

THE HOUSING AND LIVING ARRANGEMENT SITUATION OF PEOPLE WITH DISABILITIES IN HUNGARY: REGIME CHARACTERISTICS AND INDIVIDUALIZED RISKS

ÁBEL CSATHÓ – ÁGNES KOZMA – GÁBOR PETRI¹

ABSTRACT: *Our study explores the living arrangements of people with disabilities based on life course interviews. Although the focus is mainly on present living arrangement issues and challenges, the research adopts a longitudinal perspective, highlighting the legacies from the state socialist period onwards. The study distinguishes three social policy regimes: state-socialist, liberal, and illiberal, which, on the one hand, had different ideas about disability, while on the other hand, applied housing arrangement policies. Results suggest that the living arrangements of people with disabilities depend on a number of aspects that our interviewees cannot control. Based on the interviews, we identified three key areas which play an especially important role in shaping the living arrangement opportunities of people with disabilities. These are the resources and motivations of the family of origin, the geographical location of the residence, and the institution managers, care workers, and roommates around them.*

KEYWORDS: *housing, living arrangement, people with disabilities, life course, deinstitutionalization, CRPD, risk society, Hungary*

¹ *Ábel Csathó* is Researcher at TÁRKI Social Research Institute, Budapest, Hungary; email address: csatho@tarki.hu. *Ágnes Kozma* is Senior Researcher at TÁRKI Social Research Institute, Budapest, Hungary; email address: agiturnpenny@gmail.com. *Gábor Petri* is Senior Researcher at TÁRKI Social Research Institute, Budapest, Hungary; email address: petri.gabor@gmail.com. This paper presents results on housing of the project *Marginalisation of people with disabilities: changing and new mechanisms* funded by the Hungarian National Research and Development Fund (K 132293).

INTRODUCTION

The lives and housing of people with disabilities are shaped by complex processes that cannot be separated from general social and economic processes and by the social policies of the regimes in power. Following Ferge (ed. 2017), the term “social policy” is used in a broader sense to refer to the set of policies that address social issues and the underlying system of principles and ideas in which inequalities in physical and social life chances play a prominent role. Our study explores the living arrangements of people with disabilities based on life-course interviews. Although the focus is mainly on current challenges and experiences, the research adopts a longitudinal perspective, highlighting legacies from the state-socialist period onwards. There are two reasons for this. First, some of our interviewees have direct experiences dating back to the 1980s. Second, the institutional system that developed during state socialism still impacts the quality of the care system today.

We can distinguish three social policy regimes from past decades with relatively clear boundaries between their visions of society: state-socialist, liberal, and illiberal. These have shaped the lives and living arrangements of people with disabilities in two directions. On the one hand, the different social visions that underlie social policies have had different perceptions of the purpose of human existence and the most basic rules of human coexistence. These have affected perceptions of disability/impairment and the position of people with disabilities in society. On the other hand, these regimes have had a different view of the relationship between the state and citizens and the state’s responsibility to ensure basic living conditions for the latter.

Housing systems and policies influence the living arrangements of people with disabilities on the one hand and the care system, including infrastructural elements embedded in the broader social policy framework, on the other. Housing policies and the care system interact with disabled people’s needs, support networks, and socio-economic situations to shape their living arrangements and housing alternatives.

This paper aims to identify the primary factors and mechanisms that shape the housing situation and living arrangements of people with disabilities in Hungary based on qualitative data from semi-structured interviews.

POLICY REGIMES SHAPING THE LIVING ARRANGEMENTS OF PEOPLE WITH DISABILITIES IN HUNGARY

The current situation and living conditions of people with disabilities have been shaped by three political systems and regimes in Hungary: the legacies of the *state socialist system* (before 1990), the *liberal² consensus* (between 1990 and 2010), and the current *illiberal work-based society* (for a detailed analysis of these regimes, see for instance Éber (2020), Scheiring (2020)). To understand the challenges people with disabilities face in terms of living arrangements and housing, it is worth briefly analyzing each regime's social policies, highlighting the key features of social care and housing policies.

Under the state-socialist system, paid employment was both a legal and a moral obligation, the basis for full citizenship and remaining within the purview of equality-oriented social policy (Ferge ed. 2017). This conception of society reduces citizens to a resource and their *raison d'être* to productive work, which can be described using the concept of productivism (Mladenov 2017). In productivist (policy) regimes, support for people with disabilities is acceptable only insofar as they have a medically proven inability to work. Therefore, the productivist approach goes hand in hand with the medical model of disability (ibid.).

This productivist-medical approach shaped policies for people with disabilities during the socialist period. A typical feature of this system is social care institutions. These institutions, usually located in rural areas, often house up to hundreds of people with needs and abilities and remain a key element of the current landscape of services for people with disabilities (Demeter 1998; Kozma et al. 2016; Kovács ed. 2018).

The liberal consensus refers to the period from the change of regime in 1990 until 2010, the election of the second Orbán government. This was characterized politically by the rules of liberal democracy and economically by the rules of neoliberalism (Mladenov 2017). The social policy associated with neoliberal, market-based economic policies emphasized individual responsibility (Lemke 2002) by keeping social spending low. Productivism was also present in this system but differently embedded in the idea of individual freedom, wherein the incentive is the compulsion to create consumption (Mladenov 2017).

² We deliberately do not refer to this period as neoliberal. The neoliberal economic policy consensus is part of this period, but the term is used too pejoratively, obscuring the positive changes that people with disabilities experienced in this period in the name of promoting the equality of human freedom.

Following the change of regime, non-governmental organizations that emerged from grassroots and voluntary organizations led by parents or disabled people themselves in the 1980s became more instrumental in providing housing and community-based services for people with disabilities across the country (Turnpenny 2019).

