabilities to be independent is linked to their guardians' self-perception. This concept is limited to the mobility of persons with disabilities and their ability to become self-reliant in their daily activities and does not apply to their opportunities to work, start a family or care for children.

On the other hand, another study[22] indicated a high level of self-acceptance and self-reliance among students with visual impairments.[23] The study also revealed differences in self-perception between persons with disabilities and their families, as well as in how they perceived disability, the ability to be independent, the extent to which the family is able to instill the concepts of self-determination and the ability to participate and integrate.

This, in turn, is reflected in the ability of persons with disabilities to choose their place of residence and people living with them without coercion.

The findings are also consistent with a study on anxiety about the future among students with hearing impairments.[24] There are statistically significant differences between students with hearing impairments and those without any disability in terms of anxiety about the future. Anxiety levels are higher among female students with hearing disabilities compared to male students in this category, which is to be expected.

The study findings also revealed that the accessibility of public and social services to persons with disabilities was consistent with the extent to which they made use of them. This may be due to these individuals' ability to adapt socially. The findings are consistent with a study on the adaptation of students with disabilities to university life,[25] which revealed satisfaction among the sample with the services provided to them. However, there is a pressing need to examine how social adaptation can be increased.

In contrast, the findings differ from a comparative study on the rights of children with disabilities in Omani legislation,[26] which concluded that persons with disabilities have poor access to care and rehabilitation due to the lack of a comprehensive human rights approach, although its role is crucial to achieving any progress in this area.

While previous studies may be in agreement about the ability of persons with disabilities to access services enshrined in law, in practice, disparities arise in the implementation, primarily due to several terminological obstacles. The concepts of social adaptation, public services and independent living vary across different studies, groups and institutions. Disparities also emerge in the coverage of services. Public services may be available, but for a particular group, age, or geographic area.[27] Further detailed studies are therefore needed in this field.

5. Recommendations

The study concluded with the following recommendations:

- Stimulate continuous scientific research in the field of independent living and incorporate the resulting recommendations into specific laws and public policies.
- Involve all categories of persons with disabilities in the preparation, formulation, implementation and evaluation of policies related to independent living and self-determination.
- Promote the inclusion of persons with disabilities at the local and global levels through local and international events in which the country participates, which enhances the ability to focus on disability issues and give them due attention, and encourages civil society to increase the participation of persons with disabilities in community services.
- Develop a general strategic framework for promoting and working towards achieving independent living for persons with disabilities. The country has taken this step with Oman Vision 2040, but continuous follow-up and joint efforts are needed to achieve tangible results.
- Promote the concepts of independent living, self-reliance and self-determination among persons with disabilities and their families through awareness, education and training programmes.

6. Conclusion

Empowering persons with disabilities to live independently by offering the services they need and opportunities to get involved in social activities, engage in development efforts and rely on themselves is an important indicator of a society's degree of civilization.

Concern for persons with disabilities stems from a society's culture, which in turn is based on religions and social values that call for the empowerment of persons with disabilities. This concern has subsequently been translated into legislative frameworks that take their rights into account and guarantee equal opportunities and the right to social inclusion within a safe environment that enables them to participate fully in society. Rehabilitation and training programmes have sought to identify the best approaches and practices for enabling persons with disabilities to live independently. The most important approach involves taking mobility and lifestyle into account when designing and constructing housing and public buildings, in addition to using technology when engaging with persons with disabilities and ensuring that they can access public services.

In Oman, concern for persons with disabilities stems from the Government's keenness to ensure equal enjoyment of rights for this group. Oman is interested in empowering persons with disabilities through a legislative framework that safeguards their rights. National efforts have included the ratification of international conventions, the enactment of domestic laws, the establishment of institutions for matters relating to persons with disabilities and the training of specialists in the provision of care and rehabilitation services, as well as the safeguarding of access to education, health, employment and care services for persons with disabilities and support for them to start families.

The present study sheds light on the extent to which persons with disabilities are able to achieve the concept of independent living given the services provided by the state, the opinions of the study participants on these services and ways to increase their effectiveness. It reveals the need to develop a conceptual framework to consolidate comprehensive efforts and raise awareness of the independence of persons with disabilities in the family and society.

It should be noted that the provision and development of services is a continuous process that requires local efforts to be integrated with global trends in order to support the independence of persons with disabilities, raise awareness around disability and meet the needs of persons with disabilities. It remains that all members and institutions of society have a responsibility to provide services to and empower their compatriots with disabilities.

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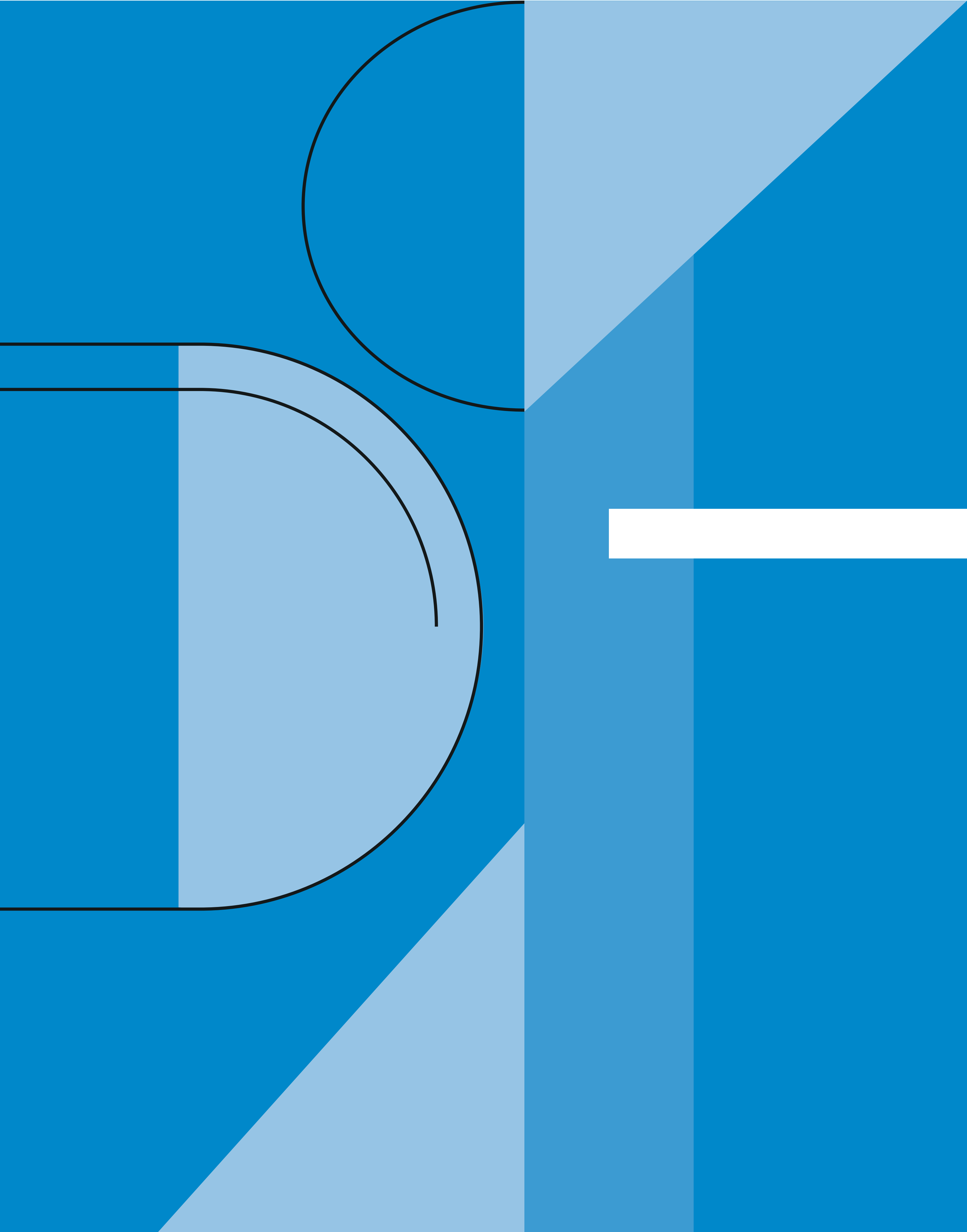


APPROACHES TO INDEPENDENT LIVING IN EUROPE

THE COMMITMENT OF THE EUROPEAN UNION TO THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND THE RIGHT TO LIVE INDEPENDENTLY AND BE INCLUDED IN THE COMMUNITY

Lazar Stefanović

Key messages

1

The European Commission (EC) employed a couple of “avoidance techniques” to stay away from sanctioning the use of European Structural and Investment Funds (ESIFs) contrary to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in the previous 2014–2021 ESIF programming period.

2

The interpretation of the CRPD offered by the EC is ineffective and hardly based on the general rules of treaty interpretation of the Vienna Convention on the Law of Treaties (VCLT).

3

Considering the problematic interpretations by the EC, even CRPD-compliant legislation may, in practice, be a framework for actions not compliant with the CRPD.

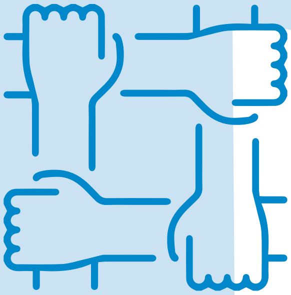
It is reasonable to suspect that the EC's concern is to avoid opposition from the Member States that use the funds to build long-stay group facilities for children and adults with disabilities.

4

5

The advocacy impact of OPDs and NGOs is visible in European Union (EU) financial regulation that adopts slightly more CRPD-aligned wording and measures that should improve monitoring of the use of ESIFs.

OPDs and NGOs are significant agents of the internalization of the CRPD in the EU and domestically, but their influence is likely overridden by Member States.



6

Introduction

The institutionalization of children and adults with disabilities is a pervasive issue worldwide, including in the European Union (EU). European countries including those constituting the EU have long histories of institutionalizing persons with disabilities, which has, to an extent, persisted until the present day. In the last couple of decades, it seems that mostly countries in eastern and south-eastern Europe have come under heavy scrutiny and criticism from the media and international agencies for the institutionalization of children and adults with disabilities. This was the case due to especially worrisome material conditions in those facilities and the treatment that sometimes amounted to being inhumane, degrading and even considered as torture. Meanwhile, some other EU countries have gone under the radar despite very high rates of institutionalization. For example, the Netherlands, France and Austria have some of the highest rates of institutionalization of children in the world, with high proportions of children with disabilities among them.[1]

The EU concluded the Convention on the Rights of Persons with Disabilities (CRPD) in 2009, which then entered into force in January 2011. This accession was not like many other treaties the EU has acceded to in its history. It is the only United Nations human rights treaty acceded to by the EU (and any other regional organization). By acceding to the CRPD, the instrument became part of EU law and binding to all its institutions, in accordance with article 216 (2) of the Treaty on the Functioning of the European Union (TFEU). In its early case law, the European Court of Justice (ECJ) held that international agreements "form an integral part of the Community legal system" (the EU today).[2]

The main question posed here is: How has the CRPD impacted EU legislation and how have EU institutions interpreted and applied the CRPD, concerning the right to live independently and be included in the community? The question is inspired by the tensions which exist between the CRPD norms and EU actions. The European Commission (EC) has provided financial support to build and expand long-stay residential care in Member States, contrary to the CRPD and the interpretations formed by the Committee on the Rights of Persons with Disabilities (CRPD Committee hereafter) of States' obligations in relation to article 19 of the CRPD. Several EU countries including Austria, Hungary, Romania, Bulgaria, Estonia and Lithuania have used EU funding to develop residential care that is not conducive to the realization of the right to live independently in the community. The EC has repeatedly justified those actions, while the CRPD Committee expressed concerns over the issue and called on Hungary to reroute EU funds to independent living services instead of the investments in long-stay residential care.[3] Some organizations of persons with disabilities (OPDs) and advocacy non-governmental organizations (NGOs) exerted strong opposition to the actions of the EC and initiated legal actions.

The underlying theory of international law followed here corresponds to the Transnational Legal Process School.[4] This scholarship is focused on the process and reasons of States' compliance with international law. It duly considers the realities of international law-making, interpretation and internalization reflected in the plurality actors, especially the significance of NGOs (and OPDs) as "transnational norm entrepreneurs".[5] This reality is evidenced in actions of OPDs and NGOs which have impacted regulation through advocacy and legal actions aimed at improving the law and practice concerning independent living in the community in the EU. (OPDs and NGOs had impacted the content of the CRPD itself as well). It also takes into account factors that influence decision-making, such as in the case of the EC's approach to complaints on the use of European Structural and Investment Funds (ESIFs), and the strategies of those actors including "avoidance techniques" when responding to those complaints.[6] Legal interpretation is seen as an important factor of "internalization" of international law,[7] hence this paper exhibits an interest in the interpretations offered by the CRPD Committee and the EC of those critical provisions. The author looks into possible future directions and strategies that may improve the implementation of the CRPD in the EU. The framework of the Vienna Convention on the Law of Treaties (VCLT) rules on treaty interpretation, which the EC referred to when responding to complaints, is taken to critically analyse the EC's actions and interpretations of the CRPD. According to article 31 of the VCLT, the three main elements of treaty interpretation are: the wording, the context, and the object and purpose. Preparatory works that are generated during the treaty drafting phase can serve as a supplemental tool (art. 32, VCLT). Any interpretation should duly consider all three main elements and supplementary means, if necessary. Interpretation of a human rights treaty should ensure that the norm is effective, meaning capable of ensuring real-life enjoyment of the human rights of individuals in given circumstances.[8] An interpretation of the CRPD by the EC is assessed in the light of those rules and principles. Also, an evaluative approach to the content of relevant secondary EU legislation is employed in the comparison with the superior international human rights treaty to assess its compatibility.

This paper is limited to the analysis of legislative acts and case law while excluding EU policy documents. Although non-binding, policy documents can significantly impact the application of EU law and the implementation of the CRPD in EU law. Furthermore, this paper does not address the effects of the CRPD on EU anti-discrimination law, which can be relevant when addressing the practices of institutionalization and segregation of persons with disabilities.

1. The status and effect of the Convention on the Rights of Persons with Disabilities in EU law ....

The EU signed the CRPD in 2007, and the Council adopted a Decision on the Conclusion of the CRPD (Decision hereafter) in 2009.[9] In January 2011, the CRPD entered into force in the EU. The accession of both the EU and all its Member States to an international (human rights) treaty is a technique commonly referred to as a "mixity". Jan Klabbers explains that this technique enables the EU and Member States to create shared competences in relation to international treaties.[10] An obligation to declare its competences at the accession came from article 44, paragraph 1 of the CRPD, which was specifically created to enable the accession of the EU.[11] This provision prescribes that "regional integration organizations" must declare the scope of their competences when acceding to this treaty. In that light, at the time of its accession to the CRPD, the EU issued a number of declarations and one reservation.[12] The purpose of those declarations was to fulfil the requirement stipulated in the treaty by defining the scope of its competences and delineating it from the competences of its Member States. This means that the EU is bound by the CRPD only to the scope of its competences.

According to the Decision, there are three possibilities regarding the competences of the EU and Member States concerning individual CRPD provisions: Both the EU and Member States share competences to act; only the EU has competence to act; and only Member States have competence to act.[13] Also, the EU can support and supplement Member States when they act in the scope of their competence.[14] Those competences are not fixed and can be expanded or decreased by amending the Decision.[15] The Decision contains a list of around 50 EU acts in the Appendix. Those acts "illustrate" the scope of the EU competence concerning the CRPD.[16] The list includes several acts concerning independent living and social inclusion and the regulation of ESIFs, which is particularly relevant for the purposes of this study.

