

AN ANALYSIS OF DE-INSTITUTIONALIZATION EXPERIENCES: GOOD PRACTICE EXAMPLES AND FAILURES

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Glossary

Institution - any residential care where residents are isolated from the broader community and/or compelled to live together, residents do not have sufficient control over their lives and decisions which affect them, the requirement of the organization itself tends to take precedence over the residents individual needs¹.

Group home – house/apartment/flat where 4-9 persons with mental disabilities live independently and may or may not receive social and health care support

Residential facility – social facility providing housing, full care, and social rehabilitation to persons who are unable to take care of themselves based on age, health condition or vulnerability.

Deinstitutionalization – a political and social process directed towards transition from institutional care to independent living. It involves the closing down of institutions and development of quality, personalized community based care.

Trans-institutionalization – movement of persons with disabilities from one institution to another or to a home with institution type settings.

Supported living - having a safe and decent home of your own, choice, and personalized assistance and support from others who care about and respect you².

Mental disability – broad term encompassing both intellectual disability and psychosocial disability.

Community based services – alternative care to institutional care allowing a person to receive social care, rehabilitation or medical services in their homes or as near as possible to them.

Long term care – social institution providing housing, full care, and social rehabilitation to persons who are unable to take care of themselves based on age, health condition or vulnerability.

Person centred planning - a set of tools designed to assist someone to plan their life and supports. It is used most often as a life planning model to enable individuals with disabilities or otherwise requiring support to increase their personal self-determination and improve their own independence.

Assessment - clinical evaluation of conditions and how it significantly affects the wellbeing of both patients and society on financial remuneration, ability to work, quality of life, current and future needs.

Personal budgets – financial allocation to persons with disabilities based on the assessment of needs.

¹ Common European Guidelines on the Transition from Institutional to Community Based Care, pg 25

² Better for you, Better for Us.

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“If I could, I would not want anyone to be in an institution. There is no freedom there. I wish my country was like Canada. I hear there are so many people from all over the world, there is freedom from institutions, you can go to the library and no one notices you are disabled...”³

³ Interview with a young man at RC ZELDA office, January 18, 2016.

1. Introduction

The chance to grow in a family, choice as to where one lives as an adult, participate in the community and make your own choice are opportunities that most humanity takes for granted. The importance of this choice is recognized by the UNCRPD in Article 19 which sets out the right to live independently and be included in the community on an equal basis with others. By doing so, it recognizes disability results from the interaction between persons with disability and attitudinal and environmental barriers that hinder their full and effective participation in society⁴.

Traditionally, persons with disabilities especially psychosocial or intellectual disability were confined to institutions or living in institution type of settings. To be fair, this is mostly in jurisdictions that rely on the medical method of disability where persons with disabilities were institutionalized as a result of various laws and policies. Others were institutionalized as a result of being abandoned by their families. Some common violations of Article 19 include segregation through institutionalization, isolation through group homes or family settings, exclusion from the community through lack of support services.

The social model of disability however adopts the view that with proper supports, all persons with disabilities can live in the society, successfully. This is the approach taken up by the Convention on the Rights of Persons with Disabilities. Independent living calls for a mechanism where persons with disabilities can live on their own based on their own choices and participate fully in society. This goes beyond deinstitutionalization. It means that one needs to be empowered to have choice and control over their lives. This includes voting rights or standing for a public office, reasonable accommodations at the work place, the right to enter into contractual agreements and should not be unduly deprived of their liberty by administrative means⁵.

Though widely accepted, there is no blanket application of the social model of disability especially on deinstitutionalization. The mechanisms underlying policy adoption and implementation differ for early- versus late-adopters of the model. Countries that are innovators in mental health care tend to face the dilemma of lack of information on policy alternatives and outcomes of costs v. benefit resulting in trial and error basis⁶. Late adopters on the other hand have the advantage of learning from early adopters. Policymakers in late-adopting countries are indirectly affected by both the availability of and access to an evidence base of mental health policy's effectiveness as it has been tested at home or abroad⁷.

Developed and developing countries face different challenges when it comes to mental health system development. The population in developing countries make up 84% of the world's population, and yet developing countries claim only 11% of the world's net

⁴ European Union Agency for Fundamental Rights, *Choice and Control: The Right to independent living*, 2012, pg 7

⁵ Ibid

⁶ Mukand S, Rodrik D. *In Search of the Holy Grail: Policy Convergence, Experimentation, and Economic Performance*. No. w9134. Cambridge, MA: National Bureau of Economic Research; 2002

⁷ Meseguer C. *What role for learning? The diffusion of privatisation in OECD and Latin American countries*. Journal of Public Policy. 2004, pg 24

health spending⁸. Developing countries grapple with an under-provision and budgeting of resources, personnel and services. The situation is different for developed countries where the process of deinstitutionalization has led to closures of mental hospitals and asylums, as well as a reduction in the number of patients in the ones left standing. However, the development of community-based residential and occupational facilities and the uptake of incident clinical cases have not been commensurate with the pace of downsizing or closing psychiatric institutions⁹. Both developing and developed countries face problems such as parity in the provision of resources between physical and mental health services, the need to promote detection and treatment of mental disorders in primary care settings, and competing demands of psychiatric and other specialty services¹⁰.

The purpose of this study is to create awareness on Article 19 by documenting good practices and failures on implementation of the right to live independently. This research will assist any country in implementing independent living or any organization that works on advocacy for persons with disabilities particularly on matters Article 19 to be able to understand the process involved legal implications and learn lessons from other countries. Thus, this research will be mainly through a desk review of laws, policies and published articles documenting best practices on independent living across selected countries. There will also be an analysis of failures and questionable practices that can help any country or organization learn which pitfalls to avoid.

In this regard, the following countries were selected for purposes of identification of best practices and lessons learnt on independent living, United Kingdom and Northern Ireland, Sweden, Canada, USA, Croatia, Czech Republic, Italy, Bulgaria and Hungary. This selection does not limit practices from other countries as well but aims at guiding the limits of this study.

To give a broader scope on independent living, this study will encompass a section covering regional approaches that can be identified as best practices. The European Union in particular will inform this paper as the European Union has made major strides in ensuring independent living becomes a reality within the Union and its member states.

In order to make a proper comparison, the countries selected represent different stages in deinstitutionalization. Some countries started the deinstitutionalization process much earlier and can be deemed to have more progressive lessons. Other countries started the process much later and have been building on experiences gained from the early starters.

⁸ Schieber G, Maeda A. *Health care financing and delivery in developing countries*. Health Aff. 1999, p.18

⁹ Thornicroft G, Tansella M. *The Mental Health Matrix: A Manual to Improve Services*. New York, NY: Cambridge University Press; 2006.