The liberal consensus also includes understanding individual liberty as a human right that extends equally to all. What exactly these human rights entail may be debatable, but this period of significant legislative reform in Hungary brought in new legislation in a number of areas impacting the situation of people with disabilities, such as education, accessibility, etc. During this time, Hungary joined the European Union. Also, it became a party to a series of European and international conventions, such as the *European Social Charter*, the *Revised European Social Charter*, and the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD). With the ratification of CRPD, the country committed itself to promoting independent living and *deinstitutionalization* (Mladenov–Petri 2020a), lobbied for persistently by organizations for people with disabilities since the 1970s (DeJong 1979). However, in Hungary, instead of deinstitutionalization, the operational objective shifted to the *replacement* of large institutions with smaller group homes and improving living conditions (Kozma et al. 2016; Mladenov–Petri 2020b).

The third era dates from the election of the second Orbán government in 2010, which has involved a clear break with the previous social policy consensus in many respects, although its precise nature is still contested and evolving. Using Viktor Orbán’s term, this system can be described as an “illiberal work-based society,” which he explicitly defined in opposition to welfare society (hvg.hu 2015).

The practical goal of this work-based society is to increase employment significantly. This goal not only meant full employment but even more than that: it meant bringing people who, for one reason or another, had not been there before, into/back into the labor market. The government sought full employment by extending the public works program, cutting social benefits, and/or linking the latter to employment. As a result, employment has increased, and re-employment has been achieved mainly among those retiring early and those previously receiving disability pensions.³ Significant changes in eligibility resulted in a substantial decrease in the number of people receiving disability-

³ How much of this was due to the government’s measures and how much to the economic upturn in Europe is debatable, but the fact remains that the number of employed persons has increased significantly: while in the third quarter of 2010, the Hungarian Central Statistical Office recorded 3 million 895 thousand persons in employment, in the fourth quarter of 2022 the figure was 4 million 703 thousand (KSH 2023b).

related benefits from 473,000 in 2011 to 268,000 in 2022 (KSH 2023a; see also Krekó–Scharle 2021).

The work-based society is thus also productivist. Although there is no legal obligation to work, the citizen remains, in principle, a full member of the state without employment, and the income gap between those in and out of work has widened massively (Gábos–Tomka 2022).

In this system, improving the situation of specific vulnerable groups, including people with disabilities, is no longer seen as a policy priority. With the *III. Act on Social Administration and Social Benefits* (Act 1993), amended in November 2022 (Amendment Proposal 2022), the state now formally places the responsibility for social care on families and relatives, then on municipalities, then on churches and NGOs, and only if these are not available takes its responsibility for its citizens. Meanwhile, there has been minimal progress in deinstitutionalization, and community-based services supporting independent living for disabled people remain limited (Kozma et al. 2020).

The three periods are also associated with particular housing policies and trends.

In the first period of state socialism, housing conditions improved significantly, especially in cities, thanks to extensive state control and support. On the one hand, a significant part of the housing stock was state-owned, made affordable by low rents and utility prices, and on the other hand, there was an extensive housing construction program (Misétics 2017). At the same time, the conditions for access to housing were unequally distributed and contributed greatly to the reproduction of social and spatial inequalities (Hegedüs–Tosics 1994; Ladányi–Szelényi 2005), leaving the rural population behind, reliant on self-building and subsidized credits, complemented by informal and reciprocal family and neighborhood practices, such as “kaláka”⁴ (Gagyí et al. 2019).

From the 1970s onwards, there was increasing financialization, which took various forms and had an indirect, later direct impact on domestic housing policy. Financialization is the process whereby capital (especially in times of crisis) is drawn away from productive processes towards financial markets and increasingly subordinates sectors (such as housing) to the logic of profit generation in financial markets (Epstein 2005; Gagyí et al. 2019). The path to housing was increasingly through private construction, cooperative construction, and the OTP (National Savings Bank), while the state, whose resources were tied up in repaying the Western loans, was becoming less and less involved as an investor in the housing sector (Gagyí et al. 2019).

4 “Kaláka” is a traditional form of community cooperative work based on returning favors.

The change of regime brought about the collapse of the previous housing benefit system. Housing subsidies as a share of GDP fell from 8.6% in 1989 to 1.8% in 1995 (Misetics 2017). In addition, although legally possible from the 1960s, housing privatization took off in the late 1980s, creating a domestic housing sector based largely on private ownership. From then on, home ownership has significantly impacted social and territorial inequalities in several ways (Hegedüs–Székely 2022). The 2008 crisis exacerbated the situation, as a very large part of the Hungarian population was indebted in foreign currency, mainly in Swiss francs. The sudden deterioration in the foreign exchange rate led to a massive increase in the housing loan burden for many families (Lentner 2015).

Under the illiberal system, the previous trends have continued in terms of access to housing, with the difference that the domestic credit market structure has become dominated more by domestic owners, and redistributive policies have increasingly benefited the upper social strata more easily able to access housing, even relying on their savings (Gagyí et al. 2019). The state (especially as the construction industry itself has become one of the most important areas of domestic capital formation) has contributed to supporting the housing market in several ways. On the one hand, it has implemented VAT reductions for the construction of new housing. On the other hand, it has made available larger housing subsidies and loans to families (typically at least lower middle-class families). In effect, housing policy became part of what Scheiring (2020) calls an accumulative state. This has further deepened inequalities since housing support programs and benefits are no longer available to the least affluent families due to strict eligibility criteria related to the characteristics of dwellings (e.g., minimum size, construction type, etc.) and applicants (e.g., two years of continuous social insurance status) (Elek–Szikra 2018).