In the hierarchy of legal sources in EU law, primary EU legislation has primacy over concluded international agreements, while secondary law is inferior to international agreements. This position of international law was crystallized by the ECJ amid the lack of such rules in EU law.[17] This means that secondary EU law – regulations, directives and decisions that fall within the scope of the agreement – must be interpreted in a manner that is consistent with the CRPD, as far as possible.[18] Delia Ferri argues that considering the exclusive jurisdiction of the ECJ, the Court could raise the CRPD to a constitutional level and equalize it with the primary EU law – the Treaty on European Union (TEU), the Treaty on the Functioning of the European Union (TFEU), the Charter of Fundamental Rights of the European Union (CFREU) and the European Convention on Human Rights (ECHR).[19]

Characteristics of a specific provision of an international agreement and secondary law are important factors when considering their interactions. The more ambiguous and prone to different interpretations secondary law is, the more it will be susceptible to the interpretation in consistency with an international agreement. The ECJ indicated the significance of the wording of secondary law in relation to international law in its case law, including in *Commission v. Germany, Demirel v. Schwäbisch Gmünd* and other cases.[20] Following the ECJ doctrine, it is inferred that the more prescriptive and precise a provision of international law is, the more of an effect it will have on secondary EU law.

The capacity of an international agreement to have a direct effect in the EU is an important characteristic of the relationship between international law and EU law. Firstly, the question of monism and dualism should be addressed here. Although formally a monist legal order, the EU has not been in actuality that welcoming for international law, according to Klabbers.[21] This author argues there is a general view that international agreements are not directly effective in EU law.[22] Cannizzaro and others warned against conflating the concepts of monism and dualism with direct effect, direct applicability and supremacy of international law in a domestic (or EU) legal order.[23] The fact that an international agreement is valid in the EU legal order does not automatically make it directly effective.[24]

On the other hand, Ferri makes the case for a special status of the CRPD in EU law, considering its specific character as an international human rights treaty. The author argues that the CRPD reflects core constitutional values of the Member States, such as anti-discrimination and equality, and that the CRPD is a "clarification" of the rights and obligations enshrined in the CFREU and ECHR, in the context of persons with disabilities.[25] Following that, she argues, the CRPD could be considered as part of the composite constitution of the EU.[26] Article 26 of the CFREU also addresses independence and social inclusion. (The CFREU uses a term outdated in disability law and scholarship – "integration"):

> The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

This provision contains a rather broad wording that carries barely any prescriptiveness and thus does not seem capable of much effectiveness in actuality. The ECJ has interpreted this provision as a principle rather than a right.[27] In *Wolfgang Glatzel v. Freistaat Bayern,* the Court found that in order to be effective, the principle from article 26 of the TFEU must be concretized in the EU or domestic legislation.[28] The CRPD provisions on independent living and social inclusion of children and adults with disabilities (primarily art. 19 and art. 23) present the concretization of the principle, as they offer more information on which measures shall be ensured by the States Parties and which forms of alternative care for children should be provided.[29]

The ECJ has established exclusive jurisdiction to interpret international agreements in the scope of its competence.[30] The Court has jurisdiction only over those treaties (or their provisions) that are directly effective. The direct effect of the CRPD is questionable in EU law, especially due to the wording of provisions that is often broad and susceptible to differing interpretations, as are most other human rights instruments. However, Ferri argues that the CRPD provisions could still be considered to have a direct effect, based on an ECJ case law.[31] The CRPD's effect in EU law should be weighed in the context that it is essentially an anti-discrimination treaty on the one hand and, on the other, a constitutional status of the prohibition of discrimination on the basis of disability enshrined in: article 10 and article 19, paragraph 1 of the TFEU; article 21, paragraph 1 of the CFREU; and the prohibition of discrimination in article 14 of the ECHR.

2. EU secondary legislation and the Convention on the Rights of Persons with Disabilities ....

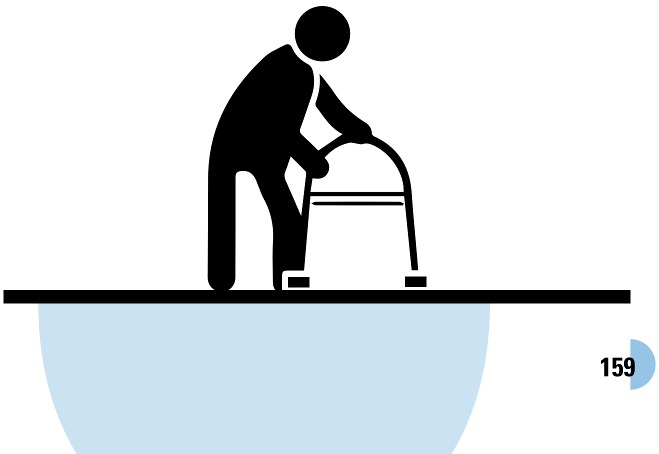
The European Union (EU) has adopted a number of acts that are relevant for the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provisions concerning independent living, community inclusion and life in a family environment. Particularly important secondary legislation relates to the European Structural and Investment Funds (ESIFs). Those documents directly refer to the CRPD, children with disabilities, rights to social inclusion and family-based care. The ESIFs are perceived as having "huge (but not realized) potential" to promote independent living and community and family living for children and adults with disabilities.[32] The EU has funded childcare systems and systems of care and support for persons with disabilities in a number of Member States. For that reason, the regulation on the use of ESIFs is especially significant for the implementation of the CRPD in the Member States. The present chapter thus firstly explores the Regulation on Common Provisions on the European Structural and Investment Funds (CPR hereafter) for 2014–2020 and 2021–2027.[33]

A. European Structural and Investment Funds and the transition from institutional to independent living in the community

The current CPR for the programming period 2021–2027 contains measures and provisions aimed at promoting, *inter alia,* "social inclusion in the community", "community-based care" for adults and family-based care for children with disabilities, but the term "independent living" is not mentioned. The previous CPR for the period 2014–2020 contained similar but even less stringent, and thus more prone to various interpretations, provisions that also aimed at promoting deinstitutionalization (DI). The flexibility of the wording, and perhaps the fact that the CRPD was still a fairly "young" treaty, resulted in those funds being widely used to support the development of different forms of institutional care, mostly the care organized in somewhat smaller groups. This paper assesses the previous programming period by addressing the complaints submitted to the European Commission (EC) and the European Court of Justice (ECJ) by organizations of persons with disabilities (OPDs) and non-governmental organizations (NGOs) in relation to the alleged misuse of ESIFs. The present programming period regulation is analysed in terms of its content and not through the application and interpretation by the EC and Member States due to the lack of data that would enable such analysis.

After the criticism of the use of those funds in the 2007–2013 programming period, the EU adopted certain measures that should have prevented misuse. For the programming period 2014–2020, the EU introduced so-called ex-ante conditionalities (EACs hereafter) to promote "effective and efficient use of the EU funding" (art. 19, CPR).[34] Also, article 19, paragraph 5 of the CPR enabled the EC to stop funds where a Member State did not fulfil EACs. One of the "general" EACs considered disability-related issues, while one "thematic" EAC was aimed at "promoting social inclusion, combating poverty and any discrimination".[35] A general EAC "disability" considered "the existence of administrative capacity" to implement and apply the CRPD in the field of ESIFs.[36] As an "investment priority" under the thematic EAC 9 for the European Regional and Development Fund (ERDF) was "the transition from institutional to community-based services".[37] Criteria for the fulfilment of those EACs were mainly related to having strategic documents in place and their implementation ongoing. However, none of those criteria specifically mentioned children or adults with disabilities.

The EACs, however, had not been efficient enough in preventing the use of ESIFs contrary to the CRPD and the CRPD Committee's recommendations. Commenting on the general success of EACs, the European Court of Auditors found that those measures had questionable results, perhaps because the EC would not halt the funding when EACs were not met by a Member State.[38] This was the case with disability-related issues too. The CRPD Committee expressed concern that the ESIFs had still been used to build and expand institutions for persons with disabilities, in spite of the new regulation.[39] This treaty body called upon the EU to ensure the use of ESIFs "strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions" and, where necessary, to halt funding if those requirements were breached.[40] The CRPD Committee also recommended improving the monitoring of the



use of funds, which the EU has arguably partly fulfilled in the current financial regulation.[41] OPDs and civil society organizations (CSOs) had several (unsuccessful) attempts to hold Member States and the EC accountable for the use of EU funds that was not in line with the EU law in this period.[42] Most recently, the European Network on Independent Living, a watchdog for the use of ESIFs, uncovered several cases where those funds were invested in the development of residential care in the programming period 2014–2020, including the use of the Recovery and Resilience Facility (a fund for COVID-19 recovery) to support residential care in a number of Member States.[43]

B. Analysis of the European Commission's position on European Structural and Investment Funds and the transition from institutional to independent living in the community

Importantly, the EC had in 2018 dealt internally with the regularity of the use of ESIFs for the investment in long-term residential care.[44] According to the Legal Service, an EC legal department reporting to the President of the Commission, the need for an expert opinion came after the Directorate-General for Regional and Urban Policy (DG REGIO) communicated to Member States that the support of ESIFs for long-term residential care is prohibited under the legal framework and especially considering article 19 of the CRPD, which was a view contested by some Member States.[45] The DG REGIO and Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL) asked the Legal Service if the use of ESIFs is irregular in the light of the thematic EAC 9 (considering it explicitly indicates that the ERDF should be used for the transition from institutional to community-based services), if the EU and Member States are legally obligated by General Comment No. 5 of the CRPD Committee (GC 5 hereafter), and whether it is possible and/or obligatory for the EC to impose sanctions where there is a breach of fundamental rights in institutions that received support from ESIFs.[46]

The DG REGIO and DG EMPL asked if the GC 5 is a legally obligating document because the CRPD Committee asserted in that document that any form of institutions, large or small, are unacceptable under the CRPD, while for children with disabilities, small group homes "are especially dangerous".[47] Unsurprisingly, the Legal Service answered that the GC 5 is not a legally binding document. This body also argued that international treaties are interpreted in accordance with article 30 and article 31 of the Vienna Convention on the Law of Treaties (VCLT) and that the treaty body "cannot alter the legal interpretation of the Convention in accordance with these provisions of the VCLT".[48] This way, the Legal Service implied that the CRPD Committee's interpretation of article 19 might not be in line with the VCLT general rules of interpretation, although it did acknowledge that the GC 5 has "policy weight and should be taken into account when it comes to the implementation of the Convention".[49] Implicitly, the Legal Service recognized that Member States and the EC do not act in line with policy goals established through an authoritative interpretation of the CRPD by the treaty body, despite the lack of a legal obligation. It is possible that the formulation of the question had restricted the Legal Service's intervention, as it focused on an unquestionable issue: the non-obligating nature of a human rights treaty body's general comment.

Nonetheless, the fact that the Legal Service questioned the interpretation by the CRPD Committee is a particularly interesting aspect of their Opinion. In another peer-reviewed work, the author analysed article 19 and article 23 of the CRPD and the CRPD Committee's GC 5, using the interpretive framework of the VCLT.[50] The author found that the CRPD Committee's interpretation is indeed in line with the VCLT and the common practice of regional and international human rights bodies' interpretations of human rights instruments. In short, the CRPD Committee (and other stakeholders such as some OPDs, CSOs and scholars) are focused on the effectiveness of CRPD provisions, in line with the background justification firstly for the CRPD itself, and then also for article 19 and article 23 of the CRPD.[51] An effectiveness approach to treaty interpretation is perhaps a backbone of human rights interpretation and is based on the VCLT rule that a treaty should be interpreted in good faith. Hence, the effectiveness approach being ingrained in the VCLT general rules of treaty interpretation makes the CRPD Committee's interpretation expressed in the GC 5 valid, also from the point of the VCLT and common interpretive practice. Interpreters, however, must be cautious about resorting to expansive interpretations and creating new obligations to parties, which was not the case with the CRPD Committee's interpretation. Nonetheless, the dynamism of human rights treaties may sometimes also lead to the expansion of obligations by courts to accommodate treaties to present circumstances.

The Legal Service engaged with the interpretation of the CRPD and the CPR to determine whether investments in long-stay institutions should be considered irregular. The Legal Service used, as a foundation, the lack of absolute prohibition to invest in long-term care both in the CPR and article 19 of the CRPD. On the basis of the lack of such a prohibition, the Legal Service saw that long-term institutions "have to be kept in good shape" as long as people are placed there.[52] This was argued in the light of the fact that the transition from institutions to community and family living or independent living is a process that will not happen overnight. The point made by the Legal Service is a strong one, and actually largely aligned with the views of the CRPD Committee and many OPDs and State Parties: investment in institutions, in the process of DI, is allowed so far as to keep residents safe and healthy before the transition is finalized.[53] However, this does not include expansion by building completely new institutions or by increasing the capacities of existing ones, as such actions are obviously contrary to the goal of DI.[54] Moreover, even extensive renovation has the potential to impede investments into DI by depleting financial resources that could have been used to develop conditions for independent living in the community and family living. Likewise, extensive and expensive renovations threaten to jeopardize the process of DI, as they indicate that those facilities are to be used for decades to come, which is strategically incompatible with DI.

Without elaborating further on the issue of expanding existing institutions and building new ones, the Legal Service concluded by analogy that investments in residential care should be allowed, as they "may serve to achieve thematic objectives of article 9 of the CPR and the overall aim of article 19 of the CRPD".[55] This is perhaps the main logical fallacy found in this analysis, as the Legal Service used an inadequate analogy to legitimize investments into building new and expanding existing institutions while basing the argument on the view that those institutions should be kept in "good shape" as long as people reside there. There is a significant difference between maintaining existing institutions in decent condition and investing in the expansion and building of new institutions.

Secondly, it is highly questionable how investments into long-stay residential care serve to achieve the goals of article 9 of the CPR and article 19 of the CRPD, which was claimed by the Legal Service.[56] Those provisions explicitly aim at promoting social inclusion by investing in health and social infrastructure for the transition from institutional to community-based services (thematic objective 9 in relation to the ERDF) and ensuring that persons with disabilities can choose where and with whom to live are not compelled to live in any particular living arrangement, have access to specialized services that support community living, and have access to and available general services, all with an aim to realize independent, community and family living.[57] Likewise, article 23, paragraph 5 of the CRPD, not mentioned in the CPR and the Legal Service's Opinion, also seeks to ensure that children with disabilities are placed in family-based forms of alternative care and not residential care. Therefore, any investments into residential care can hardly contribute to the realization of those rights, obligations and policy objectives. A standard to keep those institutions in proper shape while people still live there does not come from article 19 of the CRPD, article 23 of the CRPD or article 9 of the CPR but from the rights to life and survival, the freedom from inhumane and degrading treatment, the right to personal security and the right to the highest attainable standard of health – the adequate standard of living enshrined in the European Convention of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, and other treaties. Therefore, the Legal Service was wrong to claim that investments into long-stay residential care serve the stipulated goals, either for adults or for children with disabilities.

The Legal Service concluded its Opinion with a statement that Member States can co-finance long-stay residential care with ESIFs but should "progress in general in ensuring independent living arrangements and deinstitutionalisation".[58] In other words, there is no prohibition of investing ESIFs in long-stay residential care and there is no legal obligation to progress in DI but rather a requirement, according to the Legal Service. This finding differs significantly from the view of the CRPD Committee on DI and the views of OPDs and CSOs that attempted to challenge the EC and Member States for the use of ESIFs for those forms of care.

