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When Legislation Is Not Enough

The Adverse Environment for Independent Living in Hungary

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ABSTRACT

The history of disability policies in Hungary is one of legal progress since the 1990s and EU-funded investments since 2004, yet mixed outcomes for disabled people. To date this paradox remains unexplored, especially how it plays out in the lived experiences of disabled people and their families. This paper aims to fill this knowledge-gap by exploring disabled people's experiences of independent living over the past three decades in Hungary. Based upon 53 life course interviews – 34 with disabled people and 19 with family members – we identify seven barriers to independent living in Hungary, which create an adverse environment. We also highlight a number of facilitators that help people to overcome or mitigate this adverse environment. In the conclusion, we discuss trends in Hungarian disability policies that impact opportunities for independent living. Results suggest decades of human-rights inspired legal progress has made little difference in people's lived realities.

KEYWORDS

independent living; life course interviews; lived experience; post-socialist disability policy; disability rights; Hungary; human rights

I. Introduction

'Independent living' has been a legally recognised concept in Hungary for 25 years. Over the past few decades, successive Hungarian governments have taken several

steps to improve the life of disabled citizens: they developed disability rights legislation, launched disability action plans, ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), started deinstitutionalisation, improved legal capacity and accessibility policies, and adopted progressive sign-language policies. Furthermore, Hungary has received and spent a significant amount of EU funds on physical infrastructure and service development since 2004. Thus, it might appear that the country has created, or at least made significant progress in creating the legal and financial instruments and service infrastructure to support disabled people to live independently and with dignity in the community.

Available evidence, however, shows a different, rather bleak picture. Over 20,000 disabled people still live in residential institutions, often in ‘medieval conditions’ (Petri, 2020: 13) despite the ‘deinstitutionalisation’ programme that was launched in 2011 with the largest ever budget – drawing on EU funds – allocated to social infrastructure development in Hungary. Meanwhile, services to support people who live in the community have remained very limited and institutional in nature (Kozma et al., 2020). A recent report by the United Nations (2020) pointed out the lack of transparency, inadequate government consultation processes, and reinstitutionalisation funded by public money, including EU funds. Civil society organisations’ space in policy-making has been shrinking due to government attacks, impacting the ability of human rights organisations, including some non-governmental organisations, to promote disability rights (Gerő et al., 2020).

Beyond legislation, there are many factors that influence disabled people’s lived realities and their opportunities to live independently in the community. Based on disabled people’s first-person accounts and grounded in the social barriers model of disability (Shakespeare, 2006), this paper explores barriers and facilitators to independent living in Hungary and describes what we term the ‘adverse environment’.

2. Background

Although the concept of independent living had been known before Hungary ratified the CRPD in 2008, its meaning has evolved over time. Before 1990, state socialist politics oppressed disability activism (Mladenov, 2017): disability policies were defined ‘from the top’, by a centralised single-party system. Early activist writers of the 1980s and 1990s (Ignác, 2007) had already made the claim that independent living (‘önálló élet’ in Hungarian, which can also mean ‘self-determined life’) was a human right to be guaranteed to disabled people. At that time, independent living was primarily conceptualised for people with a physical impairment, excluding people with an intellectual disability or those with high support needs (Köncei, 1992), not unlike in the early conceptualisations elsewhere (e.g. Dejong, 1979). Parent-lead organisations for people with intellectual disabilities or autistic people emerged *after* disabled people’s organisations (DPOs) run by those with physical or sensory impairments (Hegedüs et al., 2009; Baár, 2015). Self-advocacy groups of people with intellectual disabilities or autistic people only emerged in the late 2000s.*1

It was in this context that the first comprehensive disability rights law entered into force in 1998 (26/1998 Law on the Rights of Persons with Disabilities). Promoted by the DPO-lobby (Ignácz, 2007: 187) and enjoying broad parliamentary support, the new law strengthened disability rights in healthcare, education, and a range of other public services. Progressive pre-CRPD changes included: the establishment of a government advisory body composed of DPOs; consecutive national disability strategies and action plans, with regular reporting and monitoring; and the creation of a 'disability unit' in the ministry of social affairs to promote and coordinate policy-making. However, despite the ambition and some achievements, certain disability groups, particularly those of people with high support needs, were excluded from reform proposals. Measures also lacked transformative power. For example, Hungary's state-socialist heritage included a strong reliance on residential institutions established between the 1950s and 1980s – the dominance of these in service provision remained unchanged after the 1998 law (Turnpenny, 2019). Similar to other countries in the region, instead of developing robust and needs-based social policy, Hungary embarked on neoliberal reforms – adding 'new injustices to the ones inherited from state socialism' (Mladenov, 2018: 13). Neoliberal measures are exemplified by the cutbacks of the disability pension system in 2008 and 2012 – as a result, today Hungary has one of the lowest expenditures on disability-related pensions in Europe (Krekó & Scharle, 2021). Critics have pointed out that neoliberalism and consequent maldistribution may be one of the barriers to successful deinstitutionalisation (Mladenov & Petri, 2020). In this context, disability advocacy efforts have also put a stronger emphasis on individualistic, autonomy-focused definitions of independent living (as opposed to more socio-democratic, interdependency based models), giving less attention to how profound socio-economic or political changes may be needed to achieve these (Zalabai, 2009; Baár, 2015).