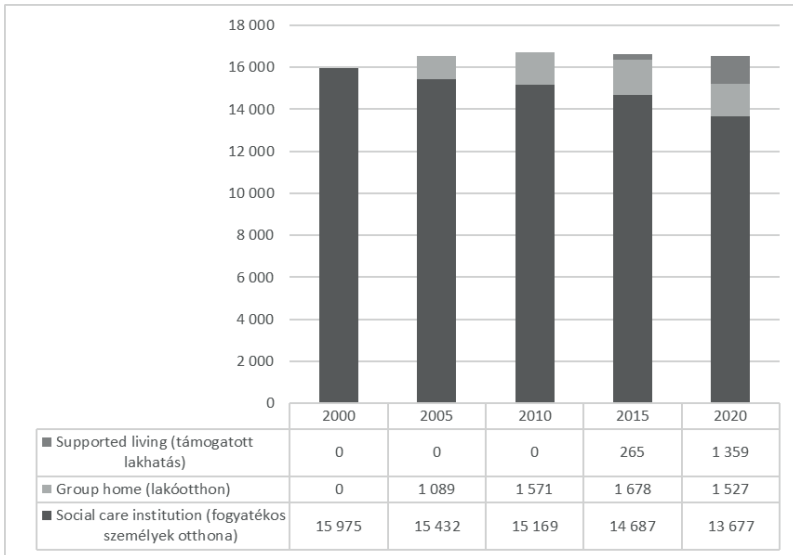
CURRENT SITUATION OF DISABLED PEOPLE IN HUNGARY

Disabled people are among the most disadvantaged groups in contemporary Hungarian society according to key socioeconomic indicators, including education, health, risk of poverty, and employment (Kozma et al. 2020).

According to the latest census data, 92% of disabled people live in private households, and 8% live in institutions, compared to just 2.4% of the total population. Apart from a small grant scheme for home adaptations, which is only available for people with physical disabilities, there is no targeted housing assistance for people with disabilities.

The conditions of the almost 40,000⁵ people with disabilities living in institutions have received more attention in the literature, thanks to the ratification of CRPD in 2007 and the EU-funded infrastructure investment program that replaced a small number of large institutions with smaller group homes and supported living (Andrácz-Tóth et al. 2011). By 2020, there were only 1,359 supported living places for people with disabilities, while the number of places in institutions remained largely the same (KSH 2021). It is important to note, however, that the figures shown here cover only a proportion of people with disabilities using residential social services since a large number of people with disabilities are accommodated in other types of institutions, such as care homes for older adults (Kozma et al. 2020). Supported living services were found to feature characteristics of residential institutions (UNCRPD 2020), highlighting the failure of the reform aimed at establishing new human-rights-compliant services.

Figure 1. Residential care available to people with disabilities in 2000, 2005, 2010, 2015 and 2020



Source: KSH (2021)

⁵ Source: 2011 census data: Table 1.7, available at https://www.ksh.hu/nepszamlalas/tablak_fogyatekossag.

A participatory research study on the experiences with living arrangements of people with physical disabilities found that the opportunities for disabled people to live independently in the community depend primarily on their families and informal support networks. Without these, it is almost impossible for them to achieve an independent life. It is rare for people with physical disabilities to access social housing, and according to participants, it requires a “huge amount of luck.” This often leads to a huge financial burden for those who rent a property on the open market, further complicated by the lack of accessible housing stock and support for adaptations. The study shows that even those who somehow can acquire their own house or flat face challenges with everyday living, particularly inadequate transportation, which represents a significant barrier (Kovács ed. 2018).

RESEARCH QUESTION

Our study focuses on the current experiences with living arrangements of people with disabilities. However, for two reasons, it is important to keep in mind the characteristics of the previous policy regimes described above. First, most people have experience not only with the care and housing policies of the current regime but also with previous ones. On the other hand, the three eras are in many ways different, although in some respects, they have always defined themselves in opposition to the previous ones. However, there is inevitably strong path dependence, both in terms of institutions and physical infrastructure, as well as attitudes.

In our research, therefore, we sought to answer the question of how ideas related to the role of the state and citizens during the three periods, the institutions and policies related to disability and housing, and the infrastructural elements of these influenced the living arrangement experiences of people with disabilities.

RESEARCH APPROACH AND METHODOLOGY

The study reported here used a qualitative method: life-course interviews with disabled people and/or their family carers enabled us to explore their lived experiences throughout the changing policy landscape. Life-course interviews allowed us to focus on the social barriers experienced by individuals in different life situations but also to capture the collective experiences of disabled citizens

in Hungary. Our approach has been designed to take into account the fluid nature of policies while respecting individual experience and interpretation. To understand how these policies manifest in the lives of people with disabilities, we conducted semi-structured interviews. In these interviews, we asked our interviewees about their life course, using prompts to explore experiences with major sub-systems such as education, healthcare, or housing. For a more detailed discussion of the approach, see Petri et al. (2023).

We used maximum variation sampling to capture the experiences of a diverse group of disabled people, including those living in rural areas, institutions, etc. Participant recruitment started in October 2021 through social media, the research team's personal networks, disabled people's organizations, and snowball sampling.

Each participant received an information leaflet and a consent form, and the voluntary nature of participation was explained to all participants. For people with intellectual disabilities, Easy Read material was used. Special adaptations were also made to the interviews based on individual needs and circumstances; for example, non-speaking participants were interviewed in writing using an assistive device. Interviews were audio-recorded and transcribed using an online transcription tool, and transcripts were checked by the interviewer. Some interviews could not be transcribed due to the participants' speech impairments; in these cases, detailed summaries were prepared and used in the analysis.

For our interview selection, we employed purposive sampling after thoroughly reviewing all transcripts and summaries. We prioritized interviews that yielded rich and diverse data, ensuring representation across disability types, genders, age groups, settlement types, and types of residence (private households and social homes). We selected 51 interviews for analysis, taking into account various socio-demographic factors. The characteristics of interview participants are summarized in Table 1.