C. Analysis of the European Commission's responses to complaints

The European Network on Independent Living submitted a complaint in 2019 to the EC about the use of ESIFs in Romania to build "sheltered housing" and day-care centres for persons with disabilities.[59] The organization named several issues with the programme, including that those facilities will be used by approximately 500 people (6–10 per unit), where units will be built in the same perimeter, indicating that the provision of care will function in a fashion similar to typical residential institutions but smaller in size and partialized; and that those facilities will be situated in "small villages or small towns" with little or no public transportation and poor prospects for community inclusion, activation, employment and maintaining contacts with close persons, which indicates a context of isolation and segregation.[60] Around the same time, NGOs submitted a similar complaint against Estonian authorities for the use of EU funds to build a "village" for persons with autism and other intellectual disabilities.[61] Also, complaints for alleged misuse of ESIFs in Poland, Austria and Bulgaria were submitted.[62] In the case of Austria, funds were used to build institutions for adults, and the latest for children with disabilities, in Upper Austria and Carinthia.[63] In all its replies to complainants, the EC was consistent with arguments used to support the position that the co-financing of long-term residential care with ESIFs is not contrary to EU law under certain conditions. An important point made by the European Network on Independent Living was that the complaint procedure is itself flawed, as the examination relies solely on the documentation submitted by the authorities, which precludes an unbiased inquiry of the actual situation.[64]

In a response to a complaint on the use of ESIFs in Romania, the DG REGIO organized its general argument – that such use of ESIFs is permitted and even desirable, and that the State did not breach EU law – around several issues: the existence of strategic documents for DI in Romania as a proof of general adherence to DI; the interpretation of the CRPD as permitting or even promoting the development of long-stay residential care in groups smaller than traditional institutions; the non-obligating character of the GC 5 of the CRPD Committee; interpretations of CPR and ERDF regulation provisions in relation to promoting social inclusion and the transition from institutional to community-based services; and the interpretation of CPR provisions related to the competence of Member States when implementing funds under shared management. This analysis will particularly focus on the interpretation of the CRPD, CPR and ERDF by the EC in relation to social inclusion and the transition from institutional to community-based care and independent living, due to their hierarchical and substantive relationship and issues surrounding the EC's understanding of those provisions.

In a response to this complaint in 2020, the EC reinstated the view of the Legal Service that the GC 5 of the CRPD has "policy weight".[65] The EC based its argument on the fact that the GC 5 is not legally binding, possibly to relativize the only authoritative interpretation of the CRPD and offer alternatives, which will be shown to fall short of an appropriate interpretation of a human rights treaty in accordance with general rules of treaty interpretation.[66] Importantly, the EC found that the support for residential facilities under the operational programme falls into the scope of the implementation of EU law by Romania, in accordance with article 51, paragraph 1 of the Charter of Fundamental Rights of the European Union (CFREU).[67]

Referring to a regulation on ERDF, the EC specifically mentioned article 5 and recitals 15 and 16 of the regulation.[68] Article 5, paragraph 9 (a) enshrines one of the investment priorities under thematic EAC 9 of the CPR, which is aimed at "promoting social inclusion, combating poverty and any discrimination by investing in health and social infrastructure ... and the transition from institutional to community-based service".[69]

The respective wordings of the aforementioned recitals are slightly more specific but still ambiguous:

> In order to promote social inclusion and combat poverty, particularly among marginalised communities, it is necessary to improve access to social, cultural and recreational services, through the provision of small-scale infrastructure, taking account of the specific needs of persons with disabilities and the elderly.[70]

> Community-based services should cover all forms of in-home, family-based, residential and other community services which support the right of all persons to live in the community, with an equality of choices, and which seek to prevent isolation or segregation from the community.[71]

The EC, in its response, proceeded to conclude that those two recitals prove that the use of ESIFs for infrastructure projects such as smaller long-stay residential institutions is not only allowed but desirable. This was primarily based on the wording "through the provision of the small-scale infrastructure" in recital 15. Notwithstanding, a conclusion that the wording means the development of long-stay residential care in smaller groups – and not, for example, small infrastructural adjustments and modifications to enable access to general services – can be characterized as an expansive interpretation of the term "small-scale infrastructure", and is certainly not in line with the CRPD. The interpretation does not adhere to the CRPD unless the CRPD itself is interpreted as allowing for such forms of care, which is an approach hardly defendable from the aspect of general rules of treaty interpretation and completely neglectful of the authoritative interpretation by the CRPD Committee.[72]

Those infrastructural developments can be related to ramps, elevators or the building of general-service facilities that are accessible and available to the named groups of people, as the purpose of that infrastructure is to enable social, cultural and sports activities, in accordance with article 9 and article 19 (c) of the CRPD and the CRPD Committee's interpretation of the latter provision.[73]

If the recital is interpreted, nevertheless, as a call for States to develop residential infrastructure, those could be affordable housing units, for example, and not small institutions. Still, it is unquestionable that the wording of recital 15 is vague and allows for different interpretations.

Here it must not be forgotten that secondary EU law must be interpreted in line with the CRPD, as far as possible. The space for different interpretations of the ERDF regulation thus shrinks, as it must not be inconsistent with the CRPD. Moreover, the ambiguity of the wording of recital 15 leaves it more susceptible to its alignment with the CRPD, as explained above. Recital 16, which is a paraphrasis of article 19 (b) of the CRPD, mentions "residential and other community services". Seemingly, the EC interprets this recital as prescribing the development of small institutions, while the CRPD Committee interpreted article 19 (b) of the CRPD to not permit States Parties to develop any "institutional forms of support services which segregates and limits personal autonomy". Again, as is the case with the EC's view on recital 15, such an interpretation can be described as neglecting the object and purpose of the CRPD, and even giving little regard to the internal context as interpretive elements (and completely neglecting the CRPD Committee).

The DG REGIO also reminded that under article 69, paragraph 3 of the CPR and ERDF Regulation article 3, paragraph 3,[74] funding long-stay residential care is not listed as ineligible.[75] Finally, the EC body concluded that there is no "general and absolute" prohibition to invest ESIFs in institutional care and that the concept of an institution is itself questionable since it is not characterized only by the size but also by the characteristics of its organization, functioning and culture.[76] Moreover, the DG REGIO held that the margin of appreciation of States Parties expressed in the GC 5 of the CRPD Committee means that where the development of long-stay residential care is part of a DI programme, that should be respected (despite the explicit expression against any forms of institutional care by the CRPD Committee in the GC 5).[77]

The EC's interpretations of the CRPD are hardly defendable from the standpoint of the general rules of treaty interpretation, and especially the need for effectiveness in human rights interpretation. This could also raise a question of the EU's respect for article 26 of the VCLT and the *pacta sunt servanda* principle, which prescribes that parties must take their international obligations seriously and in good faith (i.e. not with the intention to minimize its effects or simply ignore it). However, the CRPD provisions are susceptible to, at times, significantly different interpretations, as most provisions of any human rights treaty are. Therefore, rather than the ECJ raising the CRPD on a constitutional level, as Ferri argued, a more urgent issue is to have the CRPD provisions interpreted by this court. After all, article 3, paragraph 5 of the Treaty on European Union (TEU) prescribes that the EU "shall contribute to … strict observance and development of international law".[78]

That might have already been a case if the ECJ[79] had not dismissed an appeal by two OPDs and an NGO to the order of the General Court.[80] Namely, those organizations brought the EC before the General Court for the Decision not to stop the funding which was being used in Bulgaria to build institutions for persons with disabilities, after a complaint had been submitted to the EC by those same organizations. The General Court and the ECJ found their application inadmissible due to the lack of locus standi and have not dealt with substantive aspects of the compatibility of relevant actions with the CRPD. Neža Šubic criticized the restrictiveness in interpreting *locus standi* rules for non-privileged groups and raised an issue of curbed access to justice for persons with disabilities in the EU.[81] It should be emphasized that even if the EC would be ordered to suspend, interrupt or cancel payments, a Member State could on its own continue to finance such a project in this and other cases.[82]

In another study, Mario Mendez analysed "avoidance techniques" employed by EU courts when EU actions are challenged for the infringement of international agreements.[83] First and foremost, the author listed the restrictive standing requirements as one of the tools, then the wide margin of appreciation recognized to Member States in relation to mixed agreements, invocability of those agreements as a review criterion and lastly the interpretation of the agreements themselves.[84] In relation to the CRPD, we have seen only the first technique employed by the Court. However, the EC has commonly employed two sets of tools to avoid implications of complaints on EU actions: an "ineffective" interpretation of the CRPD, and the insistence on the wide margin of appreciation of Member States in the use of EU funds and in the implementation and application of the CRPD.

D. Financial regulation 2021–2027 and the transition from institutional to independent living in the community

Possibly due to controversies regarding the use of EU funds, complaints by civil society and feedback from the CRPD Committee, the new ESIF programming period brought another set of measures and provisions addressing the issue. Still, it is hard to say if it will significantly impact the use of those funds in Member States – in other words, if those funds will be still used to build long-stay residential care.

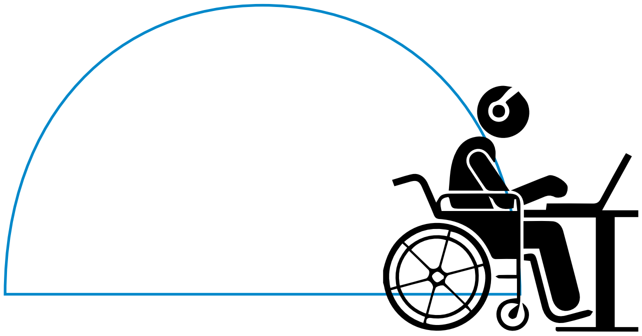
Already in recital 6 of the ESIF regulation 2021–2027[85] (CPR 2021–2027 hereafter), Member States are called to respect obligations set forth in the CRPD, and it is expressed that ESIFs "should be implemented in a way that promotes the transition from institutional to family-based and community-based care". Also, the funds "should not support actions that contribute to any form of segregation or exclusion, and, when financing infrastructure, should ensure the accessibility for persons with disabilities". This wording indicates that there is an intention to address the issues of funding projects which contributed to the segregation of and discrimination against adults and children with disabilities: the development of long-stay residential care. The use of the term "family-based care" directs attention to the situation of children with disabilities and the problem of building facilities for institutional care, unlike in the previous regulation, where it was omitted. The wording used is non-obligatory and resembles the language of a policy goal, which is common for a preamble. Regardless, it certainly reveals that the issues in the previous programming period had not gone unnoticed. Considering the non-obligatory character and knowing the argument used by the EC in its responses to the complaints, the new text does not guarantee the compliance of either the EC or all its Member States with the CRPD.

The CPR 2021–2027 introduced horizontal and thematic "enabling conditions", in accordance with article 15, paragraph 1, a tool equivalent to the *ex-ante* conditionalities (EACs) from the previous programming period. One of the horizontal enabling conditions is the "implementation and application" of the CRPD.[86] Fulfilment criteria related to this condition are, *inter alia,* a national programme for the implementation of the CRPD and a mechanism to monitor and report on the operations financed by ESIFs that are not aligned with the CRPD set in place. Also, those mechanisms should handle complaints submitted in relation to the use of ESIFs in the context of the CRPD, in accordance with article 69, paragraph 7 of the CPR 2021–2027. Such fulfilment criteria are a novelty and probably an attempt to advance scrutiny over the use of funds. National implementation plans must have measurable goals, data collection and monitoring mechanisms.

Thematic enabling conditions are related to the ERDF, the European Social Fund Plus (ESF+) and the Cohesion Fund, in accordance with article 15, paragraph 1 of the CRPD 2021–2027. Specific objectives in relation to social inclusion and persons with disabilities include the support for housing and social services and transitions from institutional to community-based care.[87] Two enabling conditions prescribe that Member States have strategic policy frameworks concerning social inclusion and long-term care in place. Fulfilment criteria include the existence of "measures for the shift from institutional to family- and community-based care". A criterion concerning the enabling condition in relation to long-term care is the existence of measures that promote community- and family-based care and DI.

The policy objectives, enabling conditions and fulfilment criteria are not substantively much different from those of the previous programming period. The current document contains the term "family-based care", which is commonly used in relation to the care for children, signifying that this is an issue recognized as relevant for the ESIFs. Thematic enabling conditions are not vastly more specific in relation to DI than the old EACs. However, a horizontal enabling condition which prescribes measures related to the implementation and application of the CRPD indicates more CRPD-focused programming. The "long-term care" is an issue relatively novel for ESIF regulation. In the current CPR 2021–2027, it is addressed to a much larger scope than in the preceding document.

The ERDF and Social Cohesion regulation do not prescribe the exclusion of investments in residential care for children and adults with disabilities from the scope of those funds.[88] One of the special objectives in relation to persons with disabilities includes the development of "new or modernised social housing".[89] Most importantly, one of the policy objectives concerns the transition from institutional to community-based care.[90] Its corresponding output is the "capacity of new or modernised social care facilities (other than housing)", while its implementation



is measured based on the “annual users of new or modernised social care facilities”.[91] The ESF+ should not be used to support any actions that contribute to segregation or social exclusion and should contribute to the implementation of the CRPD.[92]

Based on the CPR 2021–2027 and the ERDF Regulation for the same period, there are hardly any significant attempts to decidedly preclude investments in the development of long-term residential care for children and adults with disabilities detectable. The Preamble of the CPR 2021–2017 contains some promising formulations, but its enabling conditions and fulfilment criteria do not solidify those aspirations to the extent it could have been done. Provisions on monitoring, reporting and complaints in relation to noncompliance with the CRPD seem to be the most promising ones in the current legislation, as they should open the possibility to scrutinize the use of funds more transparently and invite other stakeholders to the discussion. By introducing those measures, the EU at least partly fulfils a recommendation from paragraph 51 of the Concluding Observations issued by the CRPD Committee in 2015.[93] If interpreted in line with the CRPD, based on the CRPD Committee’s interpretation and the VCLT, both regulations would virtually exclude residential long-term care for persons with disabilities. However, the EC has not favoured such an interpretation and has relativized the significance of the CRPD in the past, as explored above. In that light, it is obvious that the wording offered in the current regulation did not close down the possibility of investments in long-term residential care.

What is necessary is either the shift of the approach taken by the EC and the Member States to the CRPD (which is less likely to happen by itself) or preferably the ECJ’s interpretation of relevant CRPD provisions in order to implement and apply the CRPD in good faith and effectively. As Mendez noted, a lenient attitude of the Court will likely result in poor adherence to EU agreements, as it should not be expected by legislative and executive bodies to be strongly committed to international law.[94] Commenting on an approach of the ECJ to legislative review, Damian Chalmers observed that undertaking tasks that had shown to be challenging for domestic constitutional courts could be “political suicide for a supranational judiciary”.[95] Although the present issue considers the review of EC actions, following Chalmers’ views, a similar conclusion could not be inferred, as the ECJ had “a much more aggressive posture” against the EC measures.[96]

In light of the findings and the elaboration by Chalmers, if a *locus standi* issue were overcome, perhaps such a case against EC actions could have reasonably good chances before the ECJ. The *locus standi* requirements of NGOs that would bring a case before the Court could be met by bringing the case on behalf of one or more applicants who are directly affected by a measure. This would be associated with a number of difficulties due to a specific factual situation and often specific legal status of children and adults with disabilities who live in residential care. This was argued by appellants in their appeal to the ECJ on the General Court’s decision. Šubic dealt with this issue thoroughly in her critique of the Court’s decision, arguing that the usual interpretation of *locus standi* rules significantly impedes the access to justice of those people.[97] Another avenue to the improved access of OPDs and NGOs to the Court could be an expanded interpretation of *locus standi* rules in their favour.