Disability policies in Hungary feature a paradox between efforts, represented by new laws and EU-funded investments on the one hand, and outcomes reported from the field. Although DPOs and UN reports (UN CRPD, 2020) occasionally cite the views of disabled people, a systematic analysis of disabled people's lived experiences has been missing from literature and it remains unexplored how the above paradox has played out in the lived experiences of disabled people and their families. In this paper, we aim to fill this gap by exploring disabled people's experiences of independent living in the context of these legislative, policy, and broader societal changes and persistent mechanisms of social exclusion in Hungary. We will conclude by pointing at systemic problems that hinder independent living, despite the efforts made in the last three decades.

3. Research Approach and Methods

This paper reports on some of the results of the study 'Marginalisation of people with disabilities: changing and new mechanisms' funded by the Hungarian National Research and Development Fund*2 (2019–2022). The study uses a multidisciplinary approach, based on life course interviews with 92 participants, in addition to statistical

and policy analyses, interviews with senior experts, media analysis, and a national, representative survey about social attitudes toward the rights of disabled people. For this paper, we build on only one set of data collected in the project – the life course interviews with disabled people and their family members. Recognising that independent living has various interpretations around the world, including in Hungary (Barnes, 2003; Zalabai, 2009), we situate our paper under the definition of Article 19 of the CRPD. The latter places emphasis on both disabled people's self-determination and the right to access a range of services appropriate to their needs, on an equal basis with others (Lewis & Richardson, 2020).

Our chosen method – life course interviews – enables us to focus on the social barriers experienced by individuals in various life situations; however, by giving voice to disabled people we can capture the collective experience of disabled citizens in Hungary. In other words, accounts of individually experienced exclusion will reveal collective injustices and systemic mechanisms that hinder independent living from becoming a reality in Hungary.

Our approach was designed to account for the volatile nature of policies, whilst simultaneously respecting individual experiences and interpretations. Life course theory can be used to reflect upon change in a person's life (Elder, 1998). Individuals live through historical, societal, and policy changes and negotiate social, economic, political, and policy factors that influence how they live and how they see the way they live. Life courses can explain or critique policy trends (Priestley, 2000). Life course approaches incorporate experiences spanning over a lifetime, from childhood to education, work, family life, and older age; thus, life course interviews provide a window into the ways in which various changes over time are perceived and integrated into one personal narrative (Elder, 1994). Life course approaches have been successfully used in researching disabled people's experiences (Halvorsen et al., 2017), including those with an intellectual disability (Hamilton & Atkinson, 2009). Building on data from life course interviews also has an epistemological advantage, because disabled people's views, opinions, and preferences often remain hidden behind statements of professionals, policy-makers, academics, or experts, thereby disempowering and silencing them (Goodley, 2001). Thus, we will focus upon how disabled people and their families have lived through the last decades of rapid policy changes in Hungary, and how they perceive their daily experiences of independent living. Finally, life course interviews are also able to give voice to disabled people's expertise, and illuminate how they (re-)negotiate their own place in the world among volatile policy-changes (Hartblay, 2020). In this sense, our paper presents various individual stories of 'acquired virtuosity' (Hartblay, 2020: 34) in a context where people face persistent barriers, sometimes for several decades.

Through life stories, we examine policies that are traditionally seen as key to independent living (social care, healthcare, employment), but we advance beyond that. We took inspiration from Hasler (2003) and extended our analytical frame, because social exclusion rarely stops at formal policy matters; it penetrates most areas of human life, including how people meet and befriend each other, who they

spend time with, or how they form intimate relationships. Therefore, our life course interviews included themes outside strictly understood policy issues, for example, childhood, prejudice, family life, relationships, friendships. People with psychosocial disabilities were excluded from our study because for much of the chosen time period covered by the project (1990s to 2021), psychosocial disability was not legally recognised (2013) as defining a disability group in Hungary. We hope future research can analyse barriers to independent living faced by people with psychosocial disabilities in Hungary.