Because we did not interview children (aged under 18) and people with severe intellectual impairment, there were also 19 family members in the sample. It is essential to exercise caution when interpreting information provided by family members; their perspectives may differ significantly from those of their disabled family members.

Nine of the 51 participants lived in a residential institution. Although our sample was diverse, for analytical purposes, we focused on identifying common barriers that emerged consistently across our data. We found that these barriers were perceived similarly by participants from various backgrounds and disability groups. In relevant sections, we also discuss issues that may disproportionately affect specific disability groups.

Table 1. Socio-demographic characteristics of interview participants

	Carers/family members (n=19)*	People with disabilities (n=32)
<i>Gender</i>		
Female	19	16
Male	–	16
<i>Age group</i>		
18–30	–	7
31–40	2	9
41–50	10	11
51–60	5	2
60+	1	3
No information	1	
<i>Employment status</i>		
Full time employment	8	7
Part time employment	8	12
Retired	1	–
Does not work	1	10
Caring for family	–	1
Studying	–	1
No information	1	1
<i>Level of education</i>		
High (ISCED 5–)	14	6
Middle (ISCED 3–4)	4	16
Low (ISCED –2)	–	10
No information	1	
<i>Type of disability</i>		
Autism	3	3
Hearing impairment	1	3
Intellectual disability	6	7
Physical disability	2	8
Visual impairment	1	6
Multiple disabilities	6	5

	Carers/family members (n=19)*	People with disabilities (n=32)
<i>Settlement</i>		
Capital	8	11
City	3	5
Town	6	8
Village	2	8
<i>Housing situation</i>		
Own apartment	18	17
Rented apartment/room	1	6
Social care institution	–	9

Source: Authors' compilation.

Note: *All categories refer to the characteristics of the carer/family member, apart from 'type of disability' which indicates the disability of the person they care for.

To analyze the interview transcripts, we employed a thematic analysis approach (Braun–Clarke 2012). Coding was carried out by the second and third authors, utilizing a mixed deductive-inductive approach. The research team predefined some themes, such as education, health, social care, and employment, while others were identified after reading/re-reading the interview transcripts. The analysis presented in this paper describes the analysis of interview segments (n=50) coded under “housing” and “institutions.”

FINDINGS

In the coding process, we identified three factors related to living arrangements that may influence the housing situation of people with disabilities (see Table 2). The first factor relates to the resources – material and social – of families. The second factor refers to the spatial inequalities associated with the housing system and living arrangements, particularly the availability of housing/services and the housing market. The third and final factor relates to people who shape the everyday experiences of people with disabilities in relation to their living arrangements, namely professionals, peers, and civil actors.

Table 2. *Housing and living-arrangement-related factors*

Family-related factors	Spatial factors	People-related factors
Supportive environment	Uneven spatial distribution of available living arrangement services	Management and social care staff
Available resources (financial, relational)	Possibility of municipal assistance	Roommates
Worries about the future	Market price inequality	Civil actors

In the following, we will present each factor in more detail, focusing on the subjective experiences of interviewees.

Family-related factors

Supportive environment

Families affect the living arrangements of people with disabilities in two ways. A great deal depends on the motivation and commitment of family members to ensure the best possible conditions for the family member with a disability. Many parents make a ‘superhuman’ effort to ensure their child has the best possible conditions. Most of the parent carers we interviewed spoke about the challenges of raising children/supporting adults with significant needs without adequate support from the state.

For 21 years, I knew exactly everything I had to do every step of the way. As I like to say, God has given her this condition; it is not her fault, but as long as I am her mother and I am alive, it is my job to make sure that she has everything. (51–60 years old, parent of an adult with intellectual disabilities, female)

However, faced with the challenges of raising a disabled child, some parents make the decision to give up their child by seeking out-of-home placement. This was particularly common during the state socialist period when many parents were even encouraged/advised by professionals. These children – now adults – have spent their whole lives in an institution, as illustrated by the story of one of the participants.

At birth, it was discovered that she had Down's syndrome; the doctor advised not to take her home because she would die anyway. The family decided to tell everyone that their daughter had been stillborn and not take her home. A sister was born nine months later, and later, another [child] who was unaware of her existence. [...] The mother, who is a teacher, never contacted her. The father phones her in the institution twice a year. (31–40 years old, summary of an interview with a person with an intellectual disability, female)

Sometimes, parents/families re-appear when their children reach adulthood and receive their child benefit payment.⁶ One participant spoke about how his parents financially exploited him, and as a result, he ended up in an institution for adults with intellectual disabilities.

[A] Then I did something really silly: I allowed my mum and dad to move in with me. Unfortunately, they got me into really big trouble. That's why I'm here now.

[...]

[Q] So they kicked you out of your apartment?

[A] I've been kicked out.

(51–60 year old male with intellectual disability, lives in an institution)

Finally, family relationships can break down, but for some people with disabilities, this can increase the risk of homelessness.

She was not deprived as a child; the first change came when she became pregnant at 20 and had to look for a flat with her future husband, who is also hearing impaired. They had no job or place to live; it seemed a hopeless situation. They moved to her grandmother's house, but her parents refused to support them. Although her parents had their own house extended for her, she could never move in. (41–50 years old, summary of an interview with a person with a hearing impairment, female)

⁶ Children who grow up in social care are entitled to receive their child benefit as a lump sum. For those who grew up in social care from birth, until recently this could have been a significant amount of money.

Available resources (financial, relational)

Alongside motivation and commitment, it does matter what resources are available to the family or the individual with disabilities.