¹⁰ Gordon C. Shen and Lonnie R. Snowden, *Institutionalization of deinstitutionalization: a cross-national analysis of mental health system reform*, International Journal on Mental Health Systems, 2014 vol. 8, pg 47.

Development of deinstitutionalization

Institutions for persons with mental health conditions originally started as therapeutic asylums to help integrate those who were deemed incapable back into the community¹¹. Institutionalization however was spurred by various factors such as poverty, stigmatisation, public perception and government policies¹². Persons with intellectual disabilities were placed in institutional facilities based on the assumption that their limited potential for normal development and the 'burden' that care would impose on families and communities left few or no other options¹³. For instance, in Hungary, the psychiatry 'annexes' of general hospitals were initially conceived as dumping grounds for chronic patients who presumably had no access to the psychiatric treatments and psychotherapy that the state asylums had on offer. Towards 1900, there were only four state asylums in Hungary (with 2300 patients), but 12 general hospital annexes with more than 100 patients each, in addition to numerous other smaller psychiatry wards in general hospitals, housing a total of over 5000 patients¹⁴. In subsequent years, these general hospital units came to admit acute cases of all kinds, not just chronic patients dumped from the progressive asylums; and they also eventually acquired psychiatrists as directors¹⁵.

Calls for deinstitutionalization has been characterised between two periods i) the late 1970s and the early 1980s when much attention was given to institutional reform and ii) 1990s on activism. The 1970-80s affected the Scandinavian, the UK and North American regions and was based on reports of systematic abuse and inhumane treatment of persons with disabilities who lived in institutions¹⁶. In addition institutions were deliberately built away from cities to which was justified as contributing to the general wellbeing of persons with disabilities as well as a mean to create employment¹⁷. This only resulted in exclusion of persons with disabilities and resistance to deinstitutionalization by staff working in institutions for fear of unemployment. Around this time, the process of closure of institutions began in Sweden, as it did in USA and UK. Calls by activists and non-governmental organisations in the 1980s came to be the decade when this task began to be realised on any scale, as the development of community services reached sufficient levels to permit the final abandonment of institutional care¹⁸. The beginning of the 1990s has seen the start of a period of closure, furthered by the law in favour of community based alternatives. At a joint WHO–European Commission meeting in 1999, the consensus was that “In many cases reform

¹¹ James W. Conroy, *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities*, Center for Outcome Analysis, 2002, pg 5

¹² Ibid.

¹³ Multiple authors, “Trends in institution closure” in “Community for All” Tool Kit: Resources for Supported Community Living, Syracuse Human Policy Press, 2004 pg 70.

¹⁴ Pandey, K. Die, *Irrenfürsorge in Europa: eine vergleichende studie (The Care of the Mentally Ill in Europe: A Comparative Study)*, 1908, pg 439–40.

¹⁵ Edward Shorter, The historical development of mental health services in Europe, *Mental health Policy and Practice across Europe*, ed Martin Knapp et al, 2007

¹⁶ G. P. Wilson, *Reflections on the Ormrod Committee Report*, Modern Law Review, Vol. 34 No. 6 (Nov 1971), pp. 635-641

¹⁷ L'Arche Canada, *A resource document on Institutions and De-institutionalization*, 2014.

¹⁸ Jim Mansell and Kent Erricsson, *Deinstitutionalization and Community Living: Intellectual disability Services in Britain, Scandinavia and the USA*, 1995

initiatives originated from the non-governmental field, with governments either being largely indifferent or even hostile”¹⁹.

The second period (1990s) saw increased activism towards deinstitutionalization mostly in Central and Eastern Europe based on reports of cruel and inhumane treatment of persons with disabilities and persons being stripped of their rights. For instance in Bulgaria²⁰ was the institutionalization of children and in Hungary on calls against forced institutionalization²¹. In addition, residential institutions were a central part of social policy in most of Central and Eastern Europe and the former Soviet Union. Residential institutions were more than merely housing for marginalized populations but served as a model of social protection and social regulation²². The long history of reliance on residential institutions in the former Soviet Union and the more recent reliance on them in Central and Eastern Europe has created a large and influential constituency interested in preserving these institutions. As employment options have narrowed during the transition, these groups have become increasingly dependent on residential institutions for their work, income, and social well-being²³. All these factors have played a role in influencing the transition from institutions to community based care in Europe.

Despite the challenges of deinstitutionalisation and country level, gains have been made at a regional level against forced institutionalization. In most countries, person with mental disabilities have been institutionalized through use of guardianship laws and involuntary mechanisms. The European Court of Human Rights (ECtHR) has decided a number of cases based on Article 5 of the ECHR about when “detention” has occurred, and the safeguards needed to prevent arbitrary detention. According to the ECtHR’s jurisprudence, people who have been placed in institutions are “deprived of liberty” within the meaning of Article 5 when they have not consented to placement in the institution, and staff at the institution exercise “complete and effective control over [their] care and movements.”²⁴ Additionally, a person is deprived of liberty when placed in an institution against his or her will even if that person is not actively resisting institutionalization, the facility is not locked or lockable, or the person has been permitted to frequently leave the facility unsupervised²⁵. This interpretation is further supported by Article 12 of the CRPD, which provides for the respect for “rights, will and preferences” of persons with disabilities²⁶. For persons deprived of legal capacity, moving from an institution to the community can be far more complex and take much longer, as was the case in *Stanev v. Bulgaria*²⁷.

¹⁹ Edward Shorter, The historical development of mental health services in Europe, *Mental health Policy and Practice across Europe*, ed Martin Knapp et al 2007

²⁰ UNICEF, *Deinstitutionalization of Children in Bulgaria- How far and Whereto? Independent Review of progress and challenges*, June 2014.

²¹ Mental Disability Advocacy Centre, *My Home My Choice in Hungary: The right to community living for people with mental disabilities in 2014*, 2014

²² World Bank, *Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union*, 2000 pg 15

²³ Herczog, Maria, “Hungary.” In Matthew Colton and Margaret Williams, eds., *The World of Foster Care: An International Source Book on Foster Family Care Systems*. Aldershot, U.K.: Ashgate, 1997, pg. 116.

²⁴ European Court of Human Rights, *Storck v. Germany*, para. 74;

²⁵ European Court of Human Rights, *H.L. v. United Kingdom*, (no. 45508/99), judgment of October 5, 2004, ECHR 2004-IX, available at www.echr.coe.int, para. 191.

