My Home, My Choice in Hungary The right to community living for people with mental disabilities in 2014



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Introduction

Since the democratic changes in 1989, many political, legal, economic and social changes have taken place in Hungary, a process which has increased at pace since the country joined the European Union in 2004. There has been no significant change, however, in the number of people with mental disabilities¹ segregated in institutions, despite Hungary's formal commitment to address this situation in 2007 when the government ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).

Mass institutionalisation in large and rural institutions continues to be the predominant form of care and service delivery for people with mental health issues, and people with intellectual disabilities. The result is that large numbers of people in Hungary with mental disabilities are segregated from society, stripped of the most basic rights to decide how to live their lives and are at risk of a higher incidence of violence and abuse.² Freedom is restricted through guardianship which removes people's rights to make legally valid and enforceable decisions about their lives. As a result, their views of people with mental disabilities about where and with whom to live are ignored, as are decisions about when to get up, what to eat for breakfast, when to go out or what form of care or services they wish to use.

A human rights approach requires something different. Instead of placing people with disabilities in institutions, governments must instead take practical steps to include people in our – in their – societies. The right to live in the community is not a policy nicety: it is a human right. The Hungarian government is obliged to provide services to enable people with disabilities to live in the community following ratification of the CRPD.

Even before the CRPD existed, the Hungarian government voluntarily committed itself to moving people with disabilities out of institutions and into the community through adoption of Act XXVI of 1998 on the Rights and Equal Opportunities of Persons with Disabilities. At that time, the government set 1 January 2010 as the deadline for completing the process.³ Later, the government modified the deadline to 31 December 2013. Yet despite these formal commitments, little action has been taken.⁴

In 2011, the government adopted a deinstitutionalisation strategy introducing various forms of 'protected housing', ostensibly with the purpose of showing progress in the area of community living. The strategy has yet to deliver any significant progress. Only a small number of people have moved out of large institutions into smaller 'group homes' or 'living centres'. Even these new models continue to reflect an institutional model of congregate housing as opposed to real inclusion in the community. The small number of people who have been moved into 'protected housing' are still denied the right to choose who they live with, instead being lumped together in albeit more aesthetically pleasing mini-institutions.

The lack of political will is perceptible. At present, the Hungarian government is failing to take concrete steps to implement the right to community living for the vast majority of Hungarians with mental disabilities. The level of investment into community-based services, which are vital in securing inclusion, is actually decreasing each year, whilst large sums continue to be invested in institutions. Unfortunately the Hungarian government has even chosen to spend European Union funding on maintaining institutions, rather than developing community-based services.

Prejudice and discrimination against people with mental disabilities are widespread, with stereotypes and misconceptions being deeply rooted in popular consciousness – a situation that was vividly illustrated during the deinstitutionalisation tender process. Residents of Bélapátfalva and Szilvásvárad towns publicly expressed their

¹ We use the term 'people with mental disabilities' to refer to people with intellectual disabilities and people with mental health issues. For a more detailed description, please see *Glossary*.

² Manfred Nowak, Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, 28 July 2008, para. 38.

³ In this Act the government sets out a gradual transformation of institutions providing permanent residence for persons with disabilities by 1 January 2010. Later, the government had to modify this deadline to 31 December 2013.

⁴ Zsolt Bugarszki, Orsolya Eszik and Zsuzsanna Kondor, *Deinstitutionalisation in Hungary*, 2012-2013 (Budapest: 2013), 7.

repugnance against accepting people with intellectual disabilities as their neighbours.⁵ A vicious cycle of discrimination feeds an 'out of sight, out of mind' approach to people with mental disabilities, an approach which requires urgent change.

This briefing focuses on what the Hungarian government should have done, and still must do. It focuses on Article 19 of the CRPD, the provision which sets out the right to independent living in the community for everyone with disabilities, including people with intellectual disabilities and people with mental health issues. The briefing analyses Hungary's compliance through the lens of indicators drawn from Article 19 of the CRPD.

The intention of the briefing is to provide civil society with evidence of the gap between what the government should be doing, and the lived reality of people with mental disabilities in Hungary. On nearly every indicator the government has so far failed to take adequate or sufficient steps to guarantee the inclusion of people with mental disabilities in their communities. It is hoped that the present analysis serves as a useful basis for monitoring progress, and holding the Hungarian government to account for its obligations towards people with mental disabilities in the country.

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⁵ Oliver Lewis, 'Rancid community reactions should spur action on community living', Mental Disability Advocacy Center (Budapest: 2014) available online at: http://www.mdac.org/en/EDblog/2014/02/03/rancid-community-reactions-should-spur-action-community-living (last accessed: 23 September 2014).

Recommendations to the Hungarian government

A. Community living and choice

- 1. Adopt an immediate moratorium on new admissions to social care institutions in order to stop filling up vacancies. 'Instead find alternatives for each person on the waiting list.
- 2. Amend the Civil Code and the Act on Supported Decision Making to abolish guardianship and introduce real forms of supported decision-making based on relationships of trust and the will and preferences of people who receive such support.
- 3. Set a clear timetable with a maximum time period of five years for the development of comprehensive and accessible community-based services to ensure that people with mental disabilities can live independently in the community. This should include a focus on providing assistance to families and carers.
- 4. The deinstitutionalisation of institutions for children with disabilities should be made a priority.
- 5. Coordinate national and regional action on deinstitutionalisation and the abolition of guardianship through the designated Article 33(1) government focal point, and publish annual reports on progress made.
- 6. Abandon plans which use Hungarian and EU financing to renovate existing institutions, or to build new ones. Instead use available funding to develop individualised community-based support services to the maximum extent possible.

B. Access to individualised support services

- 1. Ensure that people with mental disabilities have equal access to a range of individualised services, including in-home support and assistance, and community mental health teams, which are in reach of all people with mental disabilities across Hungary. This should inform national budgetary priorities, moving resources from institutions to the development of individualised support services.
- 2. Ensure that all people with mental disabilities and their families can access specialised support and funding, where necessary, to purchase professional, individualised support where such services are not provided by government.

C. Access to mainstream services

- 1. Conduct accessibility assessments of mainstream public services (including schools, healthcare and employment support) with a specific view to identifying barriers for people with mental disabilities. The assessments should inform budgeted plans for reform which should be published.
- 2. Develop, pilot and implement a national 'access to work' scheme specifically for people with mental disabilities, in collaboration with civil society and industry leaders. The focus should be on providing access to the mainstream employment market, rather than the provision of sheltered work. Explore regulation and funding for the provision of reasonable accommodations in the workplace.
- 3. Develop a clear strategy on advancing the right to inclusive education for children with mental disabilities, including the closure of special and residential schools. A specific budget should be established to guarantee the provision of reasonable accommodations for all children with mental disabilities to access mainstream schools.

D. Transition from institutions to the community

- 1. The current deinstitutionalisation strategy should urgently be amended to bring it into conformity with the letter and spirit of Article 19, CRPD. The current 30-year timespan should be reduced to five years. The strategy should be amended to include children with mental disabilities and people with mental health issues. The new strategy should incorporate quantitative and qualitative indicators broken down into annual action plans.
- 2. The new strategy should contain a detailed analysis of the way in which government funding is currently spent on disability-based services (including institutions), and reallocate future funds away from financing

- institutions and towards funding community-based services. Annual reports should be made public on the way in which public finances are being spent.
- 3. Develop individualised transition plans for all people with mental disabilities currently living in institutions. The plans must be clearly and explicitly based on the will and preferences of the person concerned. These plans should provide genuine options for living in the community, including in private or family accommodation, identify individualised supports required (and how they will be provided), and should have clear timeframes.