4. Research Methods and Ethics

Our project was overseen and supported by an Advisory Committee (AC) composed of seven disabled advocates representing different impairment groups, including deaf and hard of hearing people, blind people, people with physical disabilities, and autistic people. One parent of a child with an intellectual disability was also part of the AC.

We set out to follow maximum variation sampling to ensure the representation of seldom-heard groups of disabled people, such as those living in rural areas and institutions. Recruitment of participants started in October 2021 via social media (Facebook) and personal networks of the research team, DPO's email lists, and snowball sampling.

The project's ethics policy was approved by the project's AC. All participants received an information sheet and a consent form, and the voluntary nature of participation was explained to all participants. For persons with an intellectual disability, we used Easy Read material. Special adjustments were also made during interviews, based on individual needs and circumstances, for example non-verbal participants were interviewed in written form using assistive technology. Interviews were audio-recorded and transcribed using an online transcription tool. Transcripts were quality checked by the researcher who conducted the interview. In addition to transcripts, structured summaries were also prepared for each interview.

Interviews were conducted by researchers and six peer researchers (four disability advocates and two non-disabled teachers); 92 interviews were conducted between October 2021 and February 2022. Due to COVID-19 lockdowns most interviews were carried out online (and a few by telephone), however, when national COVID-policies made it possible, some participants were interviewed in person, including people who lived in institutions. For this analysis, we selected 53 interviews (male=17; female=36). We used purposeful sampling after reading all transcripts and summaries and selected interviews that were rich in data, and diverse by impairment group, gender, age, settlement type, and types of living arrangement (private household or social care homes). Our sample included 34 disabled persons and 19 family members – the latter were included only for disabled children or when it was not possible to conduct an interview with a disabled adult and a proxy-interview was necessary (e.g. due to severe cognitive impairment). We note that life course data about disabled people narrated by family members must be interpreted carefully. Even when

such interviews provide important details of disabled family members' lives, they also tell a different story, because their perspectives are always distinct to that of their disabled relatives – for example, in how they interpret certain barriers to independent living.

We aimed for geographic diversity: we sampled interviews from all regions, including the capital (n=19), larger cities (n=8), towns (n=14), and villages (n=10). We also recruited residents of institutions (n=9) because they represent those who are victims of a system that does not support independent living – their accounts about reasons for living in institutions illuminate barriers to independent living. Although we include a diverse sample, for the purpose of this analysis, we retain a focus on common barriers that were salient in our overall dataset, perceived similarly by participants with different backgrounds or from different impairment groups. To account for differences between how various groups experience barriers, where relevant, under each section, we take note of issues that are likely to affect particular impairment groups.

Importantly, our analysis builds on participants' experiences from the last three decades. Thus, accounts of barriers are representative of the lived realities of Hungarian disabled people since the 1990s.

For the analysis of interview transcripts, we used thematic analysis (Braun & Clarke, 2012). Coding was undertaken by the first and second author, following a mixed, deductive-inductive approach: some themes (education, healthcare, social care, employment) were pre-defined by the research team, others were identified from interview texts. The analysis was driven by two questions. What are the main barriers to independent living in people's lives? What are the factors that facilitate independent living? In the following section, we group findings into two blocks. First, we present seven main barriers to independent living. Second, we briefly highlight facilitators that help people overcome or mitigate the adverse environment. In the conclusions, we integrate results with data from existing literature and suggest trends in Hungarian disability policies that impact opportunities for independent living.

5. Results: Seven Barriers to Independent Living

In this section, we discuss seven factors that were identified from data of the life course interviews as key barriers to disabled people's independent living. Some of these barriers relate to actual policy areas subject to legal reforms, others are barriers that are more indirectly influenced by public policies.

5.1 Inappropriate Social Support

We define social support for the purpose of this study as inclusive of all social services and cash benefits provided to disabled people. Participants had overwhelmingly negative experiences of social support – services were identified as either missing, or if they existed, they were considered to be inappropriate in relation to people's needs.