²⁶ Human Rights Watch, *Once you Enter you never leave: Deinstitutionalization in Croatia*, 2010. Pg 23

²⁷ The applicant was born in 1956 in Ruse, where he lived until December 2002 and where his half-sister and his father’s second wife, his only close relatives, also live. On 20 December 1990 a panel of occupational physicians declared him unfit to work. The panel found that as a result of being diagnosed with schizophrenia in 1975, the

As demonstrated above, deinstitutionalization is an ongoing process. Continuous monitoring, evaluation and improvement must be done in order to perfect the process.

The Need for Community-based Supports to Promote Social Inclusion

Independent living varies from one community to another and is highly dependent on the societal and cultural norms. This is why Article 19 embodies the positive philosophy which is about enabling people to live their lives to the fullest within society. The core of the right is about neutralizing the isolation and loss of control over one's life against the background of an inaccessible society. "Neutralizing" being understood as removing barriers to community access in housing and other domains and providing access to individualized disability-related supports²⁸. In the past 20 years, a body of literature has developed on deinstitutionalization of people with developmental disabilities. It shows what happens to the quality of life of people with developmental disabilities when they move from large congregate care settings to community living. The result was that persons living in community settings experience a better quality of life compared to those in institutions²⁹.

A primary reason for the institutionalization of people with disabilities is the severe lack of support in local communities that would enable them to live in their own homes or with their families. Also a general lack of commitment by governments to transform the system of institutional care while supporting the development of a range of services that would enable all people with disabilities to live in their communities limits the right to live independently. Though many governments have policies that seek to promote the human rights and social inclusion of persons with disabilities, progress in developing alternatives to institutionalization is painfully slow³⁰.

Failure to provide community based alternatives can lead to re-institutionalization or trans-institutionalization. Trans-institutionalization has become fairly common in the US where the numbers of persons with mental health conditions in the criminal justice system are on the increase³¹. This is because of lack of access to affordable health care or community based services leading people to seek alternative treatment in the prison

applicant had a 90% degree of disablement but did not require assistance. He is in receipt of an invalidity pension on that account. The applicant complained of his placement in a social care home for people with mental disorders and his inability to obtain permission to leave the home (Article 5 §§ 1, 4 and 5 of the Convention). Relying on Article 3, taken alone and in conjunction with Article 13, he further complained of the living conditions in the home. He also submitted that he had no access to a court to seek release from partial guardianship (Article 6 of the Convention). Lastly, he alleged that the restrictions resulting from the guardianship regime, including his placement in the home, infringed his right to respect for his private life within the meaning of Article 8 taken alone and in conjunction with Article 13 of the Convention.

²⁸ Human Rights Watch, *Once you Enter you never leave: Deinstitutionalization in Croatia*, 2010pg 4

²⁹ Spreat, S., Conroy, J., & Fullerton, A., *A Cost-Benefit Analysis of Community and Institutional Placements for Persons with Mental Retardation in Oklahoma*. Research in Developmental Disabilities, (2004) pg 17-31.

³⁰ European Union Agency for Fundamental Rights, *Choice and Control: The right to independent living*, 2012, pg 7

³¹ Criminal Justice/Mental Health Consensus Project, *Does transinstitutionalization explain the overrepresentation of people with serious mental illnesses in the criminal justice system?*, Council of State Governments Justice Center, New York, 2011

system³². Re-institutionalization has been witnessed mostly in the case of visible homelessness, drug addiction and poverty. Lack of support services such as housing, access to health care or gainful employment especially in the case of mental health conditions pushes such person to the street making their conditions more visible. Lack of political willingness and pressure to address the visibility of mental disability has caused increased calls for institutionalization of persons with disabilities³³.

The lack of community-based services also impacts upon people with disabilities who remain with their families. The families are likely to have little to no support in caring for them. Furthermore, due to the widespread and pervasive stigma attached to disability generally and in particular to mental health problems and intellectual disabilities, families may seek to hide the very existence of their disabled relative³⁴. Like their peers living in institutions, they are also marginalized, excluded, and forgotten. Unless and until action is taken to develop community-based alternatives, persons with disabilities will continue to be placed in institutions or isolated in their own homes.

Article 19 of the Convention on the Rights of Persons with Disabilities promotes the right to live in the community. It includes three clear requirements. States must: i. Recognize the right of people with disabilities to live in the community, ii. Take effective and appropriate measures to facilitate their full enjoyment of that right, with choices equal to others, and iii. Take effective and appropriate measures to facilitate people with disabilities' full participation and inclusion in the community³⁵. Further Article 19 goes beyond institutionalization to inclusion. While on one hand it calls for a firm commitment to deinstitutionalization, on the other, one should not be isolated from the community due to inaccessible facilities such as school, healthcare and lack of community support services. Institutionalization should not be replaced with other forms of exclusion such as lack of choice or no interaction with the community³⁶.

Article 19 cannot be fully achieved without implementing the CRPD in its entirety. This is because independent living is dependent on a lot of factors. For example, for one to exercise choice in independent living, they must have legal capacity (Article 12) freedom from discrimination in housing (as articulated in Article 5), liberty (Article 14), accessibility (Articles 9 and 20), access to support services such as health (Article 25) and employment (Article 27). Further social security (Article 28) acts as a safety net for persons with severe disabilities and their families. Most states should be encouraged to implement Article 19 as it envisions a wider application of the CRPD.

Most countries have some laws, practices or policies that may legalize confinement on the basis of their disability. These laws touch on Articles 14, 15, 17, 29 and 30 of the Convention. These practices are wrongfully legitimized in mental health laws which regulate the practice of commitment to psychiatric institutions and the ramifications of

³² Fredrick H. Lowe, *Clinical Psychologist to head Cook County Jail, the nation's largest Mental health institution*, May 20, 2015 available at <http://www.northstarnewstoday.com/news/clinical-psychologist-to-head-cook-county-jail-the-nations-largest-mental-health-institution/>

³³ Marina Morrow, Paul Dagga and Ann Pederson, *Is Deinstitutionalization a Failed experiment? The Ethics of Deinstitutionalization*, *Journal of Ethics and Mental Health*, 2008

³⁴ *Ibid*, pg 24

³⁵ Open Society Foundations, *A community for All Checklist, Implementing Article 19 of the Convention of Persons with Disabilities*, December 2011.

³⁶ Council of Europe Commissioner for Human rights, *The Right of People with Disabilities to live Independently and be included in the community*, Issue Paper, March 2012, pg 2

most guardianship laws. These laws validate the “normality” of exclusion and treat acts of medical violence as a “right” and “benefit”. They also alienate the community from persons with disabilities and create a situation of insecurity for persons with disabilities who are vulnerable to repeated instances of discriminatory detention at the behest of neighbours, family members, service providers and police³⁷.