E. Access to justice, monitoring and public awareness

- 1. Establish a legal right for people with disabilities to live independently in the community.
- 2. Ensure that effective and independent complaints mechanisms are made directly available to people with mental disabilities where their right to independent living in the community has been breached. This includes complaints about the failure to provide individualised services or community-living options, and failure to make mainstream services accessible.
- 3. Ensure that legal remedies are available directly to people with mental disabilities where independent complaints mechanisms have failed. The initiation of legal proceedings must never be determined by guardians or other substitute decision-makers.
- 4. Collect comprehensive disaggregated data including statistical and research data to ensure evidence-based policy and action by government authorities in advancing independent living in the community. The data collected should comply with the requirements of Article 31 of the CRPD and should be published on an annual basis, and identify:
 - a. Numbers of people with mental disabilities, including people with intellectual disabilities, people with mental health issues (psycho-social disabilities), age and gender breakdowns, etc.;
 - b. The numbers and types of accommodation they live in (institutional and community-based);
 - c. Full list of institutions, their size and capacity, breakdown of funding (including funding sources), admissions, and lengths of admissions and discharges;
 - d. The types of individualised services available, their geographical scope, funding, and how many people access them; and
 - e. Analysis of the numbers of people with mental disabilities who access mainstream services (including education, healthcare and employment assistance), and analysis of the funding of reasonable accommodations.
- 5. Implement a strategy to raise public awareness about the human rights of people with mental disabilities in conformity with Article 8, CRPD. The strategy must be clear on the concrete steps the government is going to take to reduce stigma and combat discrimination.
- 6. Crime statistics should be reported annually on the prevalence of hate crime against people with disabilities, the investigation of allegations and their disposal.

Scorecard

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) guarantees the right of all persons with disabilities to live independently in the community. In turning this right into reality, Article 19 requires government to take action in four key areas:

- 1. To recognise and give real effect to the choices of people with disabilities about where and with whom they choose to live;
- 2. To ensure access to individualised support services for people with disabilities;
- 3. To ensure that mainstream services are accessible to people with disabilities;
- 4. To take concrete actions to close institutions which segregate people with disabilities.

The following table sets out four clusters of indicators which reflect these obligations.⁶ Each indicator breaks down different elements to the right to community living, followed by a 'measure' in the form of a question. A conclusion for each indicator is provided, based on all the information made available. Indicators shaded red show that insufficient steps have been taken; those shaded orange show that there have been some promising steps but that more effort is required; green rows show that substantial and comprehensive action has been taken. More detailed explanations are provided for each indicator in the sections which follow.

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⁶ The indicators have been drawn from: Commissioner for Human Rights of the Council of Europe, "The right of people with disabilities to live independently and be included in the community", 12 March 2012, CommDH/IssuePaper(2012)3, available at https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/com.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/coe.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/coe.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/coe.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.int/coe.instranetImage=2397433&SecMode=1&DocId=2076280&Usage=2">https://wcd.coe.instranetImage=2397433&SecMode=1&DocId

Cluster One: Community living and choice

The indicators in this cluster reflect the requirements of Article 19(a) of the CRPD which states:

Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

No.	Indicator	Measure	Conclusion
1 (A)	People with mental disabilities are not required	How many people with mental disabilities live	More than 25,000 people with disabilities live
	to live in institutions.	in institutions?	in institutions. The number of people required
			to live in institutions has not changed in the
			last decade.
1 (B)	People with mental disabilities must get access	What housing options are available to people	
	to the same housing options that are available	with mental disabilities?	institutionalisation continues to remain the
	to the general population.		main form of housing made available.
1 (C)	There should be a moratorium on new	Are there limits or a moratorium on new	No, there is no limit on new admissions to
- (5)	admissions to social care institutions.	admissions to institutions?	Hungary's numerous residential institutions.
1 (D)	The choices of people with mental disabilities	Does the law respect the choices of people	People under full or partial guardianship are
	about where and with whom they live are	with disabilities about where and with whom	denied the right to decide about where or with
- 4-1	recognised and validated by the law.	they live and which services they receive?	whom they live.
1 (E)	The law recognises the right of people with	Can people with mental disabilities enter into	People under guardianship cannot enter into
	mental disabilities to enter contracts for	contracts and agreements for disability-related	contracts.
	accommodation and the use of social	supports, credit agreements to purchase	
1 (=)	services.	housing, rental or other housing agreements?	
1 (F)	People with mental disabilities can access	Do people with disabilities have access to	No. 'Supported decision-making' under
	support to choose where and with whom they	support to enable them to make decisions	Hungarian law is at odds with the
	live.	about where and with whom to live or what	requirements of Article 12 CRPD, as there is
		support services to access?	no requirement for it to be based on the will
1(C)	People with mental disabilities can challenge	Can poople with mental disabilities access	and preferences of the person 'supported'. No, there are no mechanisms available to
1 (G)	decisions made by others about where and	Can people with mental disabilities access effective mechanisms if they want to complain	people with mental disabilities to challenge a
	<u>'</u>	about their right to live in the community?	, ,
	with whom they live.	about men right to live in the community?	denial of their right to live in the community.

Cluster Two: Access to individualised support services

The indicators in this cluster reflect the requirements of Article 19(b) of the CRPD which states:

Persons with disabilities have access to a range of in-home, residential and other support services, including personal assistance where necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

No.	Indicator	Measure	Conclusion
2(A)	People with mental disabilities have a personal budget enabling them to choose the support they need.	Are personal budgets available which enable people with mental disabilities to choose the appropriate support they need to live in the community?	No, people with disabilities are not provided with personal budgets.
2(B)	Personal assistance is provided to people with mental disabilities to support them to live in the community.	Is personal assistance available to support people with mental disabilities to remain and live in the community?	Personal assistance is available to some people with mental disabilities, but only to a very limited degree.
2(C)	People with mental disabilities receive support to access funding or specialised support services.	Is assistance available to people with mental disabilities to access funding or other support services?	No. Mainstream family support services exist but these are not specialised.
2(D)	Financial and practical support is available to families and carers of people with mental disabilities.	Is support available to families/carers of people with mental disabilities? Examples include benefits, remuneration of family members for providing personal assistance, and day care.	mental disabilities, and nursing fees are
2(E)	Day services are provided for people with mental disabilities in a way which supports their inclusion in the community.	Are day services provided that can support people with mental disabilities to stay in the community?	Day care centres, support services and community care exist but are not available to the majority of the population.
2(F)	Government funding is used to develop community-based services rather than funding residential institutions.	Does the government manage its budget in a way which advances the right of people with disabilities to live in the community?	The Hungarian government spends significantly more money on the maintenance of institutions than on the development of individualised community-based services, including EU funds.

Cluster Three: Access to mainstream services

The indicators in this cluster reflect the requirements of Article 19(c) of the CRPD which states:

Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

No.	Indicator	Measure	Conclusion
3(A)	People with mental disabilities are guaranteed	Do people with mental disabilities get access	No. The majority of people with mental
	access to education in mainstream and	to mainstream education? Is it inclusive and	disabilities are educated in segregated classes
	inclusive settings.	responsive to their individual needs?	and schools.
3(B)	People with mental disabilities are supported	Do people with mental disabilities get access	No. The majority of people with mental
	to access the open labour market.	to mainstream employment? Is the	disabilities are excluded from the labour
		employment system sufficiently inclusive?	market.