Many participants stated that social services are non-existent where they live. Most mentions included legally defined types of services, such as home care assistance or

adapted transport services. Parents and family carers also talked about the lack of respite/crisis services and day centres. Some participants made more general statements, for example the parent of a young person with multiple disabilities noted: ‘the big, big problem is that Hungary does not seem to have a social protection net’. When asked about the future, several participants talked about the absence of social care. This is illustrated by this comment from the sister of a teenager with intellectual disabilities:

waiting lists are terrible ... and it's very bad that they don't have the capacity, both in the day care and in residential services ... I met parents who are aging parents, their children are 40–45 years old, and they are looking after them alone, and they are just worried that they're over 60 now, and what will happen if something happens...And supported living is still not an option in Hungary!

Personal assistance, which is seen as the core provision by independent living activists (Ratzka, 1993) and some Hungarian advocacy groups (Sándor & Kunt, 2020), did not feature in the interviews. When ‘assistance’ was mentioned at all, the word was used in a more general way, reflecting a concept that is closer to service-managed home care than user-driven personal assistance – blurring the lines between the two concepts (Mladenov et al., 2022) and suggesting that respondents may not be aware of how ‘personal assistance’ differs from most social services.

While most participants acknowledged the fact that services – where they exist – provide some help, many also stated that often, available support does not respond to their needs and they have to fit around what is available. In a context characterised by a scarcity of services, providers can ‘cherry pick’ clients and turn away those with high support needs. The mother of an autistic young woman with an intellectual disability told us about their repeated attempts to find daily support:

in social services, they like kids who are ... wheelchair-bound. The one that stays where you leave it, someone who won't run to them. Someone who doesn't need too much attention or care. And my daughter is the type of kid who requires attention and care...

Criticism of the quality of services was common, usually explained by lack of staff, low salaries, or poor funding of services. Existing day-care services were considered to be inappropriate by nearly all participants. Several participants said that services run with limited capacity and at times that leaves people without support when they need it the most. According to a person with high support needs who lives independently in a rented flat:

The problem is that the support service is officially open only on weekdays and only during office hours, like 8am to 4pm, and there is a service that is also open in the evenings and on weekends, but it has very little capacity. ... Service would be very much needed, 24 hours a day, 7 days a week. It would be much-much simpler, it would take much less energy to run my life. I wouldn't have to involve my personal social network, my friends, in maintaining personal support. This is a huge gap in the care system.

Benefits – including disability benefits, disability pensions, carers’ allowance, family support payments – were discussed by almost all participants. Most people acknowledged that these benefits provided some income, but nearly all references frame these as ‘not enough’, meaning they hardly cover the additional cost of disability and in the case of families, compensate for the income loss if a parent has to give up work. Application for these benefits is challenging, and bureaucratic procedures are time-consuming and difficult to manage.

Several interviewees stated that they lacked information about benefits or services available to them. Most participants relied on information they found online, others called local authorities, or received help from civil society organisations to navigate bureaucratic procedures. Due to lack of information, some participants may not have received all the services or benefits that they were entitled to.

5.2 Inappropriate Healthcare

Not getting appropriate healthcare is arguably one of the main barriers to independent living. In interviews, inappropriate healthcare was a recurring theme, and across the whole dataset this code was one of the most prevalent – at one point all disabled people (and their families) come into contact with healthcare providers and their experiences are very often negative. Not getting the needed medical care can adversely impact people’s long-term health and lead to additional impairment. The most common claim by participants was that health professionals are not prepared to accommodate the special needs of disabled patients. The account of a non-verbal, wheelchair using man with high support needs encapsulates many similar stories from other participants:

Once I had a serious health problem and had to have an operation on my lungs. It was scary to experience how tough I had to advocate for myself (in hospital)! Because of my condition, the protocols and procedures that doctors use don't work for me. They didn't know, they were unable to recognise this themselves. The basic needs arising from my condition were something I had to explain to them and when they challenged me, I had to prove to them I was right. For example, they wanted to do a lung scan while I was sedated but awake. Which is impossible for me because of my neurological damage.

A woman who is blind made a statement that demonstrates a similar problem – here, hospital staff displayed a total lack of understanding of visual impairments:

I had an operation on my hand last year ... and it was very strange that the hospital team didn't know what it means to be visually impaired. When I walked in with my white cane, they immediately asked me, is that a walking stick? And from then on it was all too strange. So when the nurses came to take me to operation, they told me to jump on the operating bed. I said, if I could see where it was, I'd be happy to jump on it.

Doctors’ and nurses’ approach to disabled people as patients was often criticised in accounts. Many participants talked about rude, often harsh or humiliating

comments received in clinics or hospitals, amounting to ‘shocking’ and ‘memorably terrible’ experiences.