Institutionalization however seems to be a problem associated with the developing world³⁸. Therefore some countries may not see the importance of implementing the CRPD and Article 19 in particular. Though in most countries of the global south there are few institutions, there is also very little support in the community for persons with disabilities and their families as well as very strong stigma leading to loss of choice and autonomy of persons with disabilities and isolation within their communities³⁹. These results in exclusion of the persons from the society, which is addressed under Article 19. In conclusion, Article 19 addresses those different contexts and situation. While the starting point may be different, the outcomes should be the same: choice, access to support, as well as accessible and responsive community services enabling living independently and being included in the community⁴⁰.

2. Interpretation of Article 19

I. *Legal Obligation upon states*

The opening narrative of Article 19 is to the effect that States parties ‘recognize’ the equal right of all persons with disabilities to live in the community with choices ‘equal; to others⁴¹.’ This places an obligation upon signatories of the CRPD to make Article 19 a reality.

II. *The aspect of choice*

Enabling a person to have a home can be understood as a necessary support to help develop the will and preference and legal capacity of the individual as is required under Article 12⁴². Council of Europe (CoE) Commissioner Hammarberg has endorsed this link between Article 12 and Article 19 and has emphasized that “(...)Curtailing the overall ability of individuals to make choices or have them respected naturally compromises opportunities to make more specific choices about where to live and how one’s life will look in relation to the community”. At the same time, exclusion from life within the community increases the risk of legal capacity being denied. Little opportunity exists in

³⁷ Inclusion International, *Inclusive Communities= Stronger Communities: Global Report on Article 19*, 2012, pg 55

³⁸ European Coalition for Community Living, *Focus on Article 19 on the Rights of Persons with Disabilities*, 2009, pg 5

³⁹ Inclusion international, *Independent but not alone: A Global report on the right to decide*, 2014, pg 39

⁴⁰ International Disability Alliance, Submissions on Article 19 pursuant to letter dated 8th July 2014 requesting information on Article 19 to prepare a Study on the Topic in Light of the HRC Resolution 25/20

⁴¹ Council of Europe Commissioner for Human Rights *The Right of People with Disabilities to Live Independently and be Included in the Community*, Issue Paper (2012)3 (Strasbourg, 13 March 2012

⁴² Ibid, pg 27

the strictly controlled lifestyle, and lack of choice, inherent to institutional life, for an individual to voice his or her will.⁴³

One cannot underscore the link between Article 12 and 19 when discussing choices. For one to be able to live independently, they have to have autonomy in decision making. As the Commissioner for human rights states: “Independent living occurs if, in whatever living scheme one chooses, within the family or separate from it, they have to retain control over one’s life and decision while accessing the individualized supports needed to do so”⁴⁴.

III. Personalized services to allow independence and inclusion.

This includes designing social services fitting individual circumstances. The services – or their manner of delivery – may well have met need but tended to do so in a way that accentuated isolation and exclusion from the community.⁴⁵ The personalization of social services is a general trend around the world and is partly aided by new technology and better matches resources with real needs. Many social systems are experimenting with allocating individualized budgets that enable individuals to purchase services to meet their needs against an expanding range of suppliers (including many non-traditional suppliers). So the litmus test of a ‘good’ service is not merely that it meets needs as classically understood but that it truly positions the person to engage and gain from meaningful community inclusion.⁴⁶

IV. Community services

Sustainability of deinstitutionalization is dependent on access to services within the community. This requires that resources be utilised in provision of community services rather than in institutional settings. This is evidenced by research in the US where attempts in the 1970s and 1980s at ‘deinstitutionalization’ have stumbled because of a lack of attention to community facilities and services⁴⁷ resulting in mass incarceration of persons with mental disabilities in the prison system⁴⁸.

Concepts on Independent Living

Independent living may seem like an abstract concept especially in the eyes of States. There is no country where the goals of independent living and being included in the community have been fully achieved⁴⁹. Further disability is a diverse concept and

⁴³ Council of Europe Commissioner for Human Rights *The Right of People with Disabilities to Live Independently and be Included in the Community*, Issue Paper (2012)3 (Strasbourg, 13 March 2012), p. 12.

⁴⁴ Council of Europe Commissioner for Human Rights, *The Right of People with Disabilities to live Independently and be included in the community*, Issue Paper, March 2012, pg 7

⁴⁵ Barnes and Mercer, *Independent Futures: Creating User-led Disability Services in a Disabling Society*, *Caring for independent lives: Geographies of caring for young adults with intellectual disabilities* (2008) 67 *Social Science & Medicine* 5, pg 834.

⁴⁶ Inclusion International, *Independent but not alone: A Global report on the right to decide*, 2014, pg 29

⁴⁷ Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, University of Michigan Law School Public Law and Legal, Theory Working Paper Series, 2012

⁴⁸ Darrel Steinberg, David Mills and Michael Romano, *When did Prisons become Acceptable Mental Healthcare Facilities?*, Stanford Law School, 2014.

⁴⁹ Inclusion International, *Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community*, 2014.

generalizations about “disability” or “people with disabilities” can mislead. Persons with disabilities have diverse personal factors with differences in gender, age, socioeconomic status, sexuality, ethnicity, or cultural heritage and in turn influence how they live⁵⁰. However, given the disparities, governments or organizations cannot rely on them to say that Article 19 is unachievable. Independent living, in the absence of services and natural supports in the community and the failure of communities to build inclusive systems, is unachievable meaning person with disabilities around the world have to depend on their families for lifelong support and care⁵¹.

For Article 19 to become a reality is dependent on several other Articles. The foundation of an independent and inclusive life in the community for persons with disabilities is provided for by the general principles of the Convention (art. 3), in particular the principles concerning full and effective participation and inclusion in society, and respect for the individual’s inherent dignity, autonomy and independence⁵². Full enjoyment of the right to live independently in the community is involves combating of stereotypes and prejudices through awareness (art. 8), non-discrimination (art. 5) and accessibility (art. 9) and the freedom of choice as envisioned under Article 19 (a) and (Article 12).⁵³

Article 19 calls for an overhaul of the current system to a new system that will require strong leadership amongst stakeholders⁵⁴. Some concepts may be easily achievable like closing institutions. However, setting up social services, personalized services and safety nets may not be as easy. These may be achieved progressively. As one author puts it, it is recommended that countries that are just starting the process of deinstitutionalization should avoid making the mistakes of those who have gone before and should aim from the very beginning for persons centred, individualized services and not simply modifying the nature of institutions.⁵⁵ Article 19’s language is strong and clear. Though it does not specifically call for closing institutions, its provisions are incompatible with institutionalization⁵⁶.