Cluster Four: Transition from institutions to the community

The indicators in this cluster reflect the obligation of governments to take concrete steps to move away from congregate, institutional models of accommodating people with mental disabilities, towards supporting them to live independently in the community within a reasonable timeframe.

No.	Indicator	Measure	Conclusion
4(A)	The government has adopted a national community living strategy that effectively advances the right to live in the community for all people with mental disabilities.		No. The national strategy has a thirty year implementation period, fails to set out intermediate indicators, and retains congregate, institutional models of accommodation.
4(B)	The government has undertaken pilot projects to develop models for moving people out of institutions and into the community.	Are there pilot projects on community living? Are they effective and inclusive enough?	Yes, however the number of projects are small and promising practices have not been scaled up to benefit more people with mental disabilities.

Cluster 1: Community living and choice

Most people take for granted their right to choose where and with whom they live. This right, however, is frequently denied to people with disabilities, and particularly those who have been placed under guardianship. Providing choice for people with disabilities in the living arrangements and the types of services provided is essential in empowering them to remain the masters of their lives. Living in the community means that people with disabilities can exercise autonomy in their lives just like other people. It means that they can have friends, go to the shops, and get a job – again, just like other people.

Indicators 1(A) and 1(B) identify where people with mental disabilities are required to live and the options currently made available to them in Hungary. Indicator 1(C) looks at legal barriers to living in the community. Indicators 1(D), 1(E) and 1(F) look at whether the Hungarian legal and policy framework enables and supports people to choose where to live and what services they use. Indicator 1(G) looks at how people can complain about being in institutions or inadequate community services.

<u>Indicator 1(A)</u>: How many people with mental disabilities live in institutions?

Conclusion:

Approximately 25,000 adults with disabilities are required to live in institutions in Hungary. Since ratification of the CRPD, there has been no real progress in realising the right to live in community for the vast majority.

Explanation:

According to the most recent data available from the Hungarian government from 2013, 16,024 people with disabilities – predominantly people with intellectual disabilities⁸ - and 8,760 people with mental health issues lived in residential social care institutions.⁹ According to government data from 2011, there were 303 homes and temporary homes for people with disabilities and 87

⁷ Hungarian Central Statistical Office, Hungarian Statistical Yearbook 2011, table 3.5.25, 129, available at http://www.ksh.hu/docs/hun/xftp/idoszaki/evkonyv/evkonyv_2011.pdf, (last accessed: 23 September 2014). Hungarian Central Statistical Office, Evaluation of the 2011 Census – People with disabilities, table 1.7, 18, available at

http://www.ksh.hu/docs/hun/xftp/idoszaki/nepsz2011/nepsz_11_2011.pdf (last accessed: 23 September 2014).

⁸ Tamás Gyulavári, Zsolt Bugarszki, Nóra Jakab, Vanda Katona, Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities: desk report Hungary, 8, available at http://www.humanconsultancy.com/_layouts/15/WopiFrame.aspx?sourcedoc={FCFE4AAF-1B5E-4E29-AC8E-9D2EB763E45A}&file=HU-FRA%20MH%20-%20final.doc&action=default (last accessed: 23 September 2014). Approximately 14,000 people with intellectual disabilities lived in institutions in 2007, based on the research of Kézenfogva Alapítvány (Hand in Hand Foundation), while the total number of people living in homes for people with disabilities were 16,000. See: Tamás Verdes, "A ház az intézet tulajdona" (The House is the Property of the Institution), Esély, 4 (2009): 92.

⁹ Hungarian Central Statistical Office, Table 2.4.15. A tartós bentlakásos és átmeneti elhelyezést nyújtó szociális intézményekben ellátottak az intézmény típusa szerint (1993–2013) (The number of residents in residential social care homes according to the type of institution (1993-2013)), available at http://www.ksh.hu/docs/hun/xstadat/xstadat_eves/i_fsi001.html (last accessed: 23 September 2014).

homes for psychiatric patients (see *Glossan*). ¹⁰ The number of people in institutions has remained unchanged for the last decade. ¹¹

The number of people with disabilities living in 'group homes' (see *Glossary*) grew from 123 to 1,567 in 11 years (between 2000 and 2011). In the same time period, the number of people with mental health issues living in group homes grew to 294. Yet, many of these group homes were actually built on the grounds of larger institutions, 13 reflecting their institutional model.

There was no significant improvement in the situation of children with mental disabilities in institutions either. In 2013, the United Nations expressed concern about the large number of children receiving institutional care instead of living at home. ¹⁴ It called on the government to promote and expand community-based services to ensure that children with disabilities can live with their families. ¹⁵

<u>Indicator 1 (B)</u>: What housing options are available for people with mental disabilities?

Conclusion:

Institutions remain the predominant housing option provided by the government to people with mental disabilities. Very few local or regional authorities provide any form of assisted or adapted housing.

Explanation:

For many people with mental disabilities, institutionalisation continues to remain the only form of housing available. Many families and carers of people with disabilities are left to cope on their own. According to the most recent government data available (2011), 73% of people with mental disabilities lived at home. The remaining 27% lived in institutions, and of these, 59% were people with intellectual disabilities.¹⁶

In January 2013, the government introduced 'living centres' and 'group homes' as forms of 'protected housing' (see *Glossary*) for people with mental disabilities.¹⁷ These alternative forms of accommodation have only been made available to a small number of people, and reflect an institutional model of congregate housing.

The link between guardianship and institutionalisation is strong: the vast majority people with intellectual disabilities in institutions are under guardianship.¹⁸ This suggests that, in many cases,

¹⁰ Hungarian Central Statistical Office, Hungarian Statistical Yearbook 2011, table 3.5.25, 129.

¹¹ Hungarian Central Statistical Office, Table 2.4.15, The number of residents in residential social care homes according to the type of institution (1993-2013).

¹² Hungarian Central Statistical Office, Hungarian Statistical Yearbook 2011, table 3.5.25, 129.

¹³ According to data from 2007, six out of ten group homes belonged to the institution, were either inside or close to its fence and were functioning under the institution's authority. Tamás Verdes, "A ház az intézet tulajdona" (The House is the Property of the Institution), *Esély*, 4 (2009): 107.

¹⁴ Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Periodic Report of Hungary, 2013, CRPD/C/HUN/CO/1, 22 October 2012, paras. 21-22, available at http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en (last accessed: 23 September 2014).

¹⁶ Hungarian Central Statistical Office, Evaluation of the 2011 Census – People with disabilities.

¹⁷ Section 75(2) of the Act III of 1993 on Social Management and Social Benefits.

¹⁸ Tamás Verdes, Marcell Tóth, A per tárgya, Gondnokság alá helyezett személyek társadalmi kirekesztődésének mozgásformái a rendszerváltás utáni Magyarországon, (Budapest: ELTE Eötvös Kiadó, 2010), 81.

guardianship is sought to make it easier to place people with disabilities in institutions. For people with intellectual disabilities living with their families, 58% are under quardianship. 19

Indicator 1(C): Are there limits or a moratorium on new admissions to institutions?

Conclusion:

No.