Many people did not receive sufficient information about medical procedures or about their own condition. One man with a spinal-injury-related impairment said that he was not informed about the operation, nor about his condition:

And I actually did ask the doctor to tell me something about my condition, because I didn't know anything about it, what I had surgery for, or what was going to happen to me, or anything, anything ... and all he said was that we put screws into your spine, and now you're paralysed.

In the accounts, inappropriate healthcare was often related to understaffed hospitals and explained by low salaries in public healthcare. A parent of a child with multiple impairments who attended the same provider for many years said ‘we get much less now than, say 16 years ago, much fewer nurses, much busier doctors’. Three participants stated that they considered seeking self-funded medical care from private providers, because they found public services inappropriate. One autistic person was even told to ‘go to a private clinic because we cannot treat you here’.

Inaccessibility in healthcare also featured in interviews. For example, one person with limited mobility was unable to attend a general practitioner's office but the physician refused to visit them in their home. An autistic participant talked about not being able to cooperate with staff in a clinic due to sensory stimuli, but staff refused to acknowledge this need. A person who has hearing impairments did not get written information and was blamed for not hearing the information conveyed to her by nurses.

Most participants voiced a general mistrust in public healthcare. This mistrust, however, was somewhat moderated by satisfactory stories about specific professionals or hospital units that participants trusted. Trust was usually related to personal relationships with professionals.

5.3 Precarity and Exclusion from the Labour Market

Employment opportunities are fundamental to independent living, first and foremost because these provide individuals with an income beyond that which is available from social assistance. In addition, employment opportunities can provide relationships, structure to daily routines, and meaningful activities. Most participants lacked regular and stable income from employment and had to rely largely on other financial sources, mostly (inadequate) benefits. Participants shared numerous stories about not being able to find a job for long periods of time; losing jobs; being laid off without explanation; or finding only jobs that they found meaningless and/or badly paid.

We identified three typical patterns of precarity and exclusion from the labour market. The first group consists of people who have not found a job for many years. This is illustrated by this account from a man who has visual impairments:

I was going to the job centre regularly every month for at least a year and a half, but they would always only say 'hello, we have nothing for you' and then stamp [records to evidence attendance and job search].

The second group were people who had a job, but worked outside their profession and felt their job was below their skills and competences. One participant, who is deaf, had three different professional qualifications but only found a position unrelated to these, after a lengthy search. Another participant, a wheelchair-user, who has a university degree, said:

I have four qualifications. I've lived here for eight years and I've just got to the point where I'm paid a salary that's sort of commensurate with my qualifications.

The third pattern was about precarity and instability – having had numerous positions, often for a short period each time, which highlights the lack of job security. This was often the case for people with an intellectual disability.

Some people mentioned that personal networks helped them to find a job, and such references were sometimes made in the context of prejudice – in the words of an autistic man who lives with his family in a rural area: 'A friend of my father's knew the director of the company I'm working for now, and then I was called in to make sure I wasn't aggressive.' Similar accounts suggest that personal networks sometimes mitigate the adverse effects of labour market stigma. Notably, several participants who felt happy in their present jobs worked at DPOs or businesses/projects run by social entrepreneurs.

5.4 Lack of Accessibility and Assistive Technology

Accessibility is another key prerequisite to independent living – people need to have access to services, places, information, or events. Barrierfree cities and housing (Ratzka, 2015); accessible information for all; assistive technology to provide people with the opportunity to work, study, and travel – these are just some of the main components of accessibility. Most interviewees stated that they lacked accessibility or access to assistive devices.

Several participants, mostly people with physical or multiple impairments said they almost never used public transport because it was inaccessible to them, although many noted that in larger cities there are improvements. Accounts about difficulties on public transport were very common, such as this story by a person with limited mobility: 'I tried the bus twice, but it was so unhelpful ... I mean the bus driver. The bus driver was either not helping me at all or he didn't know how to get the ramp down.' An additional challenge is that some 'accessible' transport options have to be booked in advance, thus creating additional barriers to travel.

Accessibility also affects children. One participant, who uses a wheelchair, said he attended school without a lift, so 'the boys would grab my chair and take me to the next class'. Another person told us about not being able to make their own house accessible due to low funding by the state:

We considered getting a new house, or maybe just to remodel this one, but they (the state) give us 300,000 forints (~760 EUR) to make your house accessible, which is just ridiculous if you think about it ... it doesn't even cover costs for the bathroom.