Inclusion International in its report pointed out that in order to deinstitutionalize persons, institutions must be guided by those values and principles that are known to achieve positive outcomes. A deinstitutionalization plan must ensure that people have: the right to choose where they will live, and with whom, services/programmers that are person centred, directed and controlled by the person within the context of their culture, the right to individualized living arrangements and control over the needed resources, necessary disability related supports needed to fully participate in the community, support, as necessary, from friends/family/advocates to assist in decision making (supported decision making).⁵⁷

⁵⁰ World Health organization, *World Report on Disability*, 2011, pg 8

⁵¹ Ibid pg 8

⁵² General Assembly, *Thematic study on the right of persons with disabilities to live independently and be included in the community*, Report of the Office of the United Nations High Commissioner for Human Rights, December 2014, para. 7

⁵³ Ibid, para. 8

⁵⁴ ZELDA, *The accessibility and Costs of Mental health and Social Care community based services compared to institutional care in Latvia (2004-2011)*, 2013, pg 24

⁵⁵ Ibid, pg 24

⁵⁶ H. Rodney Sharp and Steven M. Eidelman, *It’s not Independent Living: Article 19 and the Declaration of Interdependence*, Journal of Human Services Policy and Leadership, 2012,

⁵⁷ Inclusion International, *Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community*, 2014, pg 112

The International Disability Alliance identified key elements of Article 19 as follows:

- Respect for **choice** on equal basis with others, of an individual about her/his living arrangement (where and with who) and about her/his participation in community
- Duty to provide access to necessary **support** services as conditions for free choice on equal basis with others. This implies availability, affordability and quality of services.
- Duty to ensure that all community services are **inclusive**, accessible and responsive to the needs of persons with disabilities (including labour market, housing, transportation, health care, education etc.) and develop according to universal design.⁵⁸

The CoE Commissioner for Human Rights highlights three elements that are necessary to achieve the objectives of article 19⁵⁹:

1. Choice which means giving a person the opportunity to weigh on how alternatives are shaped.
2. Individualized support services which presupposes the need to set a standard of support below which inclusion is not possible. A standard below which states cannot derogate from.
3. Inclusive community services. This means that facilities that are open to the general public should be responsive to the needs of person with disabilities. Such services include those offered in healthcare, education, employment, transportation etc.

3. Good Practices

There is no clear guideline on what would amount to a best practice under Article 19. This is because there are various approaches to Article 19. For instance, Article 19 is closely connected to provisions in other human rights treaties, including the International Covenant on Civil and Political Rights,⁶⁰ the International Covenant on Economic, Social and Cultural Rights⁶¹ and the Convention on the Rights of the Child.⁶² The right to live independently and to be included in the community has also been recognized in regional human rights documents, such as the European Social Charter (art. 15) and the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (art. 4, para. 2 (b))⁶³. In addition, the UN Committee on the Rights of Persons with Disabilities has repeatedly urged State parties to adopt adequately funded strategies for deinstitutionalization with clear time frames and benchmarks, in cooperation with organizations of persons with disabilities.⁶⁴

⁵⁸ International Disability Alliance, Submission on Article 19, Letter Dated 8.7.2014 in response to HRC resolution 25/20

⁵⁹ Council of Europe Commissioner for Human rights, *The Right of People with Disabilities to live Independently and be included in the community*, Issue Paper, March 2012

⁶⁰ For instance, articles 9, 12, 16 and 17, International Covenant on Civil and Political Rights

⁶¹ For instance, articles 11 and 12, International Covenant on Economic, Social and Cultural Rights

⁶² For instance, articles 2, 9, 16, 20, 23, 25 and 27, Convention on the Rights of the Child

⁶³ General Assembly, *Thematic study on the right of persons with disabilities to live independently and be included in the community*, Report of the Office of the United Nations High Commissioner for Human Rights, December 2014, para. 10.

⁶⁴ General Assembly Thematic report on Article 19 while quoting concluding observations from various countries, paragraph 25

Secondly is the aspect of personalized services. Mental health conditions are diverse with different means of addressing the challenges presented by each condition that are unique to the individual. For deinstitutionalization and independent living to become a reality, it is important to consider everyone who needs services when planning the transition from institutional care to services in the community. Some people formerly cared for in institutions will be able to live independently with very little support; others will need constant help from staff to accomplish activities of daily living at home and in the community. The spectrum of services available will need to include options for people with widely differing needs for support. Individuals will also vary in their needs over time – sometimes needing more support, sometimes less. Some of this support might need to be in the form of respite or short break care, or for assessment and treatment in (general or psychiatric) hospital⁶⁵. Thus decision makers have to plan for a system of services in the community that will meet various needs. Decision-makers need a thorough understanding of the structure of service provision.

Third, underlying financing arrangements, and the ways in which services are funded determine the success or failure of deinstitutionalization and which approaches to take. The assumption is that institutions are cheaper to run than community based care. The reality though is that community based care is more cost effective and ensures quality service delivery when compared to institutions⁶⁶. The underlying rule is that when services are developed in the community for people with more severe and complex needs, they are likely to be more expensive than the existing community services. Thus where a service is cheap to provide then the quality must be lacking⁶⁷ Also using persons with complex needs as a benchmark works to the advantage of any community based program in that persons with complex needs will always require more services. Thus if a community can meet their needs, then it would be easier to meet the needs of those with less severe disabilities⁶⁸.

Finally, the difficulties of coordination across agencies and budgets could be better addressed if provision is spread across public, voluntary (non-profit, charitable) and private sectors. In some countries the state sector dominates provision though strategic responsibility for setting the policy, legal and financial frameworks for provision, access, allocation and quality Assurance⁶⁹. In some countries, the civil society has taken the lead especially in matters involving advocacy, family support and supported decision making. For independent living to be successful, the issue of coordination across government and civil society interventions needs to be addressed. The European Union

⁶⁵ Mansell J, Knapp M, Beadle-Brown J and Beecham, J *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, pg 43

⁶⁶ Office of the High Commissioner, Europe Regional Office, *Getting a life, living independently and being included in the Community*, April 2012, pg 80.

⁶⁷ Mansell J, Knapp M, Beadle-Brown J and Beecham, J *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, pg 43

⁶⁸ Knapp M, McDaid D., Financing and funding mental health care services. In: Knapp M, McDaid D, Mossialos E & Thornicroft G, Eds. *Mental Health Policy and Practice across Europe*. Buckingham: Open University Press, 2007: 60-99

⁶⁹ Kendall J, Knapp M, Forder J., Social care and the nonprofit sector in the western developed world. In: Powell W & Steinberg R, Eds. *The Nonprofit Sector: A Research Handbook*. Second Edition ed. New Haven: Yale University Press, 2006.

for Fundamental Rights (FRA)⁷⁰ has pointed out basic human rights indicators that capture the above:

1. Structural- legal, policy and institutional framework. Is there a commitment to human rights work, adoption of appropriate legislation, policies, strategic plans, actions plans and/or guidelines, existence of a complaints mechanism?
2. Processes have to be effective. This means through budgetary allocations, implementation of policies, guidelines, actions plans, and an effective complaints mechanism.
3. Finally outcome of the structure and process should result in awareness creation of rights, measurable impact of the process and reduction in occurrence of violations.