3. Concluding remarks

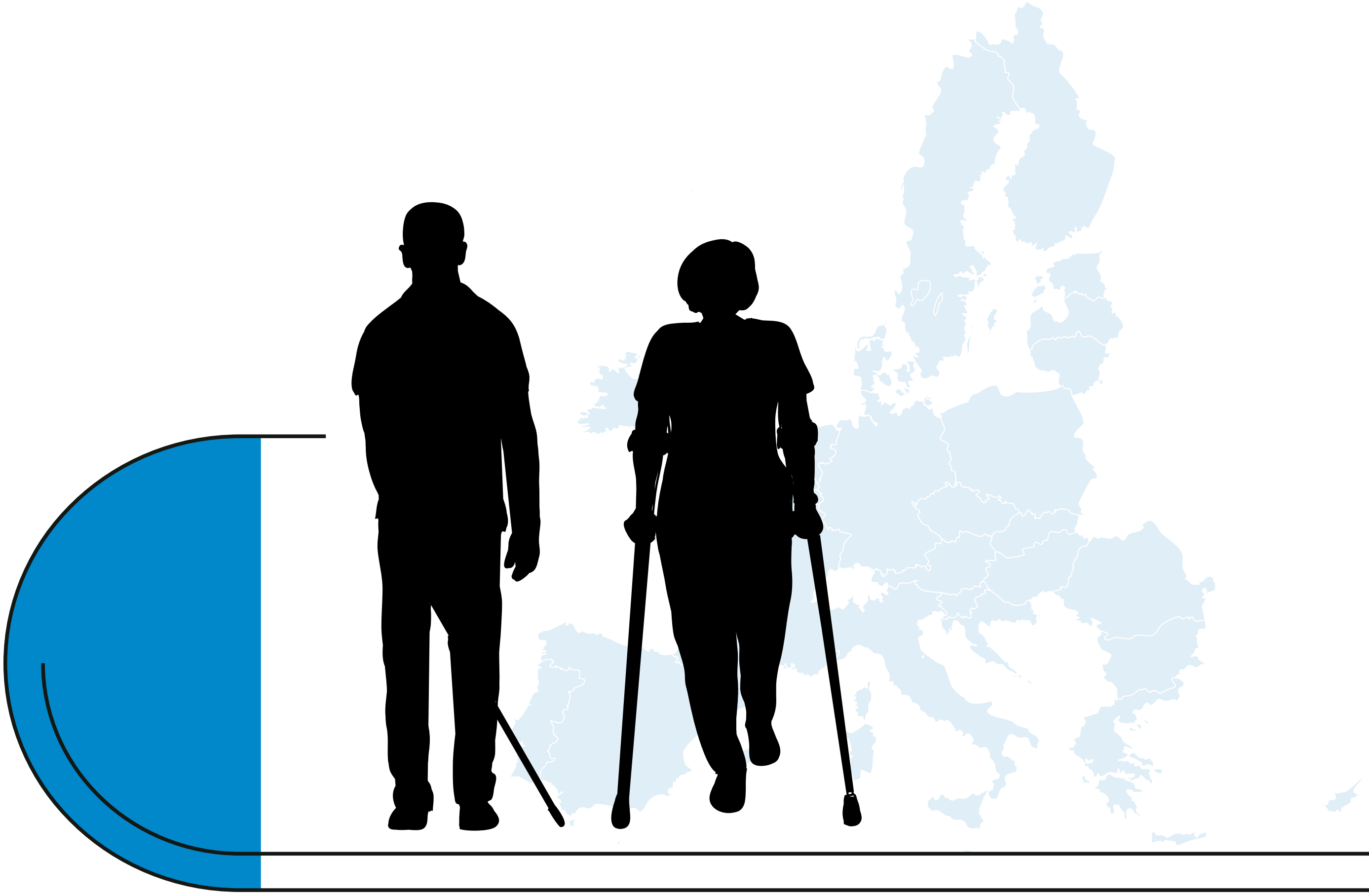
The inferior secondary law of the European Union (EU) must be interpreted in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), as far as possible, but only in the scope of the EU's competence which also considers the issues surrounding independent living and community inclusion, and life in a family environment. However, the issue of interpretation of the CRPD in the EU persists, as the European Court of Justice (ECJ) has yet to employ its exclusive competence to interpret the relevant CRPD provisions (art. 5, art. 19, art. 23).

The EU courts' decisions on admissibility may indicate that the courts would rather lay aside the issue for the time being. Still, the insistence on the ECJ taking the interpretation of the CRPD into its hands makes much sense since, as Mario Mendez explained, it can be hardly expected that the EU administration will be particularly dedicated to the implementation and application of the human rights treaty on their own. After all, avoidance techniques employed by the European Commission (EC) such as the argument of the wide margin of appreciation to support an "ineffective" interpretation of the CRPD, together with restrictive standing requirements of the ECJ and the continuing funding of long-stay residential care through the European Structural and Investment Funds (ESIFs), call into question the EU's dedication to the CRPD but also international law in general. The Vienna Convention on the Law of Treaties (VCLT) prescribes that States must take their obligations seriously and in good faith, meaning that the EU may be in breach of the VCLT itself.

Interpretations offered by the CRPD Committee have not convinced the EC, which categorized them as having only "policy weight", but then also neglected their policy value too. In fact, the EC has gone as far as to offer an understanding of the CRPD Committee's General Comment No. 5 (GC 5) as allowing for the development of long-stay residential care based on a wide margin of appreciation given to States when conducting deinstitutionalization (DI), despite the explicit opposition of the CRPD Committee to such forms of care in the same document. While the EC's view of the GC 5 is almost nonsensical, its interpretation of article 19 of the CRPD is hardly in line with the general rules of treaty interpretation of the VCLT. The EC's interpretation strips the CRPD of its effectiveness, which is a cornerstone of human rights treaties interpretation derived from the principle of good faith in treaty interpretation and firmly rooted in article 31 of the VLCT. An effectiveness approach to interpretation is commonly employed by regional and international human rights courts and bodies, and it seeks to achieve real and concrete protection of the human rights of its beneficiaries. In opposition to that, the EC went to great lengths to justify the investments in long-stay residential care, even where it meant neglecting the general rules of treaty interpretation. After all, a likely motive of the EC to apply such an interpretation was to avoid arousing too much opposition from Member States that benefited from those funds. The opposition of some Member States to the communication by the Directorate-General for Regional and Urban Policy (DG REGIO) to stop using ESIFs to develop residential care facilities is what generated the need for an opinion from the EC's Legal Service in the first place.

On the other hand, we have seen the introduction of measures (ex-ante conditionalities; enabling conditions) in ESIF regulation that should promote investments in independent and community living for adults and life in a family environment for children with disabilities. However, the efficacy of those measures has not been satisfying. This is not surprising considering the EC's interpretation of the CRPD. Regardless, the current regulation has brought some improvements, especially in the sphere of monitoring, leaving the impression of a seemingly more dedicated approach to the right to independent and community living by the EU when compared to previous such regulations.

The actions of civil society and other actors, as well as the CRPD Committee's recommendations, have an impact on the content of EU legislation. Considering the noticeable trend of the increased sensitivity of financial regulation for the critical CPRD norms on the one hand, and the fact that EU courts are especially cautious in addressing legislative acts while being a lot keener to strike down administrative actions of EU institutions, indicates a path to the increased compliance of EU actions with the CRPD. From the perspective of organizations of persons with disabilities (OPDs) and non-governmental organizations (NGOs), energetic advocacy towards lawmakers in the EU, which has been employed in the past several years, bears fruit. The efforts of OPDs and NGOs as "transnational norm entrepreneurs" to push for a specific interpretation of those CRPD provisions is a significant factor of internalization of the CRPD in EU law. Considering that problematic interpretations of article 19 and other relevant CRPD provisions by the EC persist, even a CRPD-compliant legislation may, in practice, be a framework for actions not compliant with the CRPD. Therefore, the insistence on bringing cases before the ECJ, despite the issues with restrictive standing requirements exerted by the Court, is perhaps the most significant of all avenues.



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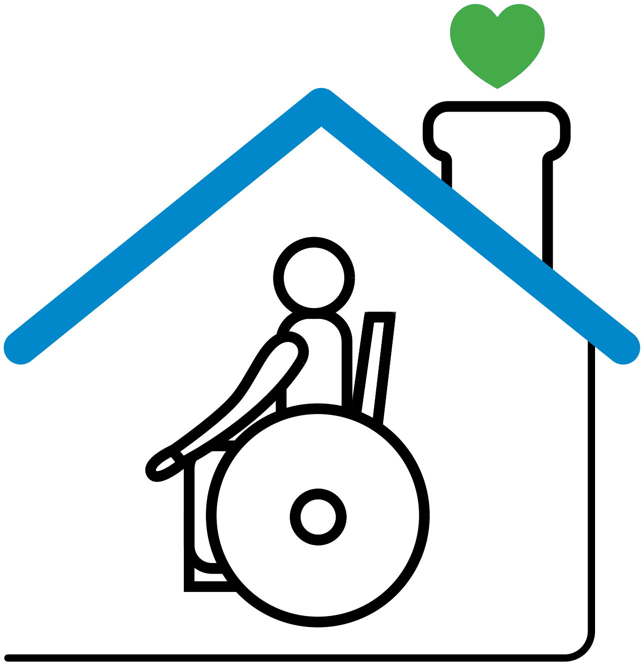


A PUBLIC-PRIVATE PARTNERSHIP APPROACH FOR ACCESSIBLE AND AFFORDABLE INDEPENDENT LIVING IN ESTONIA

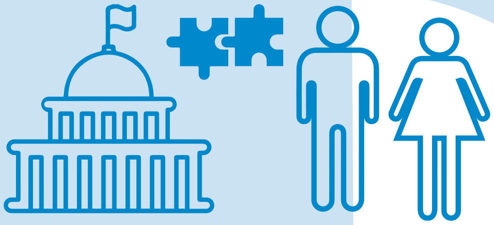
Meelis Joost

Key messages

1

In Estonia, de-institutionalization for persons with disabilities has been taking place from the early 1990s through the dismantling of institutions and the movement of their inhabitants to community-based living units.

The adoption of a private-public partnership approach in Estonia has had promising results in providing accessible and affordable support for persons with disabilities to live independently within their communities.



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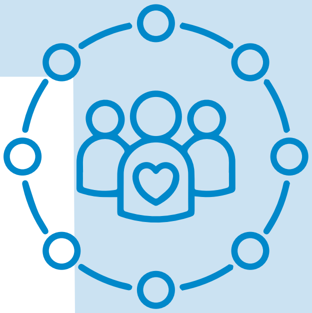


One of the challenges of providing services for persons with disabilities in Estonia is the fact that it is a sparsely populated country. Hence, it is crucial to map the needs of persons with disabilities for inclusion in the community at the local level.

1. The importance of policy analysis in the context of the CRPD

Estonia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 30 May 2012 with a declaration to Article 12. According to this declaration, the Republic of Estonia interprets Article 12 as not forbidding the restriction of persons' active legal capacity in cases where a disabled person is unable to understand or direct their actions due to mental illness, mental disability or other mental disorder; Estonia retains the position that there are circumstances under which it is necessary to restrict the active legal capacity of disabled persons.[1] De-institutionalization for persons with disabilities has nevertheless been taking place from the early 1990s through the dismantling of institutions and the movement of their inhabitants to community-based living units. The process is ongoing and the aim is to establish the community-based units in major urban centres. The present paper seeks to explore whether the current policies and programmes in place for independent living are achieving their purpose. It aims to explore the possible solutions and shortcomings in this process. The paper also analyses and discusses the availability of assistants, the optimization of unit accessibility and the availability of high-level support.

Article 19 of the CRPD highlights that "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". The de-institutionalization processes have been taking Article 19 into account and experiencing various shortcomings in the process, some of which are analysed in this paper.

The Estonian Chamber of People with Disabilities also highlighted shortcomings related to Article 12 in its alternative report[2] to the State report. It has called for the creation of supported decision-making mechanisms and the withdrawal of the declaration issued when the CRPD was ratified.

The present analysis aims to determine whether the proposed intermediate step to full independent living is effectively assisting all stakeholders in a satisfactory way and contributing to finding independent living solutions. It is important for policy makers and civil society alike to understand the shortcomings and challenges that may arise in establishing independent living and to avoid mistakes in the ongoing de-institutionalization process.

Challenges also arise from the fact that Estonia is a sparsely populated country, where many municipalities have a small number of inhabitants; municipal populations range from 179 inhabitants on Ruhnu island to 458,586 inhabitants in the capital city Tallinn, with only a few other major urban areas. These challenges are also addressed in the analysis.

> 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

2. Methodology of the analysis

For the analysis of interval care provision for adults with intellectual disabilities, which has been offered since 2018, administrative data from the Estonian Social Insurance Board as facilitator of the services have been used. The administrative data shows how much service capacity has been established and how much of that capacity is already occupied by service users. Full analysis of funding and of how service provision is evaluated by all providers and users is not yet available. However, interviews with the users and staff of two providers have been analysed.

A study on the impact of providing all social services in an accessible way has been commissioned by the Ministry of Social Affairs and conducted by a consortium led by Civitta Ltd. The study was completed in March 2022 and the results have now been published.[3]

The two topics of interval care provision as an intermediate step towards independent living provision and the accessibility of services have been combined due to the expectation that making service provision fully accessible would lead to saved funds and increased economic means, which could be channelled towards increasing the amount/hours of services provided. The analysis aims to give an overview of the kind of assistance most needed today to complement the overview it provides of available assistance.

It is equally important for the development of user-centred service provision to map as many aspects as possible to convince decision makers to take solid steps towards the fulfilment of the rights of people with disabilities in the light of CRPD Article 12 and Article 19.

3. Legislative background

In Estonia, social protection for people with disabilities has been gradually developing over the years since independence in 1991. A new level of development was kick-started by Estonia entering the European Union (EU), as EU pre-accession funds and structural funds were made available, largely contributing to improvement of social protection, equal opportunities, de-institutionalization and resolving work-life balance issues.

Since 1 January 2009, it has been possible to apply for childcare for children with disabilities, enabling families to strike a balance in situations where the burden of care is substantial and to preserve their ability to participate in the labour market. Local authorities can provide further support with childcare for children with disabilities, and during the EU 2014–2020 programming period, the European Social Fund also supported staying in the labour market by helping to tackle the burden of care. All these measures have enabled development at the individual level and preserved healthy relations within the family but have predominantly focused on assistance for children. When an individual turns 18 and becomes an adult, the relatively generous offer would disappear.

Having realized that the need for care and guidance remains, becoming even stronger when individuals reach adulthood, Estonian legislators have in 2018 introduced a **new service for adults,** enabling step-by-step decision-making towards independent living. Legislators foresee 23 days of interval care per month for persons with intellectual disabilities and adults with complex dependency needs, who would be able to try out living independently (with relevant assistance) without needing to immediately decide on a permanent solution; rather, they would be able to map different approaches to find the most suitable one.

Consequently, since 1 January 2018, it has been possible to offer special care services for a limited time (interval care) for adults. A description of the target group for whom the assistance is designed, prepared by the Estonian Social Insurance Board, the authority assigning service users to available places, is presented in the box.

In recent years, policy makers have moved away from descriptions of a particular group's need for assistance such as the one above, instead aiming for every person in need of help – regardless of their diagnosis, administrative status or whether or not they have disabilities – to receive assistance.

In reality, as often a lot of assistance is provided at municipal level, Estonian organizations of persons with disabilities are concerned that assistance will often be refused, and based on that have launched a dual approach: advocating for high-quality assessments of needs that would lead to both administrative status for persons with disabilities as well as wider availability of services to all who need them, regardless of their administrative status. This is in line with the CRPD definition of persons with disabilities, provided in Article 1: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

It is the removal of barriers, together with increasing the number of individuals benefiting from help, that will enable the realization of independent living. A step towards a more flexible approach that gives all stakeholders time to get used to a new living situation has been the aim of the interval care for adults services, which will be looked at closer later in this paper.