Many participants heavily relied on assistive technology, including the use of wheelchairs and other assistive devices. However, participants who used these, often reported limited access and too little support to acquire special aids. For example, one man who is non-verbal only received his first assistive device (a communication board) in his teenage years after he left school – today, he uses such devices for everyday communication and work. Another man with high support needs received the first wheelchair of his own when he was 15 years old. Others reported not receiving good-quality devices, or having only limited access to them, such as this person with a physical impairment:

I wear orthopaedic shoes because I shuffle. They prescribe one pair a year. Think about it, if you wore one shoe a year. Summer, winter, autumn, spring, same thing, no slippers, no nothing, just that.

Various participants also talked about being ‘creative’, improvising, and ‘making do’ with whatever they had available, whether this is using mainstream devices as assistive technologies or finding ways to manage, like this example of a young woman with a physical impairment illustrates:

[When asked about how she can transfer from her wheelchair to a bath or the car:] We came up with this ourselves. It was trial and error until we found the right way. I try to look after my Mum because she’s not that young anymore.

5.5 Low Income and Housing Problems

Income is closely related to housing – not being able to cover costs of living, including rental costs, or not having the ability to moving to an appropriate and accessible dwelling, are serious barriers to independent living. Disabled people in Hungary often find themselves in the situation where they have lower-than-average income, but at the same time they encounter higher costs, for example due to having to use adapted transport or own a car, or having to pay for therapies privately, or purchase and service assistive devices. These create a financial barrier to independent living that featured in many interviews. Poverty and lack of housing opportunities were found to be contributing to institutionalisation, as demonstrated in this example, highlighted by a man with an intellectual disability:

[Interviewer:] So were you kicked out by your mum? Did you come here right away?

[Participant:] No. I lived with colleagues and friends for a couple of years.

[Interviewer:] Colleagues?

[Participant:] Yeah, yeah. Then I got a flat from the local authority in an area that I knew well. I was close to the market and the school. There were (people) living there, always beating me up. Then I told a friend to do something, because I wanted to get out of there. That’s how I got in here (the institution).

Several participants, including people with high support needs and autistic people, lived with their families, mostly due to lack of housing alternatives, and they also relied on their families’ financial support. Most participants stated that they – alone

or with their family – are doing ‘just okay’. Many told us about having had experienced periods of poverty in their lives. High costs of housing are reflected in the words of a woman with limited mobility:

It was in Budapest when I actually had periods of poverty, because I had to pay the rent there, which was very demanding financially. So, I moved to X (small town), and that changed here. Actually, it's a bit of a liberation, that we can now spend this money on ourselves.

Several participants who lived in institutions – mostly people with an intellectual disability – talked about limited housing options outside institutions. Those who lived in supported housing or rented apartments were very aware of the fact that, due to the lack of other options in the housing market, many disabled people must live with their families or move into a residential institution.

5.6 Restricted Decision-Making Opportunities

Independent living, as defined by its advocates, means the ability to exercise self-determination and have choice and control over one's life. In policy, decision-making is often framed around debates on legal guardianship and its alternatives (Gooding, 2017). In interviews, we asked all participants to tell us about who decides in matters of their lives. We found three typical patterns.

First, some parents said their disabled family members were under guardianship and they found it satisfactory. One parent said this was necessary because her (adult) daughter was ‘on the level of a child’ and she needed the legal protection guardianship could guarantee. Such carers' views were markedly different from disabled participants' own accounts.

The second type of answer came from those who were under guardianship. In our sample everyone under guardianship had an intellectual or multiple impairments. All participants who were under guardianship wanted to gain full legal capacity. One resident in a rural institution, a man with an intellectual disability, said: ‘I am under guardianship, but I was tricked into it. I do not trust my guardian.’ For a woman with an intellectual disability who lives in an NGO-run supported living, fighting for legal capacity was a long journey:

[Participant:] I was under guardianship for a while, yes. I recently brought it up with my sister, because she was the guardian, what she thinks about getting the guardianship taken off me. She felt a bit offended. (laughs) ... And finally, with a heavy heart, she agreed. She's a bit angry with me now, but I hope she'll see that it will work out really good.

[Interviewer:] Why did you want to be out of guardianship?

[Participant:] It was strange to me from the beginning that this (guardianship) was even suggested. That I would be under this guardianship thing. I was born free, lived free for a long time, until it was put on me. So when they put me under guardianship, it was painful. There was talk before that I might have to live with my sister. We'd build a house in the garden there, they'd have the upstairs and I'd have the downstairs, but life didn't work out that way. That's when guardianship came up. I was forced to accept it. And that's why, after all these years, I don't want to live my life until I die under guardianship.