Explanation:

There is no limit on new admissions to Hungary's numerous residential institutions. When a resident dies or leaves, the bed is filled by someone else. In some institutions the waiting list is 5 or 6 years long.²⁰ Government services to people with mental disabilities, including institutions, are founded on a paternalistic notion of 'needs', rather than reflecting a rights-based approach. Habilitation, rehabilitation and other services for people with disabilities are focused inside institutions, with the ongoing demand for new admissions reflecting a failure to develop community-based services.

Indicator 1(D): Does the law respect the choices of people with disabilities about where and with whom they live and which services they receive?

Conclusion:

No. Of all European countries which strip people with disabilities of their right to make choices in their lives, Hungary comes in at number one place.²¹

Explanation:

The right to choose one's residence is guaranteed by the Hungarian Constitution, 22 and by the CRPD. However, this right is denied to people placed under guardianship.²³ More than 55,000 people are placed under guardianship in Hungary, a higher per capita rate than any other country in Europe.²⁴ Many people with mental disabilities are placed in institutions because a guardian has placed them there. 92% of people with intellectual disabilities living in institutions were under guardianship the year after Hungary ratified the CRPD,²⁵ and this proportion has remained unchanged to date.

¹⁹ Ibid.

²⁰ Tamás Gyulavári, Zsolt Bugarszki, Nóra Jakab, Vanda Katona, *Fundamental Rights situation of persons with mental* health problems and persons with intellectual disabilities: desk report Hungary, 9.

²¹ Mental Disability Advocacy Center, Legal Capacity in Europe, (Budapest: MDAC, 2013), 22, available at: http://mdac.org/sites/mdac.info/files/legal capacity in europe.pdf (last accessed: 23 September 2014). ²² Article XXVII of the Fundamental Law of Hungary, 25 April 2011.

²³ Where a person is placed under plenary guardianship, the guardian has the power to decide where they live. Where a person is placed under partial guardianship, the person concerned can only make decisions with the approval of their guardian. Sections 2:20 (1) and 2:22 (1) of the Civil Code of 2013.

²⁴ Mental Disability Advocacy Center, *Legal Capacity in Europe*, 54-55.

²⁵ Tamás Verdes, Marcell Tóth, A per tárgya, Gondnokság alá helyezett személyek társadalmi kirekesztődésének mozaásformái a rendszerváltás utáni Magyarországon, 81.

<u>Indicator 1(E)</u>: Can people with mental disabilities enter into contracts and agreements for disability-related supports, credit agreements to purchase housing, rental or other housing agreements?

Conclusion:

No.

Explanation:

People under plenary guardianship are only allowed to enter into minor contracts such as newspaper deliveries,²⁶ but for more significant decisions, their signature is not valid or legally-binding. This means that they cannot enter into contracts for rental housing, gain access to mortgages, or purchase disability-related supports without the approval of their guardian.²⁷

<u>Indicator 1(F)</u>: Do people with disabilities have access to support to enable them to make decisions about where and with whom to live or what support services to access?

Conclusion:

No.

Explanation:

The 2013 Civil Code introduced 'supported decision-making' for people with disabilities (see *Glossary*), a measure which the guardianship office can impose. The conceptualisation of supported decision-making in Hungarian law does not have to be based on the choices, will or preferences of the person concerned, but can actually be imposed – contradicting the right to legal capacity guaranteed in Article 12, CRPD.

Support is only available to people who have partially lost their "discretionary ability", defined in law as their ability to manage their affairs and to make decisions. The support person is appointed by the guardianship authority rather than chosen by the person him or herself, again showing the way in which such measures are imposed rather than based on the will and preferences of the person concerned. The law does not specify, which it should, that support be based on a relationship of trust between the person with a disability and their support person. In practice, a guardian can also be a 'supporter'. An official 'supporter' can support up to 45 people at the same time.

²⁶ Section 2:22(1)-(2) of Act V of 2013 of the Civil Code.

²⁷ Section 2:20(1) of the Act V of 2013 on the Civil Code.

²⁸ Section 2:38(1) of the Act V of 2013 on the Civil Code.

²⁹ Section 2:38(1) of the Act V of 2013 on the Civil Code and Section 2(1) of the Act CLV of 2013 on Supported Decision-Making.

³⁰ Mental Disability Advocacy Center, *Legal Capacity in Europe*, 17.

³¹ Section 7(3) of the Act CLV on Supported Decision-Making.

³² Section 7(6) of the Act CLV on Supported Decision-Making.

<u>Indicator 1(G)</u>: Can people with mental disabilities access effective mechanisms if they want to complain about their right to live in the community?

Conclusion:

No. Complaints and legal avenues are not available to people with mental disabilities under guardianship.

Explanation:

No legal avenues are available to people with disabilities placed under guardianship to challenge their placement in an institution. As such, tens of thousands of people are locked in institutions without any mechanism to complain or to get out. Complaints of people under guardianship can only be initiated by the guardian who is often the same person who has authorised their institutionalisation in the first place.³³ The guardian has power over all financial and property matters related to a person placed under guardianship, creating a clear conflict of interest. People with mental disabilities placed under guardianship, with few exceptions,³⁴ are not recognised as having legal standing to initiate court proceedings.

³³ Section 49(1) of Act III of 1952 on the Civil Procedure.

³⁴ In case of initiating the review of the guardianship order –with the aim of lifting the guardianship or modifying the conditions of it – the person under guardianship has legal standing. Section 312 (3) of of Act III of 1952 on the Civil Procedure.

Cluster 2: Access to individualised support services

The purpose of providing individualised support services to people with mental disabilities is to bridge the gap between mainstream services (health, education, employment, finance, etc.) and the individual needs of people with mental disabilities. These services are essential to prevent the isolation of people with disabilities in community settings. Indicators 2(A)-(E) map the range of support services available to people with mental disabilities in Hungary. Indicator 2(F) assesses the Hungarian government's finance and budgetary priorities.

<u>Indicator 2(A):</u> Are personal budgets available which enable people with mental disabilities to choose the appropriate support they need to live in the community?

Conclusion:

No.

Explanation:

The Government provides financial support only for people with severe disabilities over the age of 18 in the form of a disability support payment. The purpose of the benefit is to provide financial support to mitigate social disadvantage.³⁵ The beneficiaries of the benefit are very limited: people with intellectual disabilities can only receive it if they have been assessed as having a severe disability and are unable to live independently or need the permanent assistance of others.³⁶ The benefit is not available for people with mental health issues. In 2013, 12,799 people with intellectual disabilities and 334 people with autism received disability support.³⁷ From 1 January 2014, the monthly amount of the support is 19,968 HUF (approximately 64 EUR).³⁸ The amount is completely inadequate to assist people with high support needs to obtain necessary services.

<u>Indicator 2(B):</u> Is personal assistance available that can support people with mental disabilities to remain and live in the community?

Conclusion:

Limited personal assistance is provided to some people with mental disabilities in the form of home assistance and a 'signalling' system. It is unavailable to the majority.

Explanation:

The cost of personal assistance is not allocated as a cash payment to people with mental disabilities, meaning that beneficiaries have no control over the services provided. Personal assistance is only available to people who are in a socially "disadvantaged situation", ³⁹ and requires medical proof related to a medical condition, age or other 'disadvantage'. ⁴⁰ Home assistance is provided based on an assessment of the care needs of the applicant. This assessment is carried out by the director of the social care provider or an expert designated by a notary at the

³⁵ Section 22 of the Act XXVI of 1998 on the Rights and Equal Opportunities of Persons with Disabilities.