Description of target group for interval care services

The service is intended for a person who has been diagnosed with other intellectual disability (diagnosis code F78), unspecified intellectual disability (diagnosis code F79), a severe intellectual disability or a profound intellectual disability (diagnosis codes F72–F73), who has an extensive need for care, needs constant assistance in activities related to daily life and is not able to perform self-care activities. Therefore, in addition to regular daily support activities, in many cases, they also need care 24 hours during a day, constant assistance or permanent guidance in daily activities by a facilitator/staff member. A person who has a moderate intellectual disability (diagnosis code F71) or who needs a lot of supervision and assistance in daily activities does not require a lot of care.

The purpose of the service is to provide a person with the necessary assistance in daily life activities, enabling them to continue living in their home environment and to postpone placing them in a 24-hour social welfare setting. It also reduces the care burden on those closest to them and supports their work and participation in social life.

What does the service provide?

- A person is guided and assisted in self-care procedures, hygiene procedures and self-service (e.g. changing clothes, changing diapers and sanitary towels, washing and eating).
- A person is also guided and assisted in establishing or maintaining social relationships, time planning, arranging leisure time and participating in hobbies. The activities of support groups are also carried out and support is provided for participation in such activities.
- The service shapes and develops a person's daily life skills according to their abilities. Job-like activities that correspond to a person's abilities are also provided. If necessary, the service advises those closest to the person, providing specific information about the person's health/diagnosis and behaviour.

Source: Republic of Estonia, Social Insurance Board (n.d.c). Erihoolekandeteenused (Social care services).

4. Analysis of service development and crucial elements for success

A. Number of users

The number of children with disabilities is slightly increasing. The number of children aged 0–17 with a profound level of disability resulting in complex dependency needs has, according to administrative data, remained stable. Social Insurance Board administrative data shows that in September 2021 the total number of children with disabilities was **9,736.** In September 2022, the number had increased to **9,865.**

The target group of the interval care for adults with severe and profound disability is people of working age (18–64 years). The number of people with profound disabilities in September 2021 was **5,553.** By September 2022 it was **4,774.** This shows a decrease, but it should be noted that the re-evaluation of disability status and re-evaluation of capacity for work have in recent years led to a number of people with disabilities being categorized under a different severity level, with the overall picture not changing. The number of people of working age with severe disabilities in September 2022 was **16,112** persons.

The number of children with disabilities

September 2021
9,736

September 2022
9,865

The number of people of working age with profound disabilities

September 2021
5,553

September 2022
4,774

B. Aim to offer choice

Since the early 1990s, de-institutionalization processes have been taking place in Estonia. With the support of the European Union, the dismantling of large care facilities for special care has taken place and the ecosystem of special care has been diversified, with State-owned providers operating under the umbrella of Hoolekandeteenused Ltd. One large institution with a capacity for 180 persons remains open but will be closed in 2023, and the State-owned service provider is offering services in 63 units across the country for 1,700 users.

A wide variety of special care providers have also been developed, including at the grassroots level. Such providers are often civil society organizations established by parents of children with disabilities, carers of young adults or stakeholders aiming to effect change in the society in terms of the rights of people with disabilities, independent living and the implementation of the CRPD.

C. EU support mechanisms for reorganizing special care

The recent EU budget for the 2014–2020 period offered co-funding for the reorganization of special care provision. In the two calls for proposals, civil society stakeholders were also able to apply for establishing community-based living units, including interval care units to support a shift to independent living.[4] €47,600,000 was used to reorganize or establish 1,756 places on community-based services, including for interval care. Thirty-seven projects were co-funded, with 1,423 reorganized service places and 333 new service places.

D. Public-private partnership approach

Special care provision and the offer of childcare for children with disabilities requires the correct environment and readiness to cater for the special needs of the service recipient. That means fully accessible premises, resilience for intensive use, the fulfilment of dietary requirements and good sound isolation should be taken into account. This is often not the case for accommodation units used publicly.

Therefore, for both childcare and interval care for adults, service providers have requested that financing is made available for the creation of service units that suit the users. Here, EU funds along with State budget funding and private sponsorships have resulted in establishing service units where NGOs are acting alongside with public body stakeholders. Units supporting independent living are predominantly established in cities, with some exceptions where service units are also placed in smaller communities (given that Estonia is an extremely sparsely populated country).

Gradually, de-institutionalizing has resulted in the reorganization of all special care institutions and replacing them with small units, moving towards increasingly offering assistance in the location where the person is living rather than moving the person out of their normal environment.

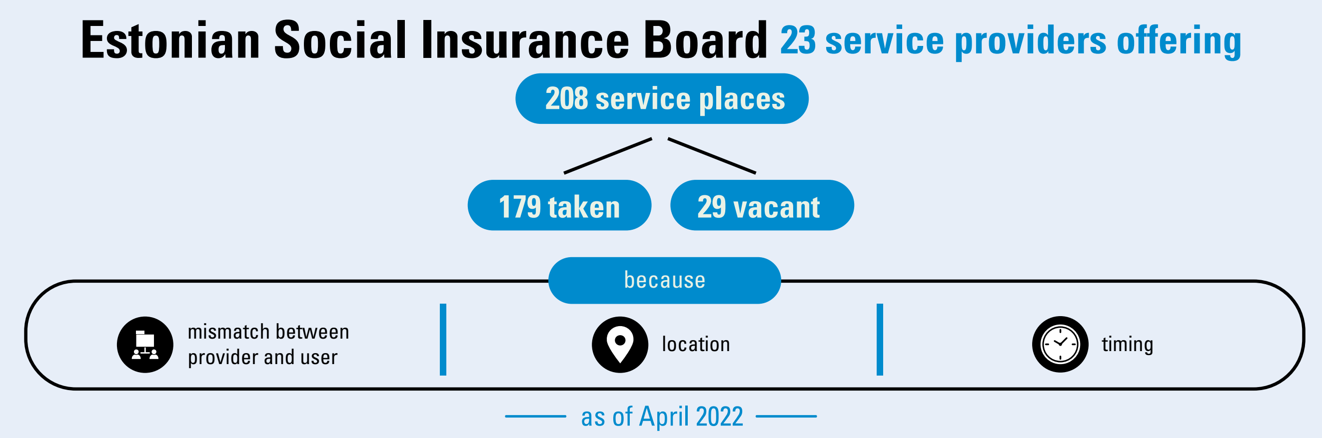
To offer childcare with the aim of letting the family rest or take a mini-vacation (respite care), the State have entered into partnership with the private Estonian-Swedish jointly established Estonian Agrenska Foundation. With the Foundation's own funding and support from the State and private donors, a new child-care provision unit was inaugurated in 2022 (ready for operation in March 2022). Normally, childcare is delivered with a 1:1 or 1:2 personnel-to-child ratio, with facilities being equipped to accommodate three persons staying in the room. Alternatively, for participants in a diagnosis-based family stay, family rooms are available in which four persons can be accommodated.

5. Interval care service provision: Size and satisfaction levels

The Estonian Social Insurance Board is the State agency funding the interval care service for young adults in search of independent living provision. Since the establishment of the service, **23** service providers have been offering **208 service places.** Of those operational places, **179** were taken and **29 were vacant** as of April 2022.[5] The reason for their being vacant was due to mismatch between provider and user, location and timing, but also the current situation where it is very difficult to hire care staff, in particular for adults with extensive care needs.

The distribution of provision across geographical locations in Estonia is somewhat uneven. Furthermore, the State-run special care units of Hoolekandeteenused Ltd. are not offering the service, as it is more time-consuming due to need for planning, interaction with families and identifying their needs, among other considerations, as well as a relatively high level of predictability – as the service is meant to fit each family's schedule and be readily offered when the family requests it.

Such provision requires the flexibility of personnel, which is very difficult to ensure, given increased commodity prices and the general shortage of care personnel. The need



for an increased hourly rate from the Social Insurance Board, who is administrating the service, is addressed in a separate chapter of this paper.

Geographical division

Estonia has a small population and generally is a sparsely populated society. Major urban areas are the capital area of Tallinn and neighbouring municipalities, making up 500,000 inhabitants, and the Tartu area with about 110,000 inhabitants. The 23 service providers are located in almost all counties although some of these counties have very few service places.

1. Tallinn and Harju County – the capital area

The relatively new service for interval care leading to independent living is one of the special care services. Many potential users are put on waiting lists and it is often not possible to access services close to home, hence the waiting lists. In the capital area, **197 individuals** are on the waiting list.[6] Also, not everyone who potentially needs the service has filed an application to become a service user, meaning the number of people who are expecting a service but cannot get one could be higher.

While the interval service leading to independent living options is predominantly meant for people whose care needs are high, it is not possible to determine the exact number of potential users. While the overall number of people of working age with the most severe level of care need, according to administrative data from the Social Insurance Board for the end of September 2022, amounts to **4,774 individuals,** even if only **2,000 individuals** require interval care, the **208 places available** mean that only about 10 per cent of the total number of potential beneficiaries are currently being assisted.

2. Governance and service issues across municipalities

Municipal governance has improved in recent years. After the municipal reform in 2017, instead of 213 municipalities, only 79 remain. Given the small population, the fact that there are still 79 municipalities conducting different municipal policies is a challenge for service users. Civil society organizations for people with disabilities are calling for equal treatment of people across locations, in urban and rural areas. The significant difference in municipal populations poses a challenge to offering good quality services.[7]

Furthermore, the total amount of interval care hours per person per year is not without limit, meaning that the hours required are also much higher than the currently available provision.

The service is also staff-heavy given the need to be flexible and take into consideration the needs of service user, the time of the year and the working cycle of the family members, among other elements. The number of staff involved in service provision could be as high as the number of service places. The case studies explored later in this paper indicate the current number of staff involved in service provision.

In the current economic situation, the staff wages of €4.50–€5.00 per hour are not feasible, making it very hard to find staff.

6. Societal acceptance of community-based services

Despite the current challenging and worsening economic situation, the acceptance level in the society for people with disabilities, such as intellectual disabilities, living in their neighbourhoods is slowly improving. A study commissioned by the Estonian Ministry of Social Affairs in November 2022, conducted by Norstat Estonia[8] shows that over 1.5 years since 2021, the percentage of people who would feel uncomfortable about meeting a person with learning disabilities/mental health issues has decreased from 65 per cent to 60 per cent, while the percentage of those afraid of such people has decreased from 32 per cent in 2021 to 27 per cent in 2022.

The study interviewed 1,000 people all over Estonia. The positive trend is minor, but along with media coverage addressing the advantages of community-based independent living solutions, it is a step in the right direction.

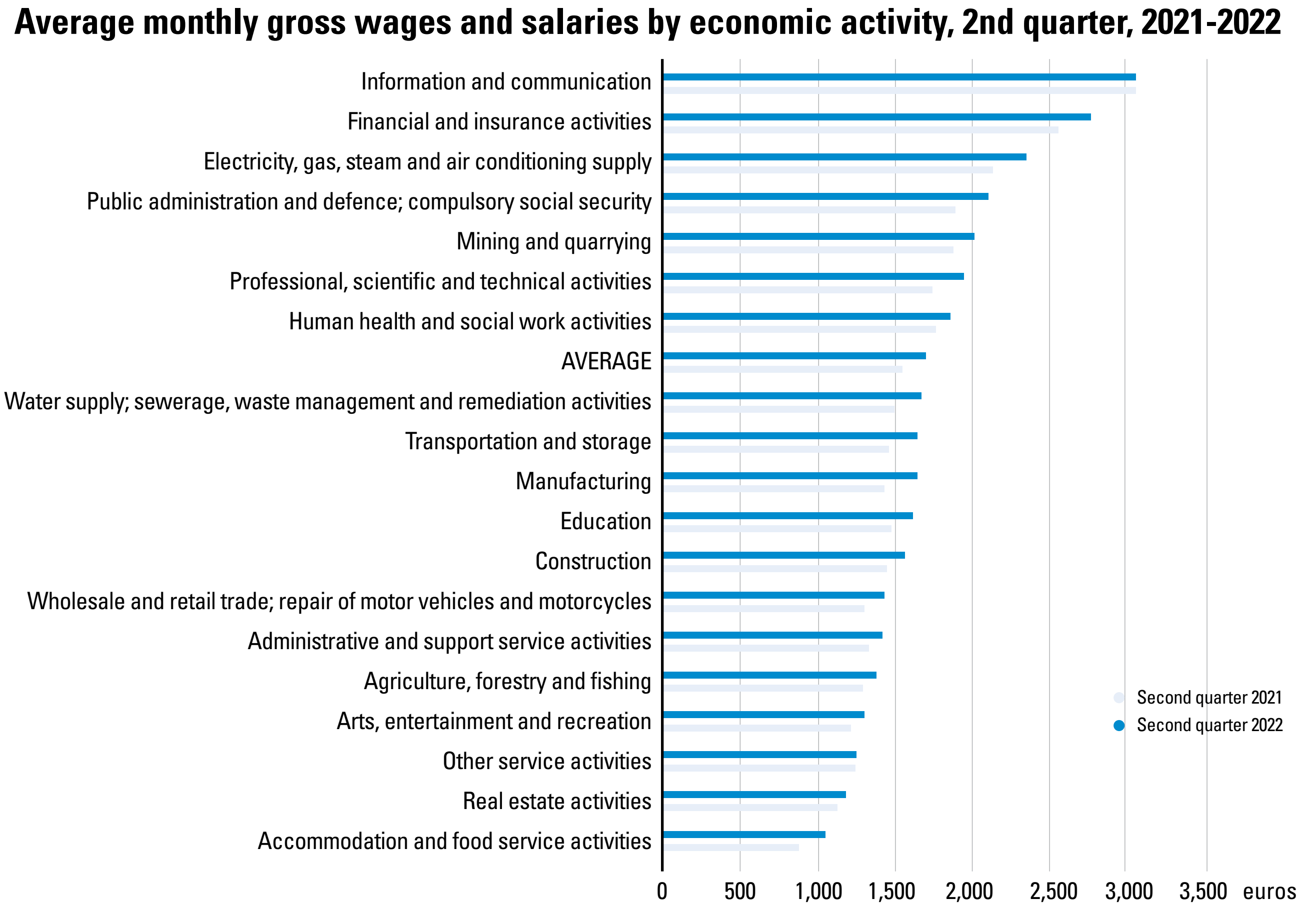
7. Salary levels for social care personnel and interval care service providers

Figure 1 shows that salary increases have occurred in all sectors since 2021. Figures for health care and social protection are just above average, but that is because the health sector is included within social care statistics.[9]

According to the aforementioned review of all 23 service providers of interval care for young adults seeking a solution for independent living, the service is mostly offered by private or grassroots-level stakeholders. Two case studies are provided in the present paper to explore how public funding has been used to develop the offer – in both cases, EU funds have been used. In one case, it was necessary for the service provider to use a substantial amount of their own funds.

Today, salaries for those providing interval care are posing problems. With rising prices for electricity, fuel prices, food, and other needs, it is absolutely necessary for the per diem rate to be increased by the State. In a situation where significant flexibility for the user is guaranteed by the providers and there is a high level of dependency from service users, a considerable increase is needed.

Figure 1. Salaries in Estonia by sector, 2021–2022



Source: Statistics Estonia.

8. User satisfaction

User satisfaction has not been comprehensively analysed by this study. The reasons are that the services have been established by policy makers relatively recently and many users are still adjusting to using the service. Furthermore, in many cases, service provision was delayed due to the need to put in place suitable units for offering the service.

EU funding support during the 2014–2020 period was available for improving the infrastructure for special care, with two calls for proposals, the second of which was only issued in 2017. This means most service units only became operational in the second half of 2021 or in 2022.

Analysing user satisfaction is very important and shall be undertaken separately, building on the present study. An interactive method of assessing user satisfaction needs to be used, as in many cases, direct interviews with users that use traditional interviewing techniques do not provide adequate results.