The third pattern covered everyday decision-making – how someone is able to exercise control over their own life. Most participants who had physical or sensory disabilities stated that they were in control over their own decisions. However, for people with higher support needs, practical as well as attitudinal problems were considered. We talked with three people who had difficulties signing official papers due to limited hand mobility and this hindered their entering contracts. One of them, a man in his 30s, was not under guardianship, but his mother signed documents for him. Another person, a man without spoken communication, said:

Who on Earth would even think that I am able to manage my own things!! Almost unthinkable. Yet it is possible. I usually have problems in offices, because signatures are a problem. A real handicap ... because I cannot physically hold a pen and sign. It's difficult in a bank, in a government office, or even when signing for a property, where I need to make a number of signatures in a short period of time.

5.7 Prejudice and Stigma

Probably the most prevalent theme in our coding was prejudice and stigma, and this is also one of the main barriers to independent living in Hungary and elsewhere. This is an overarching barrier that is outside legally defined services, yet it is also present in most other barriers. Participants talked extensively about painful experiences of everyday prejudice and stigma. Many of these accounts were related to certain institutions such as schools or healthcare settings, others were more general and experienced in everyday interaction in the street, at the park, in shops, playgrounds, hotels, etc.

Prejudice is experienced at every stage of life by all disability groups. Emotional harm caused by stigma is long-standing – autistic children receive derogatory treatment in schools that they recall even 20 years later: ‘you will never become a normal person and find a job’. Adults with high support needs share that: ‘we are used to being stared at in the street, I do not care anymore, we do what we do’. Another example – family members avoid a disabled nephew with an intellectual disability ‘as if disability was contagious’. The story of a woman with an intellectual disability encapsulates the everyday prejudice of many of her peers:

[Participant:] There was a time when I went for an examination (to the clinic). An appointment ... I was waiting there, and they always rescheduled me. There were always, um, other people going in before me. They'd say, 'Well, that's ...

[Interviewer:] What did they say?

[Participant:] 'Half-human, this can wait'. It was painful to hear. I had to wait until the end of the day, because I already had my papers in the office. I was the last to go. My turn came at eight o'clock at night.

Everyday experiences of prejudice and stigma intersect with cases of discrimination in public or private services. This may contribute to sending children to segregated or home education, not getting the right medical treatment, or not being hired in jobs. The boundaries between ‘rudeness’ and hate speech may also be blurred. Years

of experiences of stigma can lead to isolation or mental health problems (e.g. Ditchman et al., 2013).

5.8 Facilitators of Independent Living

We also identified factors that mitigate or help people overcome barriers to independent living. Below, we briefly outline three such factors or facilitators that were identified as key from the interviews: support networks, civil society organisations (CSOs), and internet/mobile phones. Future articles will consider these in greater depth.

Many people mentioned relying on the everyday help of their informal support networks – in the absence of formal services or support arrangements, informal support networks help people to stay afloat and be able to manage their everyday lives. Examples included neighbours who help with shopping or help around the house; friends who act as informal personal assistants; or friends/relatives who offer their flats to live in for free. Such networks sometimes help participants to survive on low income or help them to find a job. Many participants also felt that they were finding a safe place within informal support networks, where adjustments are made (concerning communication or with regard to physical disability) and where stigma is not present.

CSOs may also act as facilitators. Several participants found work at or through civil society organisations, including but not limited to DPOs. CSOs are often a source of useful information, and sometimes give access to accommodation or services. Several people said that they met others (friends, partners, peers) via these organisations, and many of them received help or gained skills to advocate for themselves. Some participants even established a CSO to collect donations and support others.

Finally, most participants mentioned using the internet in the context of seeking or finding information, for example about education opportunities, jobs, benefits, legal help, and services. Many people keep contact with friends and peers through mobile phones, including those living in institutions. For many participants, using the internet was a main mode of connection with friends, family, and peers. Some disability groups (e.g. of people who are deaf or have visual impairments) receive crucial help through mobile and internet-based assistive technology. The relevance of being an active digital user has been boosted by the COVID-19 pandemic lockdown period.

6. Conclusions

Our findings show that disabled people still face numerous and often disabling barriers to independent living in Hungary. In these reflective accounts, human rights-inspired legal reforms, including CRPD-driven laws post-2008, seem to be making very little difference in the everyday problems people face in the community. While some of the barriers we presented relate to public services subject to financial investments (healthcare, social care, accessibility), or mechanisms of redistribution and the economy (income, employment), others (stigma and prejudice) are clearly outside these yet remain salient in personal narratives.