³⁶ Ibid., section 23(1).

³⁷ Hungarian Central Statistical Office, A fogyatékossági támogatásban részesülők száma (2001-2013) (The number of people receiving disability support), available at http://www.ksh.hu/docs/hun/xstadat/xstadat_eves/i_fsg006.html (last accessed: 23 September 2014).

³⁸ Hungarian State Treasury, Disability support, available at http://www.allamkincstar.gov.hu/maganszemelyek/fogyatekossagi_tamogatas# (last accessed: 23 September 2014).

³⁹ Section 56(1) of Act III of 1993 on Social Management and Social Benefits.

⁴⁰ Section 22(1)-(2) of Decree of the Ministry of Social and Family Affairs 9/1999. (XI. 24.) on the requisition of social services providing personal care.

municipality level.⁴¹ Home assistance provides basic care, support for independent living and protection from 'emergencies'.⁴² Such assistance can only be provided for a maximum of 4 hours a day.⁴³ Where a person's care needs are higher, an assessment is conducted which is likely to result in placement in an institution. In 2012, 125,281 people used the service.⁴⁴

'Signalling home assistance' is available for both people with intellectual disabilities and people with mental health problems who are living independently, but who find themselves in a 'crisis'— a term which is not defined by the law. ⁴⁵ This service is only available for those people who live alone or who live with someone else but who need the service because of his or her health conditions. ⁴⁶ The person wears a small device on his or her wrist or neck which is connected to a dispatch centre which functions 24 hours a day. In case of emergency, the person can push a button on the device and call the dispatch centre from where a social worker is sent to their home to solve the problem immediately. If the social worker finds it necessary he or she can initiate the use of further medical or social care, ⁴⁷ which can result in hospitalisation or institutionalisation.

<u>Indicator 2(C):</u> Is assistance available to people with mental disabilities to access funding or other support services?

Conclusion:

No specialised assistance is provided to enable people with mental disabilities to access funding.

Explanation:

A general family support service exists which can provide support for both people with intellectual disabilities and mental health problems and their families, who have social or mental health issues or who need help because of 'other crisis situations'.⁴⁸ This is a mainstream support service. The aim of the service is to prevent the causes of crises, to bring an end to crises where they have occurred, and to preserve personal and social skills.⁴⁹ The service can be initiated through a referral by a notary at the municipality, a social or health service provider, child welfare services, probation officers, legal aid services, NGOs, churches or private persons if they become aware of such a crisis. A person can also, themselves, initiate the service.⁵⁰

Family support services are provided by the local government. A number of different services can be provided: social, lifestyle and mental health counselling, assistance in receiving financial benefits, facilitating the resolution of family conflicts or organising mediation programmes. ⁵¹ In 2013, 630 service providers existed – providing services to the population of 2,448 settlements – and 451,053 people used the services offered by them. ⁵² No data is available on the number of people with mental disabilities who received support from such services.

⁴³ Section 63(7) of Act III of 1993 on Social Management and Social Benefits.

http://www.ksh.hu/docs/hun/xstadat/xstadat_eves/i_fsg003.html (last accessed: 23 September 2014).

⁴¹ Section 63(1) and Section 63(4) of the Act III of 1993 on Social Management and Social Benefits.

⁴² Section 63(2), ibid.

⁴⁴ Hungarian Central Statistical Office, Szociális Alap- és Nappali Ellátás (Social basic and day care), available at http://statinfo.ksh.hu/Statinfo/haViewer.jsp (last accessed 11 September 2014).

⁴⁵ Section 65(1), ibid.

⁴⁶ Section 65(4), ibid.

⁴⁷ Section 65(2) c), ibid.

⁴⁸ Section 64(1), ibid.

⁴⁹ Ibid.

⁵⁰ Section 64(2), ibid.

⁵¹ Section 64(4), ibid.

⁵² Hungarian Central Statistical Office, Családsegítő és gyermekjóléti szolgálatok (1998-2013) (Family-support and child-welfare services), available at:

<u>Indicator 2(D):</u> Is support available to families of people with mental disabilities? Examples include benefits, remuneration of family members for providing personal assistance, and day care.

Conclusion:

There are some financial benefits available to families, and limited assistance with care, but these are insufficient and unavailable to the majority of people with mental disabilities.

Explanation:

A family member who takes care of a person with a 'severe' intellectual disability can receive a 'nursing fee'.⁵³ People who have a family member with a less than severe intellectual disability and/or family member with mental health issues are not entitled to this financial assistance. A condition of this benefit is that the family member is limited to spend at most 5 hours per day in school, day care services or any other social care services.

In 2012, 57,973 people benefitted from the nursing fee – with the average monthly payment amounting to 30,000 HUF (approximately 95 EUR).⁵⁴ The basic amount of the benefit is 29,500 HUF (approximately 94 EUR) per month, and this can be raised to a maximum of 53,100 HUF (approximately 167 EUR) per month in cases of people with the highest support needs.⁵⁵ The amount of the nursing fee is very low and only allows the caregiver to work part-time – 4 hours a day. Exclusive reliance on the nursing fee can lead to the exclusion of the carer from the labour market, as well as the isolation of the person with an intellectual disability from the community.⁵⁶

The minimal support provided to families can result in impoverishment of entire families who are left to choose between living extremely restricted lifestyles or taking steps to have the person with a disability placed in an institution.

<u>Indicator 2(E)</u>: Are day services provided that can support people with mental disabilities to stay in the community?

Conclusion:

Yes, some day care services are available, however these are scare and not accessible to all.

Explanation:

Day care services are provided for people with mental health issues from the age of 18 and for people with intellectual disabilities from the age of 3. People with mental disabilities can spend the whole day in day care centres where food is provided for them.⁵⁷ Day care provision includes the provision of personal care, and services are based on 'self-help'. In 2012, 7,125 people with disabilities accessed day care services provided by 277 day care centres.⁵⁸

Support services are provided for people with severe intellectual disabilities. The aim of the support services is to provide care for people with severe intellectual disabilities in their local community,

⁵⁴ Hungarian Central Statistical Office, Table 2.4.7. Jövedelempótló szociális támogatások adatai (2000-2012) (Data regarding income replacement social care benefits), available at http://www.ksh.hu/docs/hun/xstadat/xstadat eves/i fsp010b.html (last accessed: 23 September 2014).

⁵⁵ Ibid., at section 44.

⁵⁷ Section 65/F of Act III of 1993 on Social Management and Social Benefits.

⁵³ Ibid., at section 41.