Therefore, in order to identify best practices, the author shall rely on the minimum standards and indicators identified.

3.1. Legal Obligation

Article 19 of the CRPD requires that states put in place key laws and policies to make deinstitutionalization effective. Laws and policies are influenced by both internal and external factors. The mechanics underlying policy adoption and implementation on deinstitutionalization is depending on internal and external factors. Under internal factors, are issues such as lack of information on the merits and demerits of deinstitutionalisation, alternatives to deinstitutionalization and cost verses benefit analysis of the policy and evidence based mental health policy effectiveness which enables the government to make rational decisions⁷¹. External factors include constructive logic where countries are engaged in various policies to improve their legitimacy on the global stage. This is where a country may pass laws and policies a symbolic gesture with no intention to implement, enforce or monitor its implementation⁷². This section will analyse how both internal and external factors have been used to deinstitutionalize person with disabilities in Sweden, Bulgaria and Hungary.

Regional Approach to Legal Obligation in the European Union

Across the EU, psychiatric hospitals/residential institutions continue to play a central role in a number of countries. However, for some countries, hospitals are no longer used or have no more a central role in the mental health system e.g. Italy, Sweden and the UK have closed all or the majority of their psychiatric hospitals⁷³. Between 2005 to 2011, of the 21 countries for which information is available, only 8 countries provide access to home treatment to more than 50% of people with mental disorders; and 5% ensure access to 21-50 % of the population; of the 20 countries with reliable information, only 12 offer access to community-based rehabilitation to more than 50% of the people with

⁷⁰ Martha Stickings, *Independent Living: Assessing the Effectiveness of Policy measures*, Presented at the Deinstitutionalization practices and further development of social care policy in Europe, Riga, June 25, 2015.

⁷¹ Gordon C Shen and Lonnie R. Snowden, *Institutionalization of Deinstitutionalization: A cross-national analysis of mental health system reform*, Journal of Mental Health Systems, 2014.

⁷² Gordon C Shen and Lonnie R. Snowden, *Institutionalization of Deinstitutionalization: A cross-national analysis of mental health system reform*, Journal of Mental Health Systems, 2014

⁷³ JM Caldas Almeida, Pedro Mateus and Gina Tomé, *Joint Action on Mental Health and Well Being: Towards Community Based and Socially Inclusive Mental Health Care*, 2014, pg 103

mental disorders⁷⁴. These changes can be attributed to various factors as discussed below.

The EU has been instrumental in ensuring deinstitutionalization of person with disabilities in the region. In particular the EU has been largely successful in engaging governments in ensuring that disability rights become a reality compared to other regional bodies such as the African Union or the Inter American Commission. First is the European Social Charter 1961, (revised in 1996) which explicitly *...guarantees to persons with disabilities the effective exercise of the right to independence, social integration and participation in the life of the community*⁷⁵. Secondly the EU is the first and only regional body that has ratified the CRPD⁷⁶ and was recently reviewed by the CRPD Committee. When the European Union joined the CRPD in 2010 it became an integral part of EU law⁷⁷. In addition EU treaties, regulations, directives and decisions of the European Court of Justice are binding on member states. Thus once a treaty/directive/regulation/decision is adopted, member states are required to abide by it. Of particular importance is Article 26⁷⁸ of the Charter for Fundamental Rights (CFR) which reinforces the views enshrined in Article 19 of the CRPD though it does not indicate if it is a positive or negative right. In the alternative, Article 6 and 21 on non-discrimination can suffice. In addition, the EU has internalized the right to live independently and be included in the community through adoption of the Europe 2020 strategy (on social inclusion), European Disability Strategy 2010-2020⁷⁹. One theme that cuts across these strategies is to ensure 'economic, social and territorial cohesion' by rising awareness and recognizing 'the fundamental rights of people experiencing poverty and social exclusion, enabling them to live in dignity and take an active part in society.'⁸⁰

EU law does not deal with specific questions related to the involuntary placement and involuntary treatment of persons with mental disabilities⁸¹. However the Council of Europe adopted an Action Plan to ban institutionalization of persons with disabilities based on their disability or against their will⁸². Further under the same declaration, person who chose to live in institutions are guaranteed their human rights under the charter⁸³. The Parliamentary Assembly noted in its resolution on "Access to rights for people with disabilities and their full and active participation in society" that the ECHR protects everyone, including people with disabilities and that Article 15 (the right of persons with disabilities to independence, social integration and participation in the life

⁷⁴ Ibid, page 103

⁷⁵ Article 15 of the European Social Charter.

⁷⁶ The EU ratified the CRPD on 23rd December 2010.

⁷⁷ Open Society Foundations, *Community not Confinement; The Role of the European Union in Promoting and protecting the Right of People with Disabilities to live in the Community*, 2015.

⁷⁸ The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

⁷⁹ European Union, Initial Report to the CRPD Committee, 4 December 2014, CRPD/C/EU/1

⁸⁰ Open Society foundations, *The European Union and the Right to Community Living: Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities*, pg 27

⁸¹ European Union Agency for Fundamental Rights, *Involuntary placement and involuntary treatment of person with mental health problems*, 2012, pg 13.

⁸² Council of Europe, Recommendation (2006)5, Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, adopted on 5 April, 2006.

⁸³ European Union, Initial Report to the CRPD Committee, 4 December 2014, CRPD/C/EU/1

of the community) of the EU's Disability Strategy states that the European Commission will promote the transition from institutional to community-based care.⁸⁴

The above paragraphs allude to external factors that can influence government policies on deinstitutionalization. However, individuals can also use EU accession to the CRPD as an internal factor to advocate for deinstitutionalization. While individuals may not use the CRPD directly as a cause of action (except when a member state has ratified the Optional Protocol) they may rely on the CRPD indirectly via a duty of consistent interpretation in the application of EU law. Article 19 of the CRPD's negative obligations can be enforced indirectly via Articles 6 and 21 of the CFR. Article 19 of the CRPD's positive obligations cannot be enforced using the same legal device. However, it may be possible to enforce Article 19 of the CRPD's positive obligations using incidental effect if an individual could rely on a cause of action for instance, by deciding to reject a deinstitutionalisation project proposal, or by adopting calls for proposals that do not include deinstitutionalisation projects⁸⁵. Such projects may include the use of EU structural funds to improve institutions rather than improving access to community services.