Temporality featured in our interviews: nearly all accounts were characterised by implicit references about barriers that have remained largely unchanged over the last decades. People who acknowledged better laws (or EU-funded projects) almost always talked about these as external observers who do not see many improvements in their own lives. Several participants made a distinction between laws and 'real life', because they do not see written laws improving their lived realities. Beyond minor positive changes (e.g. increased carers' allowance) and some perceived downward trends (e.g. worsening healthcare and education), participants talked about sometimes decades of experiences with a sense of permanence. Indeed, three decades of human rights-driven legal and policy changes in Hungary were largely unaccounted for by participants.

The seven barriers discussed above mutually reinforce each other. For example, unemployment or precarious jobs result in low income and mean that many disabled people are unable to seek private healthcare when public healthcare does not answer their needs; inaccessible public spaces, poor access to assistive devices, and prejudice contribute to isolation and make it even harder to find jobs or build support networks; being employed by and living in residential institutions restrict independent decision-making, because people are afraid to speak up for fear of losing their work and housing; being forced out of cities due to the cost of living restricts access to employment opportunities, especially in the absence of accessible transport options. The compound effect of the seven barriers constitutes an 'adverse environment'. This adverse environment is experienced by people through their limited mobility, poverty, lack of housing, inappropriate social support or medical care, or when they receive rude comments at services or in the street. The impact of the adverse environment – also observed by others (e.g. Drake, 1996) – is serious and exacerbates the singular effects of barriers; it often includes isolation, disempowerment, poor mental and physical health, negative identity (Shakespeare, 1996), and so on. In an adverse environment, self-organisation such as collective forms of disability advocacy and speaking up for the right to independent living may seem impossible (Shakespeare, 1996) or even futile.

People with intellectual disabilities and those with high support needs may be more vulnerable in this adverse environment. People with intellectual disabilities are overrepresented in institutions, and they are also the ones who are most likely to lose their legal capacity. A recent representative survey found that people with an intellectual disability (and autistic people) are less accepted by the Hungarian population than other disability groups (Bernát et al., 2022). Media analysis also highlighted that intellectual disability is the most under-represented in Hungarian media (Svastics et al., 2022). It may not be a coincidence that autistic people and people with an intellectual disability are also invisible in the Hungarian disability movement, lacking direct representation (Petri et al., 2017).

Our findings also contribute to the international literature on independent living. The way disabled people explained barriers in our study reminds us that independent living as a concept goes well beyond legal understandings. This may be an

explanation for the paradox mentioned earlier: many participants think that laws have not helped them. This problem is also conceptual. We recall that, from the beginnings of the disability movement, independent living emerged as a concept developed by disabled advocates (e.g. Oliver & Barnes, 2006; DeJong, 1979). It has always had various understandings and altered meanings over time and across cultural contexts – and its meaning is still changing today. The Hungarian example shows that independent living, when framed dominantly under an individualistic-liberal paradigm with a focus on particular legal matters, is not enough to bring about transformative changes. This argument is not new. Legalistic approaches to disability advocacy have been criticised by founders of the social model (Oliver & Barnes, 2006), and legal scholars have also observed that the human rights movement has failed to address significant inequalities (Moyn, 2018). Individualistic framings of citizenship, emphasis on personal responsibility, and welfare are deeply rooted in post-socialist, neoliberal societies (Mladenov, 2017). Perhaps more radical advocacy agendas targeting transformational changes, building strongly on social and economic rights, may be needed to achieve independent living.

In conclusion, our analysis of the personal narratives of disabled Hungarians suggests that the new, human rights-inspired laws – including the CRPD – and EU-funded infrastructure investments of the past decades have not achieved a transformative change towards independent living in Hungary. Their impact appears elusive in the everyday experiences of people. It also highlights the importance of fundamental transformations of wider systems and public policies such as social support, housing, health, education, employment, and social assistance to dismantle the adverse environment and create real opportunities for people to live independently.

NOTES

*1. Note on terminology: in this paper we used the term ‘people with intellectual disability’ because this English term is the closest to the Hungarian term ‘értelmi fogyatékosággal élő emberek’, preferred by self-advocacy groups in Hungary. We are not aware of a similar consensus among autistic people in Hungary. Thus, while we acknowledge that people on the autism spectrum have diverse preferences about terminology (Keating et al., 2022), we use consistently ‘autistic people’ in this paper – a term that is used by several autistic-led advocacy organisations internationally.

*2. Project reference number: NKFIH K 132293.

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