⁵⁶ Tamás Verdes, Az otthoni ápolás zsákutcája (Nursing fee as a dead end), A TASZ jelenti (TASZ reports), 19 August 2014. See more on this issue at http://ataszjelenti.blog.hu/2014/08/19/mi_a_baj_az_apolasi_dijjal (last accessed: 23 September 2014)

⁵⁸ Hungarian Central Statistical Office, Szociális Alap- és Nappali Ellátás (Social basic and day care).

mainly to assist them in accessing public services and providing them specialist support at home.⁵⁹ Services include assistance in accessing public transport, social and health care provision, and gaining employment and social assistance.⁶⁰ These services are mostly provided by local governments, as well as by churches and NGOs, and are predominantly state funded.⁶¹

Community care is provided for people with mental health issues. This can be a long-term service providing care and rehabilitation on a voluntary basis, 62 with the aim of promoting reintegration. 63 Over time, these services have been expanded away from just providing community psychiatric services to also include education, employment and housing support. However, the limited community care services that are in place are underdeveloped. 64

In general, there is a wide geographical variance in the provision of services in the community, meaning that little to no services are provided outside towns and cities.⁶⁵ As of 1 January 2009, local governments are not obliged to provide support services for people with intellectual disabilities or community care services for people with mental health issues.⁶⁶ Instead of strengthening and expanding these services, the government has actually rolled back services in smaller conurbations across the country. Legislative changes meant that only conurbations with over 10,000 residents are required to provide day care services. Prior to this, local governments had to provide day care services in conurbations exceeding 3,000 residents.⁶⁷ 80% of families with a person with an intellectual disability said they were unable to access services.⁶⁸ Those who are not provided community-based services are significantly more likely to end up placed in institutions.⁶⁹

<u>Indicator 2(F)</u>: Does the government manage its budget in a way which advances the right of people with disabilities to live in the community?

Conclusion:

No. The Hungarian government continues to spend significantly more money on institutions than on supporting people to live independently in the community.

⁶⁸ Ibid, at p. 124. According to a survey in 2006-2007, 80% of families with a family member with an intellectual disability said that they had no access to any of the services which local governments are required to provide.

http://www.asz.hu/ASZ/jeltar.nsf/0/24CB3F07C598D096C1257497004B40FE/\$File/0820J000.pdf (last accessed: 23 September 2014).

⁵⁹ Ibid., at section 65/C(1).

⁶⁰ Ibid., at section 65/C(3).

⁶¹ The performance of duties delegated to local governments is regulated in sections 120-122 of Act III of 1993 on Social Management and Social Benefits.

⁶² Ministry of Social and Family Affairs Decree No. 1/2000 (I. 7.), section 39/F, paragraph (1).

 $^{^{63}}$ Section 65/A of Act III of 1993 on Social Management and Social Benefits.

⁶⁴ Community care is provided in 37-38% of the required settlements and only 13% of the settlements have day care services. Hungarian Central Statistical Office, Statistical Mirror, Volume III, Issue No. 189 (18 December 2009). There were only 82 registered community care services in 2010.

⁶⁵ Tamás Verdes, Ágota Scharle and Balázs Váradi, *Intézet helyett* ("Instead of Institution"), (Budapest: Budapest Intézet/Budapest Institute, 2012), 12.

⁶⁶ Hungarian Disability Caucus, *Disability Rights or Disabling Rights?*, *CRPD Alternative Report*, August 2010, 125, available at http://mdac.org/sites/mdac.info/files/english_crpd_alternative_report.pdf (last accessed: 23 September 2014).

⁶⁷ Ibid.

⁶⁹ Based on a report of the State Audit Office, in 2006, only 17% of the residents of the institutions had received basic social services before and this figure dropped in 2007 to 13.9%. State Audit Office, Report on the audit of the utilisation of financial means of municipality hospitals and residential social institutions appropriated on nursing and care, July 2008, available at:

Explanation:

Government funding for the maintenance of institutions is almost double the amount spent on day care services for people with intellectual disabilities and almost triple the amount spent on day care for people with mental health issues. Since 1998 when the government set deinstitutionalisation as a priority, the government has spent 23 billion HUF (approximately 80 million EUR) on renovating and building new institutions which continue to segregate people with disabilities from the community.

Between 1998 and 2006 the Government spent 14 billion HUF (approximately 49 million EUR) on refurbishing institutions from the central budget.⁷² A further 214 million HUF (approximately 750,000 EUR) was spent on refurbishing institutions from European Union structural funds since 2008.⁷³ A deinstitutionalisation tender⁷⁴ issued at the beginning of 2012 resulted in a further 6 billion HUF (approximately 20 million EUR) being allocated for moving persons with mental disabilities out of large institutions into living centers, group homes and apartments (see *Glossary*).⁷⁵

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 $^{^{70}}$ Act CLXXXVIII of 2011 on the Budget of 2012.

⁷¹ Hand in Hand Association (ed.), Expert Material for the Reform of Residential Institutions, (Budapest: Hand in Hand Association, 2008).

⁷² Társaság a Szabadságjogokért, *Csak a tények: mire költjük az EU pénzét? - 1.rész (Only the facts: what do we spend EU funding on? – Part 1)*, available at http://tasz.hu/fogyatekosugy/csak-tenyek-mire-koltjuk-az-eu-penzet-1resz (last accessed: 25 August 2014).

⁷³ TIOP 3.4.2-08/1 Bentlakásos intézmények korszerűsítése (Refurbishment of residential institutions) available at http://palyazat.gov.hu/doc/1019 (last accessed: 23 September 2014).

⁷⁴ TIOP 3.4.1.A-11/1 Bentlakásos intézmények kiváltása (Deinstitutionalisation) available at http://palyazat.gov.hu/doc/3342(last accessed: 23 September 2014).

⁷⁵ The funding comes from two sources: the EU Regional Development Fund (ERDF) and the Hungarian state budget.

Cluster 3: Access to mainstream services

To be fully included, people with mental disabilities must have access to services which are available to the general public. Indicators 3(A) and 3(B) examine the extent to which people with mental disabilities can access mainstream services and the extent to which these services are responsive to their needs.

Indicator 3(A): Do people with mental disabilities get access to mainstream education? Is it inclusive and responsive to their individual needs?

Conclusion:

No, people with mental disabilities are not provided with a real opportunity to participate in an inclusive education at all levels of the Hungarian education system.

Explanation:

According to the Fundamental Law of Hungary, the state ensures the right to education by 'extending and generalising public education'.⁷⁶ Primary education is compulsory for all children, without exception.

The level of educational attainment of people with mental disabilities is remarkably lower than that of the general population. According to statistical data from 2011, half of people with intellectual disabilities have not finished primary school. Exclusion and isolation continues in the course of secondary and higher education too. Not 1.8% of people with intellectual disabilities were reported to have finished secondary school, and just 0.7% graduated from college or university. Children with intellectual disabilities are frequently placed in segregated schools, a situation which caused the CRPD Committee to express concern. The provision of reasonable accommodations to children with mental disabilities is not compulsory, resulting in the exclusion of many from mainstream educational provision.

<u>Indicator 3(B)</u>: Do people with mental disabilities get access to mainstream employment? Is the employment system sufficiently inclusive?

Conclusion:

No.

Explanation:

The law creates barriers to the employment of people with disabilities and particularly those under plenary guardianship, as they are not able to sign and enter contracts of employment.⁸¹ In practice, many employers avoid offering employment to persons under plenary guardianship.⁸² The

⁷⁶ Section XI (2) of the Fundamental Law of Hungary.

⁷⁷ This figure drops to 35% in the case of autism to 17% when it comes to people with mental health issues.

⁷⁸ Hungarian Disability Caucus, *Disability Rights or Disabling Rights? CRPD Alternative Report*, August 2010, 155, 158-159

⁷⁹ 6.7% of people with intellectual disabilities have received some kind of vocational training.

Hungarian Central Statistical Office, Evaluation of the 2011 Census – People with disabilities, table 1,5, 16.

⁸⁰ Committee on the Rights of People with Disabilities, Concluding Observations, Hungary, CRPD/C/HUN/CO/1, 29 September 2012, paras 39-40.