Another push factor is the review of the EU by the CRPD Committee in September 2015. Under Article 19, the Committee recommends that the European Union develop an approach to guide and foster deinstitutionalisation, to strengthen the monitoring of the use of ESI Funds - to ensure they are being used strictly for the development of support services for persons with disabilities in local communities and not the re-development or expansion of institutions. It further recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached⁸⁶. Bulgaria, Croatia and Hungary, the countries under review in this section; all 3 are signatories to the CFR and members of the EU which then requires them to comply with the provisions of Article 19 on deinstitutionalization. In addition, all three countries receive funding from the EU which largely influences how policies on deinstitutionalization are adopted by each country.

In summary, a clear public policy supporting community living should be established to provide the foundation for community living rights and a clear message that institutional models will no longer be supported by public policy or funds⁸⁷. Government and community leaders must share a clear, unequivocal, public commitment that the institution will be closed, that resources will be allocated to the community and that planning will ensure that each person residing in the institution will be supported to move to his or her own home in the community with clear timelines.⁸⁸

⁸⁴ Open Society Foundations, *The European Union and the Right to Community Living: Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities*, Pg 27

⁸⁵ Open Society Foundations, *Community not Confinement, The Role of the European Union in Promoting and Protecting the Right of People with Disabilities to live in the Community*, 2015, pg 44

⁸⁶ UN CRPD Committee, *Concluding Observations on the European Union*, 4 September 2015, CRPD/C/EU/CO/1, Par. 51

⁸⁷ Joint Task force on deinstitutionalization, *The right way: A guide to closing institutions and reclaiming a life in the community for people with intellectual disabilities*, 2010, pg 15

⁸⁸ *Ibid*, pg 15

Sweden

It has been estimated that 20% to 40% of the Swedish population suffer from some type of mental health disorder, ranging from mild to moderate to severe mental health disorders and psychos⁸⁹. The development of health services in Sweden has undergone major legislative and organisational changes since the 1960s. In 1967, the county councils and their responsibilities were restructured, marking the end of the State mental hospital system⁹⁰. As part of the reform, Sweden was divided into 26 administrative units (county councils), under which operated general hospitals, primary health care units as well as psychiatric care services⁹¹. In the 1970s, several county councils established strategies to develop the psychiatric care system at a regional level. The aim was to abolish the system of separate mental hospitals and to move all psychiatric inpatient treatment to general hospitals. This engagement resulted in, for instance, the reduction of psychiatric beds: between 1973 and 1980, the number of psychiatric beds in Sweden dropped from 4.17 to 3.42 per 1 000 populations⁹².

The emergence and impact of a strong disability rights movement in Sweden during the 1980s saw the government adopt the Disability Act which introduced the use of a multi-level approach as part of their cost shifting strategy to guide deinstitutionalization and provision of community based care. The Disability

Up to the 80s, Sweden had a number of psychiatric institutions to cater for the needs of persons with mental health conditions. Around this time disability rights advocacy gained momentum causing a gradual shift from institutional care to community based care. The implementation of the Swedish Psychiatric Reform Bill passed in 1995 led to a structural change of the mental health care system and to the reallocation of financial resources from the counties to the municipalities. At the same time, outpatient and inpatient facilities were further extended and decentralised. The current system provides integrated outpatient and inpatient care in community-based units that have a small number of beds. Services are organised in a way that reinforces accessibility to services, continuity of care, integrated care, and the involvement of families and key organisations in the community. There are no units directly connected with a psychiatric hospital and all of them are located in residential areas. There are a small number of in-patient care beds (75 beds for 270,000 inhabitants). Most of the efforts are concentrated on outpatient care and over 65% of the resources are directed towards outpatient care. Psychiatric health care at home with home visits is the primary working method. Daytime activities, working in groups and family- and network-oriented working methods are an important part of outpatient care. The 9 inpatient care facilities have an integrated responsibility for both in-patient and outpatient care of the long-term patients. The mental health teams have an extensive collaboration with the social services in each residential area. On-duty and open care centres have a long-term collaboration with primary health care centres in the residential areas. In order to provide care adapted to some specific needs, there are specialised units/programmes for forensic patients, people with eating disorders, geriatric patients and psychotherapy. As part of the reform, municipalities should provide acceptable housing and support connected to housing, employment and some leisure time options.

Jose Miguel Caldas and Helen Killaspy, *Long term mental health care for people with severe mental disorders*, 2011

⁸⁹ Sweden National Statistics, Regeringskansliet. (2012). PRIO psykisk ohälsa - plan för riktade insatser inom området psykisk ohälsa 2012-2016 Available at: <http://www.regeringen.se/content/1/c6/19/37/97/644e4dfe.pdf>

⁹⁰ Silfverhielm, H. & Kamis-Gould, E. (2000). The Swedish mental health system: past, present, and future, *International Journal of Law and Psychiatry*. May-Aug;23(3-4):293-307.

⁹¹ Tuori, T., Gissler, M., Wahlbeck, K., and the Nordic reference group (2007) "Mental health in the Nordic Countries. In: NOMESCO: Health Statistics in the Nordic Countries 2005, pages 149-211" Nomesco, Nordic Medico-Statistical Committee 80, Copenhagen

⁹² OECD Health Statistics 2013, OECD Publishing, Paris, <http://dx.doi.org/10.1787/healthdata-en>

Act, fundamentally changed both the scale and scope of services available to people covered by it; in that care is provided within a universalistic care regime, underpinned by a “care responsibility culture” encompassing the roles of the private sector, public sector and the family. One defining feature of the Swedish care regime is that families do not have a legal responsibility to provide for the care needs of their adult members, even though in practice families play a considerable role⁹³.

A special government investigation was carried out in the early 1990s to investigate the conditions of treatment for people with long-term mental health disorders. The final report of this investigation highlighted important shortcomings in terms of the quality of care and social support for these patients⁹⁴. Following the findings of this investigation, a mental health care reform including changes in legislation was carried out in 1995 in Sweden. The main objective of the reform was to enable long-term psychiatric patients to live outside psychiatric institutions and nursing homes and to integrate these patients into the community. Psychiatric units and social service agencies were to increase efforts to coordinate care and support, given that social services held the responsibility for housing, daily activities and rehabilitation in the community. Adequate treatment methods were to be developed in specialised psychiatric care, and families and individuals were to be increasingly involved⁹⁵.