However, the two case studies included in the analysis involved interviews with users and those closest to them to assess their satisfaction and the added value of the initiative.

A. User satisfaction according to case studies

User satisfaction in the case studies is evaluated weekly, asking users how satisfied they are with their quality of life. A thorough interview with service users, family members and staff takes place annually, where all parties evaluate their satisfaction. Often the service user is the most satisfied, followed by their family members, with staff being most critical. The reason for this criticism lays in knowing that the full potential of the service may not be utilized at all times.

A very important step in evaluating the satisfaction of service users is the evaluation plan used for service users who are unable to express their satisfaction verbally. Four types of behavioural signs are taken into account: most satisfied is indicated by a state of calmness, followed by slightly displeased, heavily displeased and fully displeased, which may be reflected in aggressive attacks that require urgent responses.

The weekly evaluation is applied to all service users, interpreting non-verbal answers, based on which an evaluation is made and presented in the context of co-vision meetings, which are held regularly, generally once a month.

B. Satisfaction of service providers

1. Satisfaction at management level

Service managers have shown appreciation for the new service, seeing such interaction as necessary in order to prepare the person for independent living. They also see it as important to introduce tailor-made support, which may lead to yet further government-funded solutions for support.

The flexibility offered to users is, however, very complex and time-consuming, and comes with significant risk of losing qualified staff if the service is no longer needed, for example if a user returns home.

2. Satisfaction at staff level

The satisfaction level of staff was analysed by interviewing staff of the two providers featuring in case studies. Staff are often already familiar with the service users and their family members as both providers also offer other services focusing on early intervention and therefore know the user from a young age. However, there is a general shortage of staff in the care sector and individuals working in care tend to have a specific profile: some prefer to work only with children, and as a child grows and becomes an adult, different needs appear which might pose a challenge for these staff members.

In the context of the service provision environment, staff appreciate that the environment is new, fully accessible, equipped with suitable assistive technology and needed to take care of the service users with the highest level of support need.

The unsatisfactory level of income has already been addressed by the study. The hourly rate of €4.50 is not satisfactory, as even employees with lower levels of education generally earn €7–€10 for this kind of work where hourly rates are used and the need to step in is varied.

9. Case studies

Case study 1 – Tartu Maarja Support Center – offering **14 places, of which 12 are in active use**

A. Background of service provider

The NGO was established due to the needs of parents of children with disabilities, often with severe disabilities, in order to offer help for the family in the field of education, every-day life, respite care for preserving good relations in the family and many more needs.

The NGO at first focused on education, starting a school for children with special educational needs but has since developed many different branches, some of which have become their own legal entities and today are also service providers in their own right.

Tartu Maarja Support Center NGO was established in 2002.[10]

The following services are offered: Social rehabilitation, employment rehabilitation, childcare for children with disabilities, care home for children with disabilities, support home – in which children's support services and accommodation are organized, activities centre for daily activities support, unit for trying out independent living (interval care for finding an independent living option), training and free-time courses.

Many activities are organized for children and young adults with learning disabilities. The environment where the services are offered has been developing at a rapid pace during its existence. Combined ownership is used; the NGO sourced construction resources for the interval care unit while the municipality, the City of Tartu, is the owner of the property. Since the Maarja School was established due to the initial need for education provision for young people with severe disabilities, several branches of activities and service provision offering independent living options have evolved, such as the Maarja Support Center itself and two other initiatives outside the city limits (one in the neighbouring Põlva county and one other in the neighbouring rural municipality).

The added value to society from the grassroots initiatives is the educational impact for different stakeholders, the ability of persons with disabilities to have a say on what service offering for independent living should look like, improved understanding of the target group's needs among business and the public sector, and public sector and business involvement in the development of the environment for independent living, as well as the shaping of public opinion.

Both case studies in this paper are private bodies, established based on a mapped need for assistance and action and working for public benefit. Both have also been able to attract substantial public funding (domestic funding from State and municipal budgets) and private donations, in order to create fully accessible environments that are well-equipped and user-friendly to enable an experience similar to living in a home environment. Communicating to societal stakeholders and users of the service that more and increasingly flexible solutions are needed has proven successful, in particular as interval care leading to independent living is predominantly offered by such private stakeholders and not so much by the public or municipal providers.

B. Structure of service provision

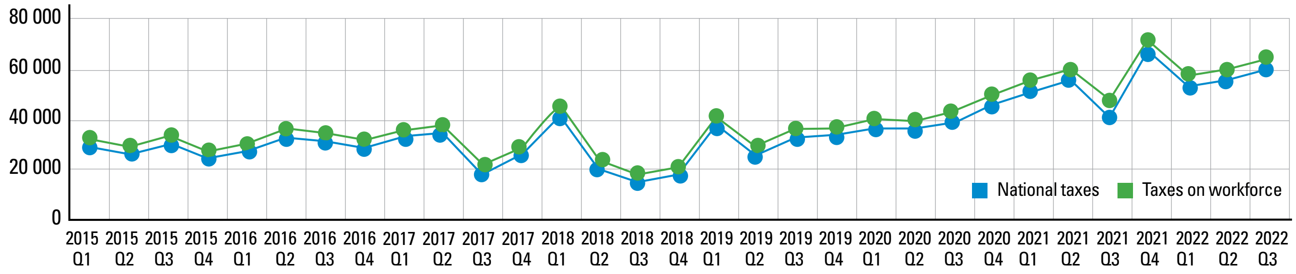
As of the third quarter of 2022, Maarja Support Center had a total of 70 employees for all of the different services offered, of which **25 employees** conducted special care services as part of interval care leading to independent living. Service capacity was as follows:

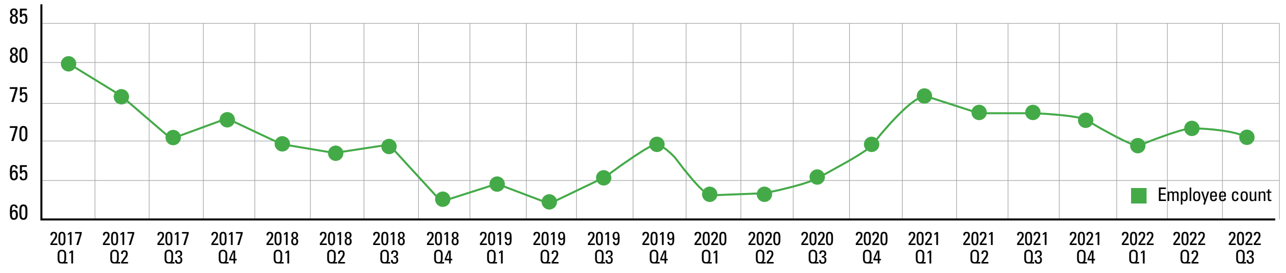
- Support for daily activities: 4 places.
- Support for daily activities for persons with autism spectrum disorders: 2 places.
- **Interval care for preparing for independent living: 14 places.**
- Supported living: 2 places.
- Supported employment: 10 places.

The figures show an increase in income tax. While the number of employees is currently rather stable, it has decreased slightly since early 2021.[11]

Figure 2. Paid taxes, taxable turnover and number of employees for Maarja Support Center, 2020–2022

Paid taxes, taxable turnover and employee count				
Period	**National taxes**	**Taxes on workforce**	**Taxable turnover**	**Employee count**
2022 yr Q3	58 814.13 EUR	63 119.70 EUR	0.00 EUR	70
2022 yr Q2	54 589.02 EUR	58 788.06 EUR	0.00 EUR	71
2022 yr Q1	52 453.22 EUR	56 518.48 EUR	0.00 EUR	69
2021 yr Q4	65 665.64 EUR	69 677.48 EUR	0.00 EUR	72
2021 yr Q3	41 490.27 EUR	46 890.94 EUR	0.00 EUR	73
2021 yr Q2	53 781.47 EUR	58 784.53 EUR	0.00 EUR	73
2021 yr Q1	49 763.35 EUR	54 468.39 EUR	0.00 EUR	75
2020 yr Q4	44 432.36 EUR	48 747.17 EUR	0.00 EUR	69





C. State of play today

Tartu Maarja Support Center is running a unit to support those getting used to independent living.

Source: Tartu Maarja Support Center.

The photographs above show the outside view of the Tartu Maarja Support Center independent living interval care units at Jaamamõisa 22 and 22a in Tartu, the second largest town in Estonia.

Three units are in operation: **one** for users **with a high level of care needs and two for those with a moderate level of care needs.** The division is to address staff needs.

Source: Tartu Maarja Support Center.

Inside the unit is designed for 10 users. Every person can have their own room if they do not wish to share a room. The kitchen area is shared with all users. The possibility to try out living independently can also be for the duration of a few days. The flexibility of the service is an important contribution on the path to find a more permanent solution, though it requires a lot of coordination efforts by service providers.

D. Major issues highlighted by an interview with staff

Ms. Helle Känd, founder of the NGO and manager of service provision, highlighted the following in an interview in November 2022:

- There are challenges in **finding educated and professional staff** who at the same time match the service provision requirements. Given price increases, salary expectations are higher. It is important to check the background of the staff, as if formal requirements are not met, professionality alone is not sufficient.
- It is crucial that staff are able to handle the workload. The **local authority is offering operational grants** to cover the support a person needs. In the event that a service user needs to attend a doctor's appointment or would like to participate in a cultural event, the ability to appoint a support person to help is crucial.
- There is a need to **become digitally competent** so as to be able to help users to navigate the virtual world and e-services the Estonian society is actively developing while user groups are in need of assistance to be able to use those services.
- There is a need for a general **supported decision-making mechanism,** which currently is not developed. Relevant stakeholders are looking into options to elaborate a supported decision-making mechanism and educate stakeholders. However, these processes have been relatively slow.
- There is a need to ensure that the interval care for adults' service is **maintaining its highly flexible provision level.** The complexity of combining the needs of users and the need to provide staff is a challenge; the current hourly rate alone is impossible to maintain in the long term.

E. Major issues highlighted by feedback received from service users

Service users range from persons who need 24-hour support (such as childhood arterial ischemic stroke patients) to those able to conduct most everyday tasks themselves and who would need minor assistance while using the service.

Feedback from three service users was gathered. Each user had a different need for care: a 21-year-old man fully dependent on external help, a 32-year-old woman with limited assistance needs and a 36-year-old man with minor assistance needs. The three service users are henceforth referred to as M21, W32 and M36, respectively.

In positive feedback, the proximity to home, flexibility of the service based on individual timetables, availability of professional staff, and modern, comfortable environment were highlighted most.

The need to maintain a similar level of each service provision was highlighted, as there has been variation in aspects such as clothing and the way supported persons are secured in vehicles when returning from interval care. Furthermore, M36 evaluates the current living solution as too noisy and unsuitable for keeping calm. The unit is meant for then users but is not fully occupied at all times. W32 expressed that she was very satisfied. M21's satisfactory level is evaluated by the aforementioned methods of gathering non-verbal feedback on a weekly basis, and is considered to be quite satisfied.

An important request for improving the service was to establish further earmarked assistance for the home-based care service, in particular for individuals requiring care 24/7, and for whom one-to-one interval care is required when at the service unit.

Case study 2 – Estonian Agrenska Foundation – offering **13 places, of which 9 are in active use**

F. Background of service provider

The Estonian Agrenska Foundation also focuses on families with children with disabilities, often those with rare diseases. The establishment is slightly different, as the Estonian Agrenska Foundation has a broader base and is a cross-border initiative, with Swedish and Estonian stakeholders working together in a civil society unit working for public benefit.

Source: Estonian Agrenska Foundation.

The founders are the University of Tartu, established in 1632; University Hospitals, with the Children Clinic, established in 1922, as the major stakeholder; the national network of disability organizations; the Estonian Chamber of People with Disabilities, established in 1993; two Swedish founders; the Agrenska national centre for rare diseases, established in 1989; and Stenströms Ltd., a private company active in the fashion industry, established in 1899.

The Foundation was established in 2003 and in the same year started offering help for families with children with disabilities. During the course of its development, new units for supported employment, units for support with everyday care and provision of respite care for children with disabilities were established. The main hub of the NGO – located in a historical building from the 1850s that was very neglected and inaccessible and that did not have modern solutions for heating, water supply or sewage – has been made accessible, equipped with modern facilities. It serves as a good example of how neglected heritage property can be taken into active use, without compromising the need to preserve heritage or user-friendliness. The focus on children with disabilities, employment, everyday activities, social rehabilitation and working in a cross-border approach has made the initiative well-known at national level, attracting more public and private support to achieving the goals.

In 2022, a brand new service unit offering respite care for children with disabilities was opened, with 13 fully accessible rooms and the capacity to house at least 40 persons overnight. The new unit was established as part of a public-private partnership approach, with the State budget supporting about 60 per cent of the expense, sponsors from the business community covering 25 per cent, and 15 per cent being funded by the service provider.

The photos above show activities during summer 2022, which included intensive provision of childcare for children with disabilities and the launch of interval care for adults leading to independent living.

G. Funding

2015–2021 was the incubation period, with investments focusing on putting up new units. From 2019 to 2021, the new service unit providing respite care for children with disabilities was opened and the EU funded an interval care unit for 13 users finding their way towards independent living. Both units were ready at the end of 2021 and in active use as of early 2022.

EU support for the interval care unit made up 70 per cent of its total cost, with 30 per cent funded by the Foundation itself.

H. Structure of service provision

As of the third quarter of 2022, the Estonian Agrenska Foundation had a total of 170 employees for all of its services, of which **12 employees** conducted its special care services for interval care leading to independent living. Capacity for services was as follows:

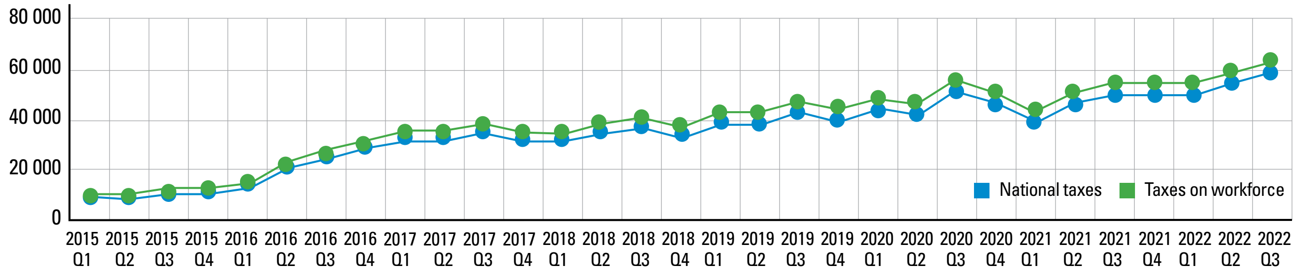
- Support for daily activities: 15 places.
- **Interval care for preparing for independent living: 13 places.**
- Supported employment: 6 places.