⁸¹ Section 21(5) of the Act I of 2012 on the Labour Code

⁸² Hungarian Disability Caucus, *Disability Rights or Disabling Rights?*, CRPD Alternative Report, August 2010, 179.

employment rate among people with intellectual disabilities is very low and has not increased since Hungary ratified the CRPD.⁸³

Only one in eleven people with intellectual disabilities has a job, and this falls to just one in every seventeen people with autism. ⁸⁴ The situation is slightly better for adults with autism over the age of 28 where the rate of employment rises to one in seven. ⁸⁵ Most people with mental disabilities who are employed work in social care institutions. ⁸⁶ Government financing of this social employment is used by institutions. No incentives are provided to staff in institutions to facilitate access to employment for people with disabilities residing in them. ⁸⁷ Rehabilitation services provided by non-profit organisations are more effective, ⁸⁸ however, their capacity is low and financing is insecure. ⁸⁹ In sum, people with disabilities do not have the opportunity to earn a living by work freely chosen in the labour market. ⁹⁰

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⁸³ Ibid

⁸⁴ Hungarian Central Statistical Office, Evaluation of the 2011 Census – People with disabilities, table 1.7, 18.

⁸⁵ Hungarian Disability Caucus, *Disability Rights or Disabling Rights?*, CRPD Alternative Report, August 2010, 180.

⁸⁶ Tamás Verdes, Ágota Scharle and Balázs Váradi, *Intézet helyett* ("Instead of Institution"), 10-11.

⁸⁷ Ibid, 11.

⁸⁸ Ibid.

⁸⁹ Ibid.

⁹⁰ Tamás Gyulavári, Zsolt Bugarszki, Nóra Jakab, Vanda Katona, *Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities: desk report Hungary*, 15, available at http://www.humanconsultancy.com/_layouts/15/WopiFrame.aspx?sourcedoc={FCFE4AAF-1B5E-4E29-AC8E-9D2EB763E45A}&file=HU-FRA%20MH%20-%20final.doc&action=default (last accessed: 23 September 2014).

Cluster 4: Transition from institutions to the community

It is crucial that governments have clear plans to implement the right to independent living in the community for people with mental disabilities. These plans need to shift investment away from financing institutions into developing and sustaining community-based support and living arrangements. This process is known as 'deinstitutionalisation', and requires governments to develop clear and comprehensive plans which make the best use of resources available. Indicator 4(A) examines Hungary's policy framework in respect of deinstitutionalisation. Indicator 4(B) looks at the development of models for including people with mental disabilities in the community.

<u>Indicator 4(A)</u>: Is there a satisfactory national community living strategy?

Conclusion:

No. The official 30-year timeframe for completing the deinstitutionalisation process is far too long, there are no measurable milestones and few concrete steps have been taken so far.

Explanation:

In 2011 the government adopted a deinstitutionalisation strategy. ⁹¹ This was the first overarching strategy on deinstitutionalisation since Act XXVI of 1998 on the Rights and Equal Opportunities for Persons with Disabilities. One of the main reforms was the introduction of protected housing. Following a needs assessment driven by professionals, people with disabilities can be placed in flats, group homes or living centres (see *Glossary*). These forms of congregate residential settings continue reflect an institutional model and continue to segregate people with disabilities from society.

The DI Strategy has a 30-year implementation period – from 2011 to 2041 – without any intermediate measurable indicators, clearly showing the low priority given to the systemic transformations required. No significant changes have occurred so far: only 700 out of 25,000 residents are on their way to move out from large congregate institutions. Moreover, the DI Strategy contains no provisions for the deinstitutionalisation of children's institutions and there are no plans for developing 'family-like and community-based accommodation' for children with disabilities. Similarly the DI strategy fails to include people with mental health issues, although a subsequent DI tender amended this.

<u>Indicator 4(B)</u>: Are there pilot projects on community living? Are they effective and inclusive enough?

Conclusion:

Yes, and these must be scaled up.

Explanation:

There are a number of pilot projects initiated by non-profit organisations and service providers. One of the promising practices is the KULCS program of Értelmi Fogyatékossággal Élők és Segítőik

⁹¹ 1257/2011 (VII.21) decree on the governmental tasks regarding the strategy and implementation of the deinstitutionalisation of residential places of social care homes for persons with disabilities.

⁹² Alternative NGO Report on the Implementation of the UN CRC in Hungary, 33, available at http://csagyi.hu/images/stories/kutatas/civiljelentes/civil_angol.pdf (last accessed 25 August 2014).

⁹³ TIOP 3.4.1.A-11/1 Bentlakásos intézmények kiváltása (Deinstitutionalisation) available at http://palyazat.gov.hu/doc/3342 (last accessed: 23 September 2014).

Országos Érdekvédelmi Szövetsége (ÉFOÉSZ, Hungarian Association for Persons with Intellectual Disability). The project was launched in the spring of 2011 at Tapolca, a town in western Hungary. The aim of the project was to assist people with intellectual disabilities to live in rented or owned apartments and to get access to social services where needed. So far three men have been selected and prepared for independent living. ÉFOÉSZ plans to extend the program with two new apartments in Veszprém.

The Down Foundation (Down Alapítvány) has had a more extensive project on independent living since 2007. The name of the service is SALSA – Saját lakás, Saját élet (Own flat, Own life). People with Down syndrome are supported by this service when other services have failed them or mainstream services are not available at all. However, purchasing support services from the market is still encouraged. So far, according to the information available on the Down Foundation's website, 3 couples and 4 individuals have been benefitted from the project.

Since both of these programs are initiated by non-profit organisations, their promising practices have yet to be scaled up to benefit larger numbers of people with disabilities. In addition, they are dependent on voluntary funding arrangements.

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⁹⁴ See more in Hungarian at http://www.efoesz-tapolca.hu/index.php/oenervenyesites and http://kulcsprogram.blog.hu/ (last accessed: 25 August 2014).

⁹⁵ See more in Hungarian at http://www.downalapitvany.hu/(last accessed: 23 September 2014).

Glossary

Apartment

Apartments are housing options and forms of institutional 'protected housing' (see below) in Hungary. They can be flats or houses accommodating up to six people with disabilities.⁹⁶

CRPD

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) is an international human rights treaty which is binding law on the governments of countries which have ratified it. The CRPD obliges these countries to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities". ⁹⁷ It was adopted in 2006 and entered into force in 2008. To date, it has been ratified by 150 countries. Hungary was the second country in the world to ratify the CRPD, on 20 July 2007.

CRPD Committee

The Committee on the Rights of Persons with Disabilities (CRPD Committee) is an 18-person expert body responsible for monitoring the compliance of countries with the provisions set out in the CRPD. The Committee is responsible for offering interpretations about the CRPD, and giving guidance to governments about how to implement it.

Concluding observations

Each country which has ratified the CRPD is required to submit reports to the CRPD Committee two years after ratifying the Convention, and thereafter every four years (Article 35, CRPD). The report must set out how the country is implementing Convention rights. After examining a country's report, the CRPD Committee makes recommendations to that county, and the document in which it does so are called "concluding observations".

