



# Lived experience of societal transformation and policy change across the life course

## Experiences of disabled people and their families in Hungary

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# Before 1990

- Disabled people were invisible in society and social policy
- “Full employment”
- From the 1970s: some expansion of residential institutions, day centres, and special schools
- Self-organisation of disabled people limited; non-existent until the 1980s, some activism from the 1980s

# Early reform period of the 1990s

- Economic and social crises, neoliberalisation and administrative reforms.
- New social policy (Act 3 of 1993):
  - Social care services were unchanged
  - Delegation of tasks to municipalities without resources
- Emerging civil society: new role as service providers
- Some progressive legal reforms: disability rights legislation in 1998
- Reforms in other areas: education

# Post-2004

- Access to EU Structural Funds
- Unprecedented investment in social infrastructure and other programmes/services – “deinstitutionalisation programme”, employment services
- Cutbacks elsewhere: reform of disability pensions in 2008 and 2012
- Progressive legislation – ratification of the UN CRPD and legal reforms

# In summary: characteristics of disability policy

- Failure to develop robust and needs-based social policy to support disabled people
- Maldistribution of resources (Mladenov & Petri, 2020)
- Influenced by international human rights legislation: individualistic approaches rather than structural & re-distributive reforms
- Administrative and statistical data show clear contradiction between rhetoric and implementation

# Aims

- To explore disabled people's experiences of independent living in the context of legislative, policy and broader societal changes and persistent mechanisms of social exclusion in Hungary over the last decades.
- To give voice to disabled people's expertise and illuminate how they (re-)negotiate their place in society in the context of volatile policy-changes (Hartblay, 2020).

# Methods

- 92 life-course interviews with disabled people and family members, 53 selected for current analysis (34 disabled persons & 19 family members)
- Maximum variation sampling
- Recruitment through personal networks and organisations
- Disabled peer interviewers: training and support
- Interviews between November 2021 and February 2022
- Impact of the Covid-19 pandemic: most interviews online but a large proportion face to face
- Accessibility: adjustments to individual communication needs
- Interviews were transcribed (using AI but checked for accuracy) and detailed summaries were written
- Thematic analysis (Nvivo): barriers to independent living and how these are shaped by social policies





# Findings

# Barriers to independent living

- Inadequate social support
- Inadequate health care
- Precarity and exclusion from the labour market
- Lack of accessibility and assistive technology
- Inadequate housing
- Restricted decision-making opportunities
- Prejudice and stigma

# Inadequate social support

## Predominantly negative experiences with services:

- lack of services
- services not responsive to individual's needs
- poor quality

## Benefits and allowances

- For many, the only source of income, even though very low
- Older generation impacted negatively by disability pension reform
- Acknowledged by participants that benefits “help”, particularly the recent increase of carers' allowance for parent carers
- Does not compensate for loss of income or protect from poverty
- Lack of information about entitlements and how to claim certain benefits

*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. (Physically disabled adult)*

*...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! (Sister of a person with intellectual disabilities)*

# Precarity and exclusion from the labour market

- Many people could not find jobs, even though they were actively looking
- Underemployment, particularly physically disabled people
- Evidence of discrimination and negative attitudes by employers
- Those who find work, often through special employment programmes or sheltered employment
- Insecure labour market position (especially people with intellectual disabilities) and low pay

*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. [Blind man]*

*A friend of my father knew the director of the company I'm working for now, and then I was called in to make sure I wasn't aggressive. [Autistic man]*

# Accessibility and assistive technology

- Inaccessible transport, although some progress in larger cities and Budapest
- Difficulties of getting the specialist devices or equipment
- Making do and being creative
- Use of mainstream technologies – internet and smart phones

*I wear orthopaedic shoes because of the way I walk. 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.  
[Physically disabled man]*

*[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. [Physically disabled woman]*



# Conclusions: how decades of policy change feature in people's lived experiences?

- Limited evidence of tangible impact, perceived barriers remained largely unchanged
- Some people acknowledged “better laws” and “EU projects” but this did not translate into positive change in everyday lives
- Many people explicitly acknowledge the gap between policy and implementation
- Observations on the impact of broader socio-economic changes: continued marginalisation and precarity
- Narratives of progress and change: technological transformation
- Limitations of the research

Thank you!

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