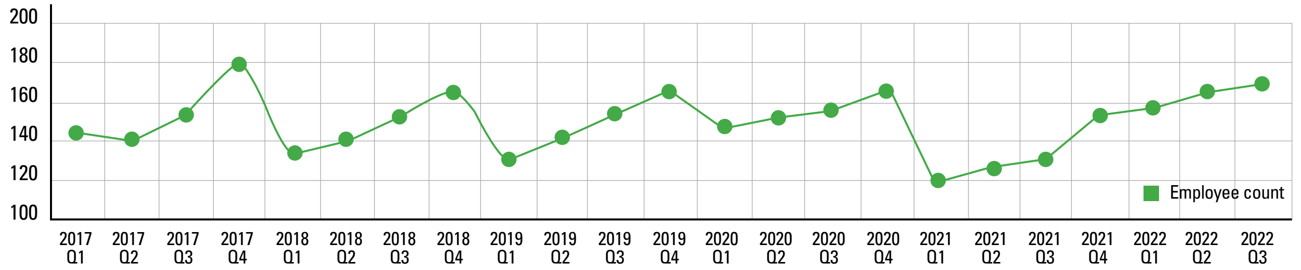
In 2022, a brand new service unit for children with disabilities was opened and funded by

the state	sponsors from the business community	the service provider
60%	**25%**	**15%**

Figure 3. Paid taxes, taxable turnover and number of employees for Estonian Agrenska Foundation, 2020–2022

Paid taxes, taxable turnover and employee count				
Period	**National taxes**	**Taxes on workforce**	**Taxable turnover**	**Employee count**
2022 yr Q3	58 953.73 EUR	63 583.21 EUR	0.00 EUR	170
2022 yr Q2	54 397.72 EUR	58 793.41 EUR	0.00 EUR	166
2022 yr Q1	49 790.63 EUR	53 668.15 EUR	0.00 EUR	158
2021 yr Q4	50 636.69 EUR	54 705.78 EUR	0.00 EUR	154
2021 yr Q3	50 561.85 EUR	54 864.40 EUR	0.00 EUR	132
2021 yr Q2	46 724.25 EUR	50 692.32 EUR	0.00 EUR	127
2021 yr Q1	39 792.10 EUR	43 143.05 EUR	0.00 EUR	120
2020 yr Q4	47 244.04 EUR	51 103.01 EUR	0.00 EUR	166





I. State of play today

The interval care for adults in the search of independent living options service became operational in 2022. There are 3 home-like units: **the ground floor unit** housing **5 persons,** the **middle-floor unit** for **3 persons** and the **upper floor unit** for **5 persons.** Each unit has a kitchenette, a common area and several bathrooms. The units are all accessible with an elevator connecting the different levels.

Source: Estonian Agrenska Foundation.

The photos above show a ground floor unit with a service bed and an upper floor unit bathroom.

J. Major issues highlighted by an interview with staff

Ms. Tiina Stelmach, board member of the Foundation and manager of the service, highlighted the following in an interview in November 2022:

- **High commodity prices** are hindering development and make finding staff a challenge. Unstable usage demand by recipients of the service makes keeping staff a challenge.
- **Peak periods** (summer holidays and school holidays) pose a challenge due to overall service use by all different user groups of the Foundation exceeding the capacity of facilities and staff. A more balanced use of the resources should be developed.
- New and **innovative solutions for handling demand** should be established that use the profiles of staff and users. There is a need for more long-term planning and improved use of today's various digital solutions to assist staff and users. Today, the overwhelming puzzle of matching needs and staff availability is a serious threat to continuous service provision, in particular for users needing a high level of assistance.
- Shaping policy and advocating for **increased hourly rates** is a challenge. Joint action of stakeholders is required to solve the issue. If not solved, the risk is that the service places may not be filled and persons in need of assistance will remain without help.
- Being a private provider working in the public domain, with all the assets (facilities where the services are provided) being owned by the provider itself, means that the ability to **attract municipal extra support** beyond the hourly rates for the service is limited. However, the rising costs of heating, fuel, electricity, food and other commodities have presented challenges for more flexible providers.

K. Major issues highlighted by feedback received from service users

Service users range from persons who need 24-hour support (such as rare genetic diseases patients) to the ones who are able to conduct most everyday tasks themselves and need minor assistance while using the service.

Feedback from two service users was gathered. Both users had a different need for care: one was an 18-year-old woman fully dependent on external help, while the other was a 23-year-old man with extensive assistance needs. The two service users are henceforth referred to as W18 and M23.

The service users cannot express themselves verbally. W18 expresses satisfaction through facial expressions and, when happy with the situation, smiles and is calm. Otherwise, they would cry and express dissatisfaction with sounds. W18 is quite satisfied with the service and would like to use it more often.

M23 is living with a rare disease and is able to walk and eat but cannot express verbally. He is very satisfied, demonstrated by his willingness to take part in all activities unprompted, his calm behaviour, very happy facial expressions and the increased use of his own initiative for executing several everyday tasks, which had previously been challenging. Living in his own apartment with very few disturbing events (compared to the childcare setting he had been using until the age of 18) has impacted positively on his well-being.

Both users are already familiar with the care staff of the service, having grown out of previous childcare services that were provided to them up to the age of 18. For M23, the service is the only suitable setting mapped so far, apart from his home. Identifying an independent living solution for M23 shall take into consideration the circumstances of the current interval care setting.

Service uses appreciate that their surroundings are well equipped, not too crowded, and allow for the use of the outdoor areas and spending time in nature. The flexibility of the service is hugely appreciated. Furthermore, 1:1 care for both service users in their living facilities is something that the service provider is continuing despite struggling with ever higher expenses for maintaining the facilities, retaining staff and securing high levels of service.

10. Linking the described needs with mapped improvement possibilities

The services described above, which assist users to find a suitable solution for independent living, struggle to meet the needs of all potential users due to the limited places available. Furthermore, more user-friendly solutions for those who are not suited to the available offer need to be established. A question remains as to whether there would be resources available to boost the solutions, secure availability and further develop the offer.

A. Accessibility as a factor for cost-effectiveness

From 2019 to 2021, Estonia had an intensive task force focusing on improving accessibility.[12] In this small society with a lot of digital development, it is crucial to enable the offering of digital services for citizens' interaction with authorities and all forms of accessibility. In August 2021, the policy recommendations of the task force were published and are currently due to be implemented.

Task force recommendations also highlighted that evidence-based information on accessibility, costs and benefits of accessible solutions should be promoted. Independent living is heavily dependent on accessible solutions for the built environment as well as access to information, including information in alternative formats. In order to achieve this, studies are being conducted and data collection is proposed to be thorough, backing up national action plans such as the Estonia 2035 strategy and the Welfare Development Plan 2023–2030.

In March 2022, analysis of the impact of accessibility for social services – requested by the Estonian Ministry of Social Affairs and conducted by the consultancy agency Civitta Ltd. together with Accessibility Forum NGO – highlighted how accessible provision of services will impact the cost of services. This raises the question of whether it is possible to offer more services if services are made accessible.[13]

More accessibility-related developments were due in 2022. Transposition into national legislation of the EU Accessibility Act was expected to be achieved by the end of June 2022, with a review of the legislation guaranteeing accessibility of the built environment expected to be finalized by the end of 2022. The EU financial programme for 2021–2027 began and monitoring of equal treatment in the use of cohesion policy instruments was expected to continue, with the Equality Competence Center of the European Union Cohesion Policy Funds having already established in 2015, hosted by the Estonian Ministry of Social Affairs. The competence centre provides support to all stakeholders who deal with implementation of the funds.[14]

The study led by Civitta Ltd. addressed the impact of accessibility in the following social services:

Accessibility in social services

- home support service
- personal assistant service
- support person service
- social transportation service
- offering accommodation service
- unemployment board travel to workplace service
- services of personalized service model for special care

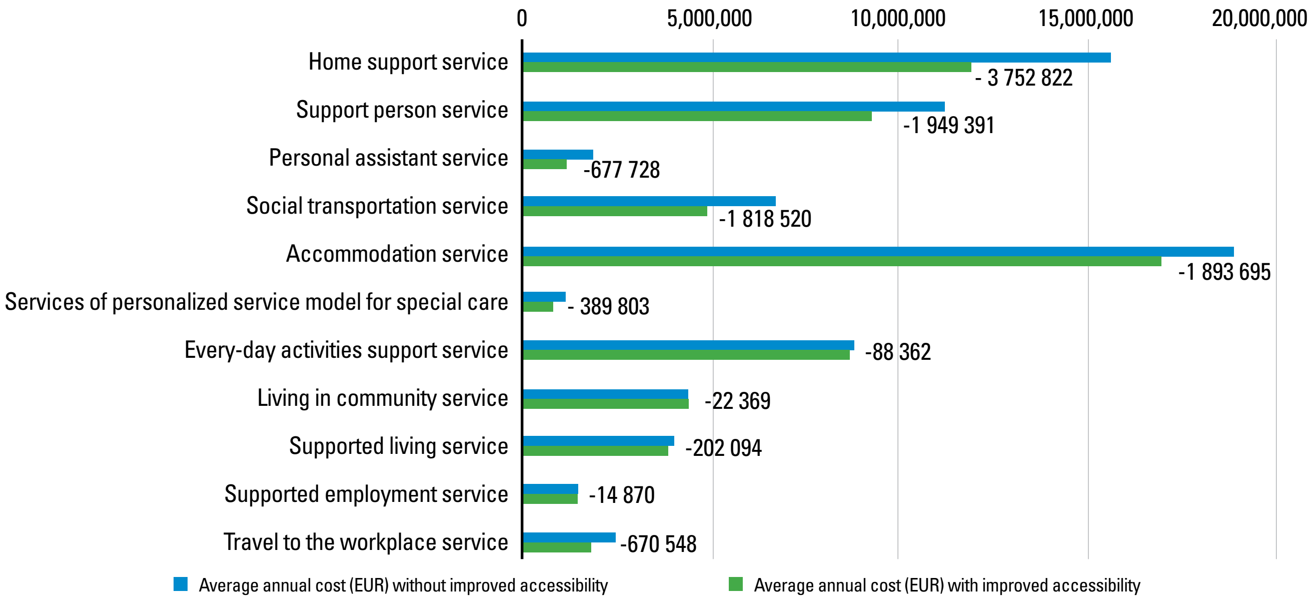
The study identified that the seven major services listed above had the highest impact if offered in an accessible way. Other services also had a direct or indirect impact if offered in an accessible way. In many cases, accessible service provision was also evaluated as having an impact on staff needs, with an accessible environment easing up staff workloads. Meanwhile, in the case of people with complex dependency needs, service need did not reduce even with improved accessibility.

The State currently loses up to **47 million euros** annually due to inappropriate levels of accessibility. Furthermore, the chart below shows which services, if offered in an accessible way, would bring savings and to what degree. Those saved sums could be used to offer more services, given increasing demand due to demographic structures and the current level of service provision being lower than needed.

The need for services is much higher than the current level of service provision. This is highlighted by the case studies of interval care provision for adults leading into solutions of independent living. Equally, certain services like the personal assistant service are struggling with multiple shortcomings, including a low level of availability (insufficient number of hours offered, as this is determined at the municipal level in each of the 79 municipalities) combined with low hourly rates and a lack of assistants.

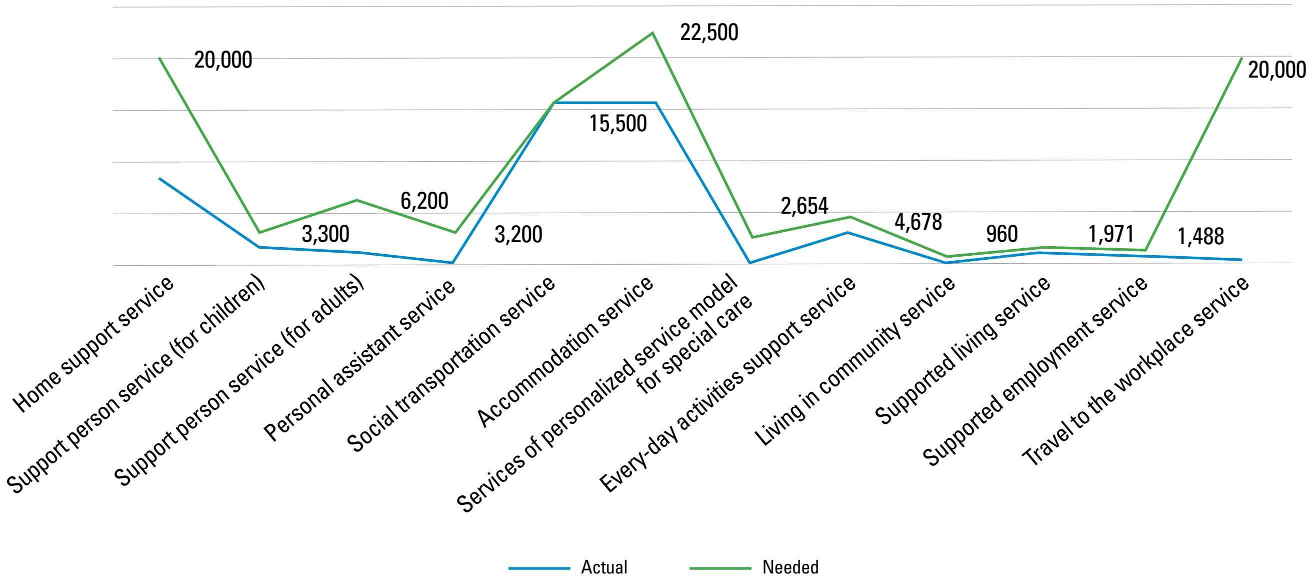
The Civitta Ltd. study is an important step forward as a contribution to a knowledge-based approach to policy making but needs to be taken into consideration in policy development and budget planning. The national legal environment requires accessible solutions. The Social Insurance Board, a State agency that guides individuals through special care solutions, has also focused on improved accessibility, with contract signing resolution solely for fully accessible service providers in the pipeline. All these steps are towards a more barrier-free society coincide with earmarked funds expected by civil society and at municipal level to improve the accessibility of the mapped shortcomings.

Figure 4. Overview of the costs of service provision



Source: Extract from Civitta Ltd. presentation for the Estonian Ministry of Social Affairs.

Figure 5. Gaps in service provision



Source: Extract from Civitta Ltd. presentation for the Estonian Ministry of Social Affairs.

Note: The blue bar shows the current level of service provision and the green bar shows the level required. In many cases, the required level is higher than the provision available today. Savings from accessible offering of services could fill the gap.

B. Recommendations to address challenges

1. Increase hourly rates for service provision

In 2021 and increasingly in the context of the war in Ukraine, energy prices along with access to certain materials have seriously affected social services provision. Fuel prices have risen, leading to higher food and other commodities prices, all of which impacts the provision of social services. State and municipal budget planners have to bear that in mind.

2. Develop suitable service provision

The Civitta Ltd. study on the cost effectiveness of accessible service provision is one side of the coin, while the use of modern tools, involvement of educated staff and maintenance of staff morale may be able to bring services to a higher, more adequate level. This is a challenge needing attention.

3. Avoid burn-out

Many NGOs and Foundations were established in the early 1990s, followed by another wave around year 2000, when the needs and possibilities for civil society stakeholders were becoming clearer in a young society regaining independence and starting to redevelop as of 1991.

This means most stakeholder organizations have been developing about 20–30 years, often with the same leadership from the very beginning. In the current circumstances where the economic situation has worsened, the war in Ukraine is impacting on people's mental health and wellbeing, and COVID-19-related measures have led to constant alerts to re-organize work to prevent harm to the users, the burn-out risk is high. The leadership of each service provider should already be looking for next generation leaders to get involved.

4. Train and motivate staff

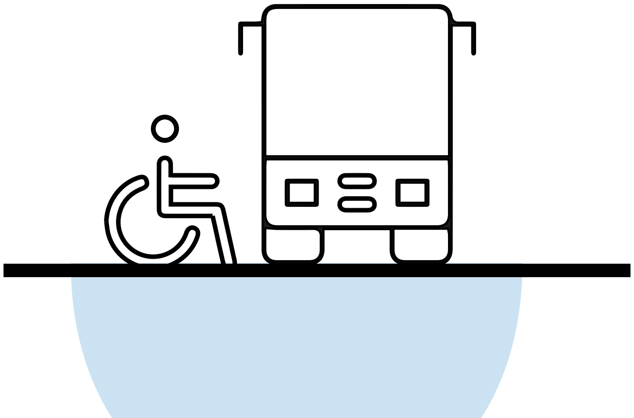
Interviews with the case study representatives also highlighted that the low level of salaries in the sector along with a high need for flexibility and few incentives to encourage staff pose real challenges to staff motivation. Cases of serious breaches of codes of conduct have taken place, which would have been avoidable with structured updates of mental health and wellbeing assistance. However, general workloads for offering the service tend to be so overwhelming that focus is lost and cases of staff-related dissatisfaction and misuse of trust can arise.