Disability support

Disability support is a financial benefit provided by the Hungarian government for adults with severe disabilities. The support is available to people with severe disabilities who are unable to live independently or need the permanent assistance of others. ⁹⁸

Group homes

A group home is a form of institutional care in Hungary. It can be a flat or house accommodating between seven and twelve people with disabilities.⁹⁹

Guardianship

Judges in Hungary can place a person with a mental disability under guardianship if the person's ability to manage his or her affairs – due to his or her 'mental disorder' – is permanently or persistently diminished¹⁰⁰ or completely lacking.¹⁰¹ Under guardianship, the authority to make legally-valid decisions is transferred to another person, a guardian. In Hungary, this can either be a carer of family member of the person concerned, or it can be a professional guardian employed by the Guardianship Authority. Guardianship in Hungary can be 'plenary' (total), where a guardian makes all decisions in a person's life, or partial, where a judge can remove the right to make

⁹⁶ Section 75 (2) a) of the Act III of 1993 on Social Management and Social Benefits, as amended by Article 7 of the Act CXVIII of 2012 on the amendment of certain social acts (in force since 1 January 2013).
⁹⁷ Article 1, CRPD.

⁹⁸ Section 23 (1) of the Act XXVI of 1998 on the Rights and Equal Opportunities of Persons with Disabilities.

⁹⁹ Section 75 (2) b) of the Act III of 1993 on Social Management and Social Benefits, as amended by Section 7 of the Act CXVIII of 2012 on the amendment of certain social acts (in force since 1 January 2013).

¹⁰⁰ Section 2:19(2) of Act V of 2013 on the Civil Code.

¹⁰¹ Section 2:21(2) of Act V of 2013 on the Civil Code.

decisions in specific areas of a person's life (e.g. finances or healthcare). ¹⁰² In Hungary this means that a person can only make decisions relating to these areas of their life if their guardian consents. ¹⁰³

Home for people with disabilities

A home for people with disabilities is a residential institution providing long-term care, nursing, housing and rehabilitation for people with disabilities who – according to Article 69 of the Social Act – can be only cared for, educated, trained and employed in institutions. ¹⁰⁴

Home for psychiatric patients

A home psychiatric patients is a residential institution providing long-term care, nursing and housing for people with mental health issues whose condition does not represent a danger to others and who do not require hospital treatment, but are unable to look after themselves due to their health or social condition.¹⁰⁵

Legal capacity

Legal capacity means the authority in law to have rights and the power to make decisions recognised by the law. ¹⁰⁶ A person under guardianship does not have their legal capacity. The recognition of the validity of a person's decisions can cover all areas of life, including financial and property affairs, residence rights, employment, marriage, parenthood, sexual and reproductive rights, inheritance, voting and holding public office.

Living centre

A living centre is a form of institutional care in Hungary. It can be a flat or a block of buildings accommodating up to fifty people with disabilities.¹⁰⁷

'People with mental disabilities'

By 'people with mental disabilities' MDAC means people with intellectual, developmental, cognitive, and/or psychosocial disabilities.

'People with psycho-social (mental health) disabilities' and 'people with mental health issues'

People with psycho-social disabilities are those who experience mental health issues or mental illness, and/or who identify as mental health consumers, users of mental health services, survivors of psychiatry, or mad. These are not mutually exclusive groups. People with psycho-social disabilities may also identify, or be identified as, having intellectual, developmental or cognitive disabilities.

'People with intellectual disabilities'

People with intellectual disabilities generally have greater difficulty than most people with intellectual and adaptive functioning due to a long-term condition that is present at birth or before the age of eighteen. Developmental disability includes intellectual disability, and also people identified as having developmental challenges including cerebral palsy, autism spectrum disorder and fetal alcohol spectrum disorder. Cognitive disability refers to difficulties with learning and processing information and can be associated with acquired brain injury, stroke and dementias including Alzheimer's disease. These are not mutually exclusive groups. Many people with

¹⁰² Mental Disability Advocacy Center, *Legal Capacity in Europe*, 23.

¹⁰³ Section 2:20(1) of Act V of 2013 on the Civil Code.

¹⁰⁴ Section 67 and 69 of Act III of 1993 on Social Management and Social benefits.

¹⁰⁵ Section 67 and 71 (1), ibid.

¹⁰⁶ Ib:d 0

¹⁰⁷ Section 75 (2) c) of Act III of 1993 on Social management and social benefits, as amended by Section 7 of Act CXVIII of 2012 on the amendment of certain social acts (in force since 1 January 2013).

intellectual, developmental or cognitive disabilities may also identify, or be identified as, having psycho-social disabilities.

Personal assistance

Personal assistance is an individualised support service mainly providing in-home support with the aim of preventing isolation and securing inclusion in the community. In Hungary, personal assistance can be provided for several activities, such as personal care and daily living, housekeeping, financial activities, education, and employment. It is limited to a maximum of 4 hours per day.

Personal budget

A personal budget is an amount of money provided to a person with a disability by the state with the purpose that they can purchase the types of individualised support services they require. The aim of personal budgets are to enable people with mental disabilities to have greater control over the support they get and the way it is provided.

Protected housing

This describes a variety of institutional care, support and accommodation services provided by the Hungarian government to people with intellectual disabilities, people with mental health issues and homeless people under Act III of 1993 on Social Management and Social Benefits (Social Act) from 1 January 2013.¹⁰⁸ Associated services include housing, mental health provision, social work and other supports. The support provided can extend to monitoring the client's living conditions, providing meals, care, personal development and learning and is aimed at strengthening the participation of a person with a disability in social life, according to their needs.¹⁰⁹ An amendment to the Social Act entered into force on 1 January 2013, however there is no data on how many protected settings have already been set up. Through the deinstitutionalisation process only 700 residents are on their way to move out to so-called protected settings, which also include 'living centres' and 'group homes' (see above).

Reasonable accommodation

Reasonable accommodation means the necessary and appropriate adjustments and modifications which should be provided to people with disabilities to ensure they can exercise their rights. For example, this could mean providing support assistants to children with intellectual disabilities so that they can access mainstream, inclusive educational environments. In respect of employment, it could mean providing easy-to-read information to employees. It is a right guaranteed by the CRPD.¹¹⁰

Supported decision-making

Supported decision-making is where a supporter helps a supported person to make choices and to communicate these choices to others, such as banks, doctors, employers.¹¹¹ The relationship between the supporter and the supported person must be built on a relationship of trust.¹¹² This relationship should be recognised by third parties, including state authorities, but not imposed or authorised. Supported decision-making leaves the legal capacity of the person intact.

The Hungarian Civil Code 2013 introduced "supported decision-making" for people with

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¹⁰⁸ Section 75 of Act III of 1993 on Social Management and Social Benefits, as amended by Section 7 of Act CXVIII of 2012 on the amendment of certain social acts (in force since 1 January 2013).

¹⁰⁹ Section 75 (1) of Act III of 1993 on Social Management and Social Benefits, as amended by Section 7 of Act CXVIII of 2012 on the amendment of certain social acts (in force since 1 January 2013).

¹¹⁰ Article 2, CRPD.

Mental Disability Advocacy Center, Legal Capacity in Europe, 20.

¹¹² Ibid

disabilities, but this measure does not comply with the above-mentioned principles. Supported decision-making under the Civil Code is a measure which is imposed by the guardianship office. The law does not require that trust should be the basis of the relationship between the supporter and the supported person.

Temporary home for people with disabilities

A temporary home for people with disabilities is a social institution which provides temporary accommodation for people with disabilities who cannot be cared for by their families or whose temporary accommodation is necessary in order to relieve the burden on their families. ¹¹³ It is provided for a maximum of one year.

¹¹³ Section 80 of Act III of 1993 on Social Management and Social Benefits.