Housing with care, such as supported living or a group home, can be prohibitively expensive, far beyond the means of the average Hungarian family:

[a deposit for a place in a group home] was five million forints. You have to pay five million forints just to get a place and then pay 200,000 forints a month just to have someone look at him twice a day and bring him food. That's not for us; that's not for my son. (41–50 years old, parent of a child with intellectual disability, female)

Those who can afford it often move to ensure that their child/adult can access better education or services:

And, in order for him to go to this school, we bought a small apartment in the city, so we divide our time between the city and our hometown. We have a family house in the countryside, with a garden, with everything. And we have a tiny apartment in the city, a one-and-a-half-room apartment. (41–50 years old, parent of a child with intellectual disability, female)

On the other hand, in addition to material resources, contacts can be very important. They can even replace material resources:

We started building the loft [in an intergenerational home] when I was pregnant, and we did not expect to have a child with disabilities. [...] We knew we didn't have the money to move. We were still paying the loan back then. And then we thought maybe we could install an external lift. But we thought that would be damn expensive, but then we found a friend of ours who builds industrial lifts, and he said he would do it. (41–50 years old, parent of a child with multiple disabilities, female)

Worries about the future

When resources are constrained, and support is not available, worries about future living arrangements are particularly strong for parents. The prospect of their death or frailty can hang like a sword of Damocles over the heads of many parents of people with disabilities. This is very difficult to resolve, both practically and emotionally, and the current housing/care system offers no support beyond institutional care.

What can you do? One thing the guardian will be able to do after I am gone is to find the right institutions for my daughter to be placed in.
(41–50 years old, parent of an autistic adult, female)

Spatial factors

Uneven spatial distribution of available social care and housing opportunities

In addition to family, another important factor is the geographical location of the residence. One problem is that the distribution of social care institutions and group homes is spatially unequal in terms of the number of places and the quality of institutions. Institutions for people with disabilities, especially larger ones, are still mainly located in rural areas in smaller settlements, as a legacy of the state socialist system, but many parents would like their child to live close to them:

I'm terrified of the mass institutions; looking at them, they are all in the middle of nowhere. In Budapest, there are no such institutions funded by the state. (31–40 years old, parent of a child with multiple disabilities, female)

Smaller homes, such as 'group homes' or supported living services often run by non-governmental organizations, are more popular among parents. They are often located in towns and cities, but capacity is extremely limited, and vacancies are rare, illustrating the huge amount of unmet need in the community:

We looked around in various homes across the country. We saw some very good and incredible places, but they only have eight places in

total. [...] (41–50 years old, parent of a child with multiple disabilities, female)

Well, the supply is so tight that we saw about two places in total where I would say we would leave our son, but one of them is not available [...] the manager said that the waiting list is like twenty years, which doesn't make any sense anyway, because obviously if you get in here, you're obviously going to spend your life here. So now you can calculate that if they are there at twenty or thirty years of age, and let's say seventy is the life expectancy unless something happens to them earlier [so] it's a surreal idea. (41–50 years old, parent of a child with multiple disabilities, female)

Possibility of municipal assistance

In some municipalities, municipal (social) housing may also be available for people with disabilities. However, even there, the supply is generally limited, and it is difficult to find a property that really meets the needs of people with disabilities for various reasons, including the lack of support to live independently.

Then, I got a social housing apartment in a place where I knew the area well. I was near the center. There were gypsies [sic!] living there; they were always beating me, hitting me. Then I told a friend to do something because I wanted to get out of there. That's how I got here [to the institution]. (51–60 years old, person with intellectual disability, male)

Market price inequality

Those who want to buy or rent somewhere are affected by market prices just like anyone else. However, people with disabilities are more likely to have low-income and insecure employment.

In Budapest, I actually had to go without food several times because I had to pay rent, which was financially very demanding. I moved to this town, and that's no longer the case. Actually, it's a bit of a liberation, and we can actually spend this money on ourselves, and it doesn't really

hurt your soul as much as if you just give it to someone else. (31–40 years old, person with physical disability, male)

People-related factors

The people around the person with a disability can also play a decisive role in how they experience their living arrangement/housing situation. An inadequate service manager, care worker, or difficult housemates are often framed as problems or supportive factors in interviewees' life stories. In the lives of several participants, the personal support of family and friends or problems caused by social care workers appear to be playing a key role in their housing situation.

Management and staff

For people who live in institutions, management and staff can shape their everyday lives in significant and multiple ways, even beyond the constraints of institutional living arrangements. Various participants spoke about the problems they had with staff and management.

At the end of the day, the biggest problem here is that they don't know about our problems, or if they do know about them, unfortunately, in many cases, they don't even try to solve them, but everything stays the same. (60+ years old, blind person, male)

With high turnover and staff shortages, the situation can change quickly, often in a negative direction:

Here, in the home for disabled children, the head nurse left. He had already been there for three years then, and there was never a complaint about him. Then the new head nurse arrived, and from then on, they kept saying that he was aggressive. [...] they're so exposed to these people and these children to these inappropriate care staff that it's very difficult. (41–50 years old, parent of a child with intellectual disability, female)

Roommates

Limited housing options to choose from make personal relationships even more important for many disabled people. Whereas most adults have at least some choice in deciding where and with whom they want to live, disabled people often have no choice and are forced to live with strangers, requiring them to adapt to situations they find difficult or challenging without adequate housing options and support.

[A] I had been moved to the group home, and the group home already had 12 beds. The situation hasn't changed. Upstairs there are three rooms, downstairs there are three rooms, all doubles. Well, my roommate, my roommates, they always changed from time to time.

[Q] And did you have any control over who your roommate was, or was that just assigned?

[A] I still don't have any control over that. [...] Because I wouldn't really choose to be with anyone. (41–50 years old, blind person, male)

I had to get used to things; for example, while I had flatmates who smoked, it bothered me a bit because I never smoked, the smoke bothers me. And then there was a tenant in that flat who had been there for a long time, and he was a bit of a pain, [...] he used to watch and listen to his videos and his video games in the big room at high volume, and it was not really easy to get along with him. (18–30 years old, autistic person, male)

Some interviewees recalled how they were forced to move multiple times during due to conflicts with roommates in institutions.