5. Focus on digital literacy

Currently, many people only use digital services with the assistance of a personal helper. The statistical overview of who is able to use the service is hence not accurate, as one digitally literate person is likely to help out several individuals. Training of individuals themselves, where possible, is crucial and is a current focus of the State Office of Estonia Innovation initiative, where the theme of better digital literacy for people with disabilities is among 22 themes for mapping the solutions to a problem in the public sector.

6. Further diversify services and improve accessibility

The need for smart provision of services where digital solutions can be utilized must be reiterated. Diversification of service provision needs to continue with personalized provision of care. Provision of services must also be evaluated for different user groups in the same way, using staff and securing staff full-time employment if needed.



7. Support processes for establishing supported decision-making mechanisms

In the 2020 Estonian State report in relation to the CRPD, it was clearly highlighted by the CRPD Committee and civil society that there was a need to focus on developing a supported decision-making mechanism to enable people with disabilities, who in many circumstances are put under guardianship, to exercise their rights under Article 12 in the CRPD. The present study highlights how in many cases there is a lack of flexibility and ad hoc approaches are used to assisting individuals in their interaction with the State and municipality.

8. Secure independent living based on individual needs

The interval care service is a step towards finding a unit for independent living. Currently, the support offered by the State and municipality depends on existing financial capabilities, services and earmarked support agreed by legislators. Tailor-made solutions are often not financially supported. The fulfilment of Article 19 of the CRPD also faces challenges due to the lack of assistants and attitudinal barriers still existing in the society. Social innovation should be increasingly used in the development of independent living solutions.

11. Conclusions

This analysis presents best practice for policy on supporting independent living. It will contribute to CRPD implementation and help secure options for independent living, including for persons with very high levels of assistance need.

Furthermore, with regard to accessibility in service provision, the Civitta Ltd. study commissioned in 2021 and presented in 2022 will improve decision-making. Policy recommendations for the Accessibility Task Force implemented from 2019 to 2021 served as the background for the present analysis. The policy recommendations of the Accessibility Task Force are currently being implemented, with priorities set for next few years and some implementation success stories already appearing.

The author of the present analysis has been involved in the civil society movement for people with disabilities in Estonian since 2000 and was then employed by the Estonian Ministry of Social Affairs – with responsibility for implementing the Accessibility Task Force's policy recommendations by the end of October 2022 – before becoming an active part of civil society again. This varied background and experience in both the public sector and civil society was helpful for accessing data and individuals working with the described services.

Despite the challenging societal situation of rising prices and the unstable international political situation, steps towards a better society can be taken based on the information mapped by this study.

The author wishes to thank stakeholders at the Ministry of Social Affairs, partners working to improving accessibility and the level of service provision, and the individuals who were interviewed.

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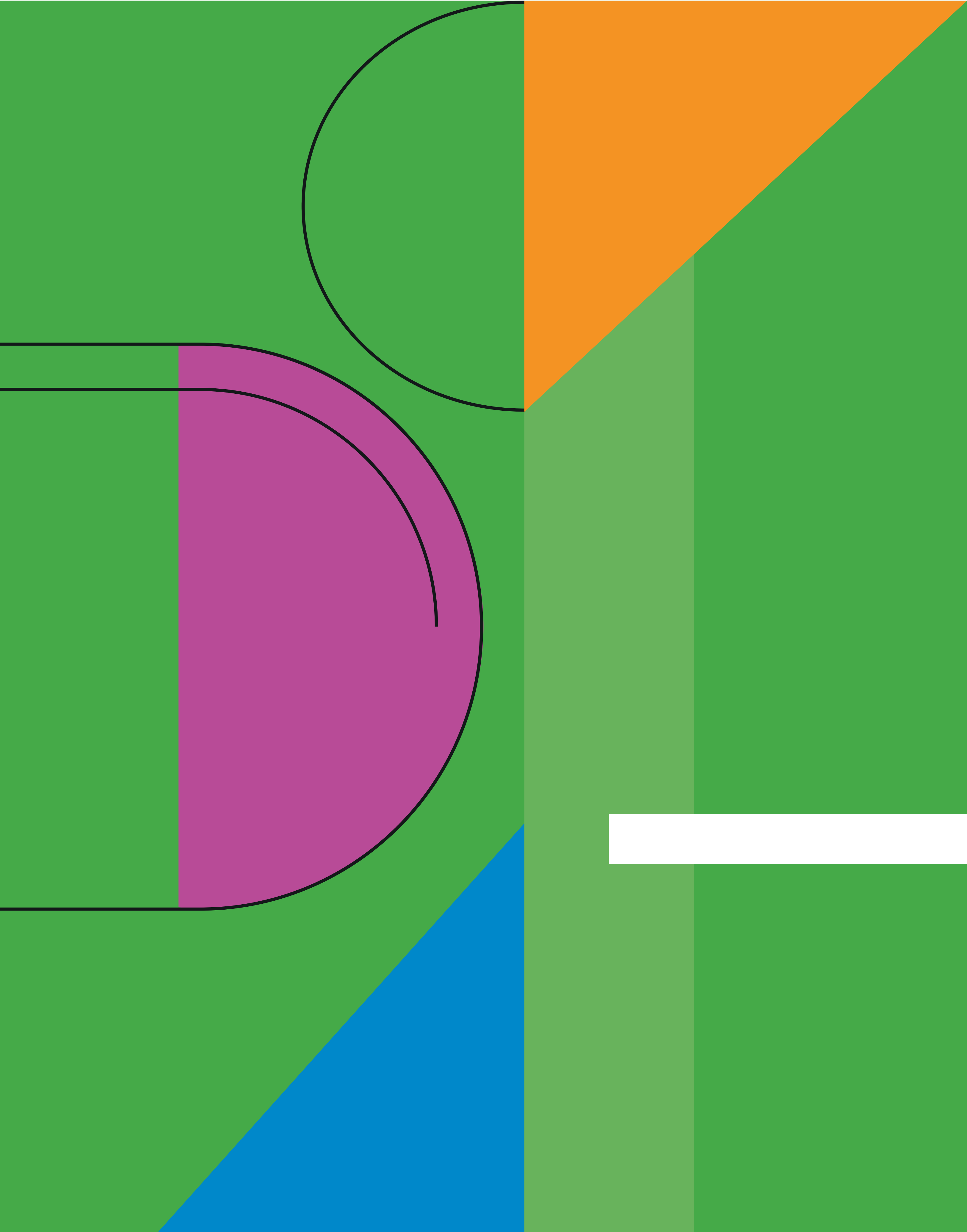

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Ms. Alčiauskaitė serves as the TRIPS Project Coordinator for the European Network on Independent Living (ENIL). She has more than 12 years of experience in the fields of disability, social inclusion and accessibility. Ms. Alčiauskaitė is a PhD candidate in psychology at Vytautas Magnus University in Lithuania. Her doctoral thesis is focused on positive psychology and discusses psychological resources and their impact on the acceptance of disability among persons with mobility disabilities. She has also worked as a human rights activist and youth trainer since 2014, devoting her efforts to raising awareness of human and social rights for young persons with disabilities.

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Tally Hatzakis co-leads the EU-funded project TRIPS that drives accessibility innovation towards inclusive urban transport. The project brings together transport experts and persons with disabilities in seven EU cities to co-design accessible mobility solutions, set innovation priorities and agendas and make joint commitments towards systemic changes in the sector. She is a strategic thinker and effectively communicates the 'bigger picture'. She has led foresight research on the ethical and human rights challenges relating to smart technologies in various domain fields for projects funded by EU, ESRC and EPSRC.

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Ms. Zaafarani is a PhD candidate at the Geomorphology Lab for Environment and Society; communication, entrepreneurship and development at Cadi Ayyad University in Marrakech. She holds a diploma in educational sciences and didactics and is a member of the Center for Inclusive Education and Social Responsibility at Cadi Ayyad University, Marrakech. Ms. Zaafarani has coordinated and supervised a number of research projects, including a national sociological study on the social effects of traffic accidents and a national study on the initial phase of a survey of Moroccan families in cooperation with the Moroccan Ministry of the Interior.

Radoš Keravica

Mr. Keravica is a disabled[1] researcher from Serbia who is a PhD candidate and teaching fellow at the University of Leeds, Centre for Disability Studies in the School of Sociology and Social Policy. He holds a master's degree in human rights law from Central European University. His doctoral research project uses socio-legal analysis and focuses on disabled children's participation in health-care decision-making in the context of impairment-related elective orthopedic treatments. It further explores the relationship between the United Nations Convention on the Rights of the Child (CRC) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in the area of child participation. He serves as a Board Member of the European Network on Independent Living (ENIL).Ikhlas Al Sawwaf

Ms. Al Sawwaf is an activist in the field of disability. She obtained her master's degree in special education, specializing in intellectual disabilities, from King Saud University in Riyadh in 2014. Ms. Al Sawwaf started her career as a teacher at the Intellectual Education Institute for Girls in Jeddah, later becoming its director, then was an educational supervisor and a member of the inclusive education team with the King Abdullah bin Abdulaziz Public Education Development Project. Ms. Al Sawwaf also served as a member of the advisory committee for the preparation of reference guides for intellectual education in the Ministry of Education in the Kingdom of Saudi Arabia. She is currently working as Director of the Special Education Department in the General Administration of Education in the Jeddah Governorate. Throughout her career, Ms. Al Sawwaf has had the opportunity to author a number of books and manuals in the field of education for persons with intellectual disabilities.

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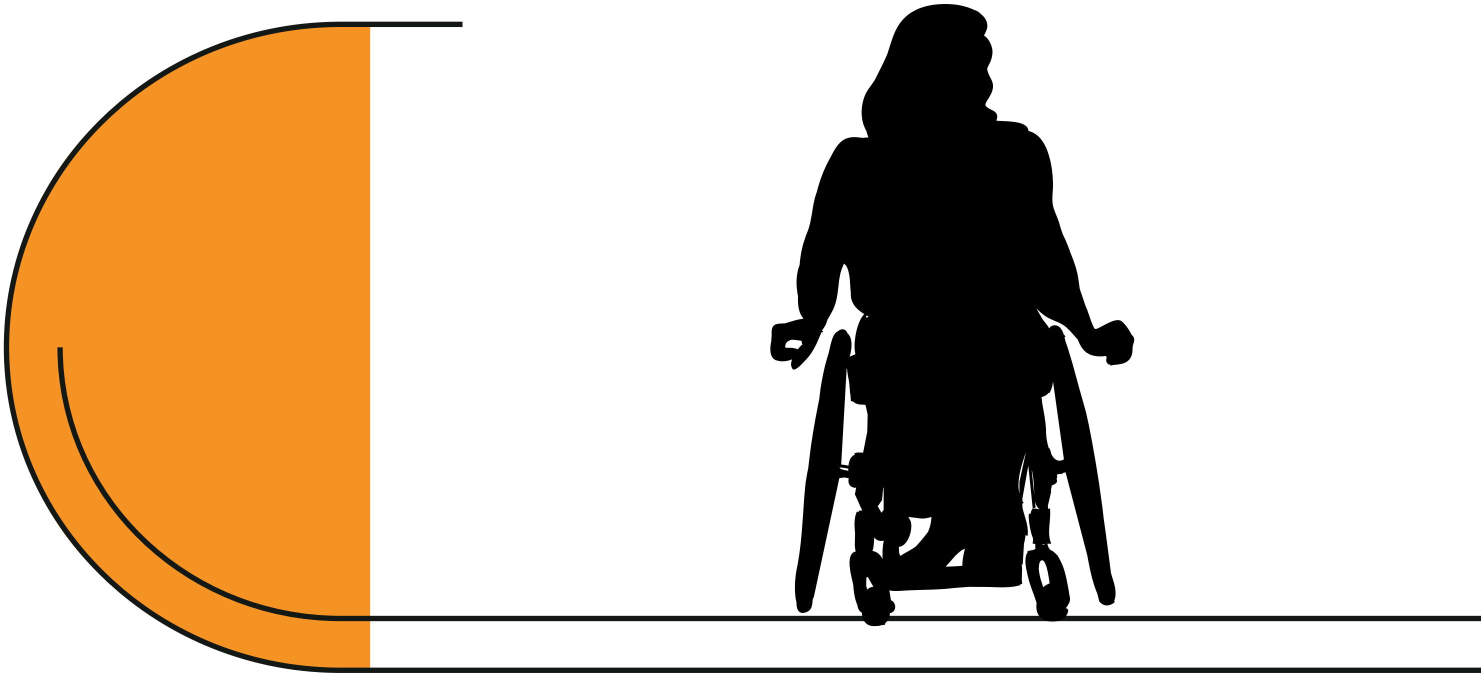
Ms. Al Kabaniya is Head of the Department of Students with Disabilities Affairs at Sultan Qaboos University in Oman. She holds a bachelor's and master's degree in sociology from Sultan Qaboos University. Ms. Al Kalbania has had the opportunity to work with persons with disabilities for more than seven years in a number of policymaking committees for students with disabilities. She worked on a proposal for a national screening programme for the early detection of disabilities in addition to the creation of an introductory disability guide for students with disabilities in higher education institutions. Ms. Al Kalbania has also had the chance to present papers on issues concerning persons with disabilities at a number of conferences.

Lazar Stefanović

Mr. Stefanović is a PhD candidate in the Department for European, International and Comparative Law at the University of Vienna and a researcher at the Vienna Forum for Democracy and Human Rights. In the past, he served as a civil society representative at the National Mechanism for the Prevention of Torture in Serbia and worked in an advocacy non-governmental organization dedicated to the promotion of social inclusion and the human rights of children and adults with disabilities.

Meelis Joost

Mr. Joost is a member and former vice-chair of the national Sustainable Development Commission in Estonia. He has been a member of the European Economic and Social Committee, an advisory body to the European Parliament and the European Commission. He is well acquainted with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), as he drafted the English version of the Estonian civil society shadow report to the CRPD Committee, which reviewed Estonia's report to the Committee in 2021. Since 2001, Mr. Joost has worked for the national network of persons with disabilities; he has also been involved in the work of a consultancy providing assistance for small and medium-sized enterprises and developing cross-border contacts. His work revolves around human rights, changing attitudes towards persons with disabilities, and caretaking issues, with a focus on diminishing the burden of care.



Endnotes

[1] **Ibid.**

On 14-15 February 2023, ESCWA in cooperation with Government of Malta, and the United Nations Special Rapporteur on the Rights of Persons with Disabilities organized a conference on “Transition towards Independent Living within the Community for Persons with Disabilities”. The conference discussed policies and programmes for ensuring independent living for persons with disabilities, a right enshrined under Article 19 in the Convention on the Rights of Persons with Disabilities. The events included presentations on national experiences and good practices from European and Arab countries. In preparation for the conference, the organizers issued a call for papers to invite researchers, including those with disabilities, to submit papers on the topic. Eight peer-reviewed submissions were selected by a committee and presented during conference sessions. The following presents these eight papers, which fall under four sub-themes: (1) technology and inclusion, (2) independent living for children and students, (3) transition after university and finding work, and (4) approaches to independent living in Europe.

These research papers demonstrate that, despite commitments to Article 19, there remains structural challenges to implementation. One key barrier is the practice of “institutionalization”, a term that refers to the often non-consensual stay of persons with disabilities in long-term residential institutions in isolation from society. Other barriers that persons with disabilities face include access to technology, education, transition after university and finding work and the equitable inclusion in social, economic and civic life.

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