Civil actors

Several interviewees talked about how their desperate housing situation was solved by helpful friends or altruistic individuals they had met by chance. Some people were able to leave residential institutions with the help of friends. Often, interview participants attributed their situation to 'good luck' in the absence of a functioning support system:

And so, I had to find somewhere to live, and then I lived with my sister for a year, and let's say they live in a block of flats, and after that, we couldn't live together, there was talk of my sister finding me a flat, but it takes a while to find a good one. And then, my sister met this lady who set up a supported living service, and that's where I live now. [There are] about eight of us here; we are independent, but we have some helpers. They are very nice, they talk to us, they ask us how we are, what we need, what they can help us with. (41–50 years old, person with intellectual disability, female)

CONCLUSION

In our research, we sought to explore the living arrangements and housing options of people with disabilities in Hungary using life-course interviews. We also attempted to highlight how the legacies of the past and constraints of current systems/regimes shape their opportunities.

We found that the legacies of the different social policy regimes of the past decades have created a chaotic, narrow institutional system. The state-socialist system, which sought to create equality among those who worked, created large social care institutions far from society in smaller settlements. While during the era of liberal consensus, Hungary ratified a range of international conventions that should have guaranteed equal human and social rights for everyone, including people with disabilities, as for living arrangements, only smaller steps can be identified with the appearance of smaller group homes. While these typically provide better conditions for their residents than institutions, the supply of places is limited and out of reach for many people due to their high cost. Furthermore, even these homes do not offer the opportunity of what the UN CRPD refers to as “living independently and being included in the community.” The illiberal work-based regime after 2010 has created further hardship by eroding the social protection available for many families and adults with disabilities. Public – state or municipal – support for housing and support for disabled people is very limited and leaves most people with a choice between institutions or some form of private arrangement such as home ownership or private rental on the open housing market. This is especially problematic because it creates an extreme financial burden for people with disabilities, who have worse labor market positions on average and are more likely to live in poverty.

The almost complete withdrawal of the state from the rental housing market and the marketization of housing prices, together with the inherited chaotic and limited institutional system, means that independent living is not seen as a viable alternative for many people with disabilities except in cases when family members can significantly help (financial or otherwise). Moreover, those who cannot find a place in the housing market or in smaller group homes are forced to live in large institutions with hundreds of residents.

Such shortcomings in social policy are also filtered through personal experience. Almost all the life-course interviews reveal some form of this uncertainty and ad-hoc character. All in all, the living arrangements and housing situation of people with disabilities fit with Ulrich Beck's (2003) concept of *individualization of risk*. Our paper identifies three factors that mediate these risks, but further research could identify additional ones.

REFERENCES

- Act (1993) *Act III of 1993 on Social Administration and Social Benefits*. Available at: <https://net.jogtar.hu/jogszabaly?docid=99300003.tv> [Last access: 04 27 2023]
- Act (1998) *Act XXVI of 1998 on the Rights of Persons with Disabilities and Ensuring their Equal Opportunities*. Available at: <https://net.jogtar.hu/jogszabaly?docid=99800026.tv> [Last access: 04 27 2023]
- Act (2001) *12/2001. (I. 31.) Government Decree on State Aid for Housing*. Available at: <https://net.jogtar.hu/jogszabaly?docid=a0100012.kor#ljb102id2a7f> [Last access: 04 27 2023]
- Act (2007) *Act XCII of 2007 on the Proclamation of the Convention on the Rights of Persons with Disabilities and the Optional Protocol there to*. Available at: <https://net.jogtar.hu/jogszabaly?docid=a0700092.tv#ljb0id80d2> [Last access: 04 27 2023]
- Amendment Proposal (2022) Magyarország biztonságát szolgáló egyes törvények módosításáról. T/1620/13. [Amending certain laws for the security of Hungary. T/1620/13.]. Website of the Hungarian National Assembly: <https://www.parlament.hu/irom42/01620/01620-0013.pdf> [Last access: 04 27 2023]
- Andráczki-Tóth, V. –É. Bódy –Á. Csicsely –I. Nyitrai (2011) Az intézménytelenítés kapujában. A Pixelből kép válhat? [At the gate of deinstitutionalization. Pixels turn into a picture?]. *Esély*, No. 2011/4, pp. 35–57; Available at: http://www.esely.org/kiadvanyok/2011_4/01bandraczy.indd.pdf [Last access: 04 27 2023]

- Beck, U. (2003) *A kockázattársadalom. Út egymásik modernitásba [Risk Society: Towards a New Modernity]*. Budapest, Andorka Rudolf Társadalomtudományi Társaság and Századvég Kiadó
- Braun, V. – V. Clarke (2012) Thematic analysis. In: Cooper, H. – P. M. Camic – D. L. Long – et al. (ed.) *APA Handbook of Research Methods in Psychology. Vol. 2. Research Designs: Quantitative, Qualitative, Neuropsychological, and Biological*. Washington, American Psychological Association, pp. 57–71, DOI: <https://doi.org/10.1037/13620-004>
- DeJong, G. (1979) Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, Vol. 60, No. 10., pp. 435–446.
- Demeter, M. (1998) A tartós bentlakást biztosító állami (önkormányzati) fenntartású intézetek és a bennük élő értelmi fogyatékos felnőttek jellemzői – különös tekintettel az eddigi és a folyamatban lévő kitagolás! kezdeményezésekre [Characteristics of state (municipal) maintained institutions providing long-term residential care and adults with intellectual disabilities in them ...]. In: Zászkaliczky, P. (ed.): *A függőségtől az autonómiáig. [From Dependence to Autonomy]*. Budapest, Soros Foundation and Kézenfogva Alapítvány
- Gábos, A. – Zs. Tomka (2022) A minimumjövedelem-ellátások szintjének alakulása Európában 2009 és 2017 között [Trends in the level of minimum income benefits in Europe between 2009 and 2017]. In: Kolosi, T. – I. Gy. Tóth – I. Szelényi (eds.): *Társadalmi Riport, 2022 [Social Report, 2022]*. Budapest, Társi Social Research Institute, pp. 53–70.
- Gagyí Á. – Cs. Jelinek – Zs. Pósfai – A. Vígvári (2019) Lakhatási helyzet a válság után. Financializációs folyamatok, kettészakadó lakáspolitikák és a háztartások túlélési stratégiái [Housing situation after the crisis. Financialization, uneven housing policies, and households' survival strategies]. *Fordulat*, No. 26., pp. 199–224.
- Goodley, D. (2001) 'Learning difficulties,' the social model of disability and impairment: Challenging epistemologies. *Disability & Society*, Vol. 16, No. 2., pp. 207–231, DOI: <https://doi.org/10.1080/09687590120035816>
- Éber, M. Á. (2020) *A csepp. Afélperifériás magyar társadalom osztályszerkezete [The Drop – Structure of the Semi-Peripheral Hungarian Society]*. Budapest, Napvilág Kiadó
- Elder, G. H. (1994) Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly*, Vol. 57, No. 1., pp. 4–15, DOI: <https://doi.org/10.2307/2786971>

- Elder, G. H. (1998) The life course as developmental theory. *Child Development*, Vol. 69, No. 1., pp. 1–12, DOI: <https://doi.org/10.1111/j.1467-8624.1998.tb06128.x>
- Elek, Zs. – D. Szikra (2018) Fordított újraelosztás a lakáspolitikában: A CSOK versengő céljai. [Reverse redistribution in housing policy: The competing goals of the CSOK]. Website of *Új Egyenlőség*, <http://ujegyenloseg.hu/fordított-ujraelosztas-a-lakaspolitikaban-a-csok-versengo-celjai/> [Last access: 04 27 2023]
- Epstein, G. A. (2005) *Financialization and the World Economy*. Northampton, Edward Elgar
- Ferge, Zs. (ed. 2017) *Magyar társadalom- és szociálpolitika 1990–2015*. [Hungarian Society and Social Policy, 1990–2015]. Budapest, Osiris Kiadó
- Halvorsen, R. – B. Hvinden – J. B. Brown et al. (eds. 2018) *Understanding the Lived Experiences of Persons with Disabilities in Nine Countries: Active Citizenship and Disability in Europe*. Volume 2., London, Routledge
- Hamilton, C. – D. Atkinson (2009) ‘A Story to Tell.’ Learning from the life-stories of older people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, Vol. 37, No. 4., pp. 316–322, DOI: 10.1111/J.1468-3156.2009.00588.X
- hvg.hu (2015) Orbán: Hungary is not a welfare society. Website of *HVG*, June 21, 2015. https://hvg.hu/gazdasag/20150621_Hallgassa_meg_hogyan_beszelt_Orban_arrol_h [Last access: 04 27 2023]
- Hegedüs, J. – J. Székely (2022) Lakásárak, jövedelmek és területi egyenlőtlenségek [Housing prices, incomes and spatial inequalities]. In: Kolosi T. – I. Gy. Tóth – I. Szelényi (eds.): *Társadalmi Riport, 2022* [Social Report, 2022]. Budapest, Társadalmi Kutató Intézet, pp. 71–91.
- Hegedüs, J. – I. Tosics (1994) A kelet-európai lakásmodell felbomlása Magyarországon (1950–1989) [The disintegration of the Eastern European housing model in Hungary, 1950–1989]. In: Kemény, I. – L. Gábor (eds.): *XXX. 1963-ban alakult meg a Szociológiai Kutatócsoport*. [XXX. In 1963 the Sociology Research Group Was Set Up]. Budapest, Institute of Sociological Research and Centre for the Study of Social Conflicts, Hungarian Academy of Sciences, pp. 125–142.
- Krekó, J. – Á. Scharle (2021) Changes in disability benefits and their impacts. In: Fazekas, K. – P. Elek – T. Hajdu (eds.): *The Hungarian Labour Market 2020. The Hungarian Labour Market Yearbooks*. Budapest, Centre for Economic and Regional Studies Institute of Economics, Chapter 7.2., pp. 179–189, Available at: http://real.mtak.hu/138759/1/hlm2020_infocus7_2.pdf [Last access: 06 23 2023]

- KSH (2015) *2011. évi Népszámlálás. 17. A fogyatékossgal élők helyzete és szociális ellátásuk [2011 Census. Vol. 17. Situation of People with Disabilities and Their Social Care]*. Budapest, Hungarian Central Statistical Office. Available at: https://www.ksh.hu/docs/hun/xftp/idoszaki/nepsz2011/nepsz_17_2011.pdf [Last access: 04 27 2023]
- KSH (2021) *Szociális Statisztikai Évkönyv, 2020 / Yearbook of Welfare Statistics, 2020*. Bilingual edition. Budapest, Hungarian Central Statistical Office. Available at: https://www.ksh.hu/docs/hun/xftp/idoszaki/evkonyv/szocialis_evkonyv_2020.pdf [Last access: 04 27 2023]
- KSH (2023a) STADAT 25.1.1.34. Nyugdíjban, ellátásban, járadékban és egyéb járandóságban részesülők száma és teljes ellátásának havi átlagösszege, január* [Number of persons in receipt of pensions, benefits, annuities and other allowances and average monthly amount of total benefits]. Website of the Hungarian Central Statistical Office: https://www.ksh.hu/stadat_files/szo/hu/szo0034.html [Last access: 04 27 2023]
- KSH (2023b) STADAT 20.2.2.3. A foglalkoztatottak száma, vármegye és régió szerint, negyedévente (ezer fő)* [Number of persons employed, by county and region, by quarter, thousands]. Website of the Hungarian Central Statistical Office: https://www.ksh.hu/stadat_files/mun/hu/mun0163.html [Last access: 04 27 2023]
- KSH (2023c) STADAT 1.1.1.2. A fogyasztóiár-index fogyasztási főcsoportok szerint, a nyugdíjas fogyasztóiár-index és a maginfláció (előző év = 100,0%) [Consumer price index by main consumption groups, pensioner consumer price index and core inflation, previous year = 100]. Website of the Hungarian Central Statistical Office: https://www.ksh.hu/stadat_files/ara/hu/ara0002.html [Last access: 04 27 2023]
- Kovács, V. (ed. 2018) *Önállóan lakni – közösségben élni [Living Independently – Living in Community]*. Research report. Budapest, School of Public Life Foundation
- Kozma, Á. – G. Petri – A. Bernát (2020) Kiszolgáltatottság és stagnálás: fogyatékos emberek társadalmi helyzete a 2010-es években [Vulnerability and stagnation: The social situation of people with disabilities in the 2010s]. In: Kolosi T. – I. Gy. Tóth – I. Szelényi (eds.): *Társadalmi Riport, 2020 [Social Report, 2020]*. Budapest, Társadalmi Kutató Intézet, pp. 381–404.
- Kozma, Á. – G. Petri – A. Balogh – M. Birta (2016) *Az Európai Unió támogatásainak a szerepe az intézménytelenítésben és a férőhelykiváltás eddigi tapasztalatai [The role of EU funding in deinstitutionalization (DI) in Hungary and the experiences of the DI programme so far]*. Budapest, TASZ. Available at: https://www.researchgate.net/publication/320757629_

- Az_Europai_Unio_tamogatasainak_a_szerepe_az_intezmenytelenitesben_es_a_ferohelykivaltas_eddigi_tapasztalatai
- Ladányi, J. – I. Szelényi (2005) Szuburbanizáció és gettósodás [Suburbanization and ghettoization]. In: Ladányi, J. (ed.): *Szociális és etnikai konfliktusok. Tanulmányok a piacgazdasági átmenet időszakából (1987–2005)* [Social and Ethnic Conflicts. Studies from the Period of Transition to a Market Economy (1987–2005)]. Budapest, Új Mandátum, pp. 155–176.
- Lemke, T. (2002) Foucault, governmentality, and critique. *Rethinking Marxism*, Vol. 14, No. 3., pp. 49–64, DOI: 10.1080/089356902101242288
- Lentner, Cs. (2015) A lakossági devizahitelezés kialakulásának és konszolidációjának rendszertani vázlata [A taxonomic sketch of the emergence and consolidation of foreign currency lending to households]. *Pénzügyi Szemle*, No. 2015/3., pp. 305–318.
- Misetics, B. (2017) Lakáspolitikai és hajléktalanság [Housing policy and homelessness]. In: Ferge, Zs. (ed.): *Magyar társadalom- és szociálpolitika, 1990–2015* [Hungarian Society and Social Policy, 1990–2015]. Budapest, Osiris Kiadó, pp. 338–363.
- Mladenov, T. (2017) *Disability and Postsocialism*. London, Routledge, DOI: <https://doi.org/10.4324/9781315306834>
- Mladenov, T. – G. Petri (2020a) Independent living in Central and Eastern Europe? The challenges of post-socialist deinstitutionalization. In: Fylling, I. – E-L. Baciú – J. P. Breimo (eds.): *EU Social Inclusion Policies in Post-Socialist Countries. Top-Down and Bottom-Up Perspectives on Implementation*. London, Routledge, Chapter 2, pp. 15–34, DOI: <https://doi.org/10.4324/9780429434549>
- Mladenov, T. – G. Petri (2020b) Critique of deinstitutionalisation in postsocialist Central and Eastern Europe. *Disability & Society*, Vol. 35, No. 8., pp. 1203–1226, DOI: <https://doi.org/10.1080/09687599.2019.1680341>
- Palmisano, G. (2017) Article 19 [Living independently and being included in the community]. In: Della Fina, V. – R. Cera – G. Palmisano (eds.): *The United Nations Convention on the Rights of Persons with Disabilities*. Cham: Springer, pp. 353–373, DOI: https://doi.org/10.1007/978-3-319-43790-3_23
- Petri, G. – Á. Turnpeny – A. Bernát (2023) When legislation is not enough: The adverse environment for independent living in Hungary. *The International Journal of Disability and Social Justice*, Vol. 3, No. 1., pp. 42–59, DOI: 10.13169/intljofdissocjus.3.1.0042
- Scheiring, G. (2020) *The Retreat of Liberal Democracy: Authoritarian Capitalism and the Accumulative State in Hungary*. New York, Palgrave Macmillan, DOI: <https://doi.org/10.1007/978-3-030-48752-2>

- Turnpenny, Á. (2019) People with intellectual disabilities in the European semi-periphery: The case of Hungary. In: Walmsley, J. – S. Jarrett (eds.): *Intellectual Disability in the Twentieth Century: Transnational Perspectives on People, Policy, and Practice*. Bristol (UK), Bristol University Press, pp. 113–128, DOI: <https://doi.org/10.2307/j.ctvh9wl8w.11>
- UNCRPD (2020) *Inquiry concerning Hungary under article 6 of the Optional Protocol to the Convention – Report from the Committee*. United Nations Convention on the Rights of Persons with Disabilities, Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeCategoryID=7 [Last access: 09 27 2023]