The Swedish state stipulates which populations municipalities are required to provide care for, how much they can charge for services, and what kind of organizations are allowed to offer services. People with severe disabilities under the Disability Act of 1993, are entitled to certain absolute rights. E.g. those with extensive functional impairments (not caused by normal ageing), local authorities are obliged to provide or to ensure these persons “good living conditions”. Disabled people who qualify for the services under the Disability Act, and who need extensive help with basic needs, may also be entitled to personal assistance, in which case the state covers the municipality’s costs for assistance up to 20 hours per week⁹⁶. The Social Services Act (SSA) introduced in 1982, regulates home-based care services and residential care including nursing homes. The goal of the SSA is to ensure a general right to claim support “if the needs cannot be met in any other way,” so that the individual can have a “reasonable level of living. “The legislation does not specify “needs” but there is a right to appeal to court if the individual is not satisfied with a decision. The challenge though is that while the Disability Act is clear on who is entitled, the SSA leaves the issue of determination to the municipalities. In addition, Sweden has the Swedish Personal Assistance Act of 1994⁹⁷ that guides the provision of services and assessment of individuals. The results of this Act have been documented as follows:

- tremendous improvement in quality of life for assistance users and their families;

⁹³ Adolf Ratzka, *Personal Assistance: Key to Independent Living as illustrated by the Swedish Personal Assistance Act*, paper presented at Colloquium “CRPD and EU Structural Funds: The way ahead for Independent Living”, United Nations Human Rights, Office of the High Commissioner, Europe Regional Office, Brussels, 7 May 2012.

⁹⁴ Tuori, T., Gissler, M., Wahlbeck, K., and the Nordic reference group (2007) “Mental health in the Nordic Countries. In: NOMESCO: Health Statistics in the Nordic Countries 2005, pages 149-211, Nomesco, Nordic Medico-Statistical Committee 80, Copenhagen

⁹⁵ Pauliina Patana, OECD Working Paper No. 82 Mental Health Analysis Profiles (MhAPs) Sweden, 3 July 2015, pg 10

⁹⁶ Kenneth Westberg, *Personal Assistance In Sweden*, Independent Living institute, 2010, pg 53

⁹⁷ Adolf Ratzka, *Personal Assistance: Key to Independent Living as illustrated by the Swedish Personal Assistance Act*, paper presented at Colloquium “CRPD and EU Structural Funds: The way ahead for Independent Living”, United Nations Human Rights, Office of the High Commissioner, Europe Regional Office, Brussels, 7 May 2012, pg 23

- greater visibility of persons with extensive disabilities in public;
- less need for services such as home helper, respite care, special transportation, etc;
- better quality of life at lower costs than municipal home helper services.

In conclusion, Sweden makes a good practice example because of its consistency in legal reform towards deinstitutionalization and successful implementation of deinstitutionalization policies.

Bulgaria

As at December 2014, the number of people under observation of psychiatric facilities, wards and consultation in Bulgaria were 64,896⁹⁸. 4.8% of this population were children aged less than 16 years. In addition, there are 28 psychiatric facilities with a bed capacity of 4,893. There is no current data on the number of persons in institutions versus those in community based care.

Calls for deinstitutionalization in Bulgaria started after the release of reports of systematic discrimination and abuse of persons with mental disabilities in psychiatric hospitals and social care homes⁹⁹. Of particular interest was the release of the 2007 documentary of Bulgaria's abandoned children in Mogilino Social Care Home which prompted the European Parliament to demand change for Bulgaria's institutions¹⁰⁰. This prompted the drafting of various laws and policies to deinstitutionalize children. One key outcome of this was the closure of the Mogilino Social welfare home with all children being transferred to social homes or family placement within the community¹⁰¹. According to the *Plan for Implementation of the National Strategy: Vision for the Deinstitutionalisation of children in Bulgaria*¹⁰² in 2010 1,376 children and young adults were placed in 24 institutions for children with intellectual disabilities. Of those, 420 were over 18. In 2013, Bulgaria spent 17.6% of its GDP on social protection benefits¹⁰³. By comparing the number of hospital beds to the number of person with mental health conditions, one can deduce that a significant number lives in the community. However, the allocated budgetary amount indicates that a small percentage do receive benefits from the government which indicates a low provision of community based care. This background informs the reasoning behind the policies adopted by Bulgaria.

The process of deinstitutionalizing and closure of institutions in Bulgaria exposed various gaps in the system that needed to be addressed. This include unresolved system

⁹⁸ The National Centre for Health Information as at 31 December 2014. People with intellectual disabilities - 28,760, people with schizoaffective disorders - 13,013, people with mood disorders - 23,123, and there are 2,495 people with dementia. http://ncphp.government.bg/files/nczi/izdania_2010/healthcare15_A.pdf

⁹⁹ Amnesty International, *Far from the Eyes of Society: Systematic Discrimination against People with Mental Disabilities*, 2002

¹⁰⁰ Kate Blewett, Director of Bulgaria's Abandoned Children, available at <http://truevisiontv.com/films/details/69/bulgarias-abandoned-children-revisited>

¹⁰¹ UNICEF, *Assessment of the Closure of DDMUI- Mogilino*, December 2012- September 2013.

¹⁰² Plan for Implementation of the National Strategy: Vision for the Deinstitutionalisation of children in Bulgaria, adopted by the Council of Ministers on 24 November 2010, p. 19, available at <http://sacp.government.bg/detstvo-za-vsichki/plan-za-dejstvie/> (accessed 10 May 2011)

¹⁰³ http://www.nsi.bg/sites/default/files/files/pressreleases/ESSPROS_2013_en_PH41L04.pdf (accessed 30 December 2015).

(structural) problems, lack of financing of the services, the access to external services, the lack of staffing and policies designed to identify the actual needs of children and young people, and the needs of the Services where they are placed, and hence the lack of real solutions to these problems. Some of the rights of children/young people are either not understood at all, or if there is certain understanding it is scarce¹⁰⁴. There are several key policies that were adopted to guide deinstitutionalization in Bulgaria:

1. The long-term strategy - Strategy for Equal Opportunities for People with disabilities 2008 – 2015, of the Republic of Bulgaria adopted by the Council of Ministers in 2007. The policy outlines the country's objectives with regards to person with disabilities. One key strategic objective of this policy was to prioritize the deinstitutionalization of children with its main source of funding being the EU structural funds.
2. The National Policy for persons with disabilities whose main objective was to guide the implementation of the National Strategy in the short term.
3. The Action Plan for Implementation of the Convention which outlines 10 strategic and operational objectives one of which was to identify key areas for legal reform, defining and implementing a coordination mechanism and capacity building. To coordinate the implementation of the Action Plan for Implementation of the Convention, a group of experts was established in 2013 with representatives who were to conceptualise the implementation of Article 19 in Bulgaria and be contact points at all responsible state authorities.
4. The National Reform Programme of the Republic of Bulgaria and the National Programme for the Development of the Republic of Bulgaria: Bulgaria 2020, Priority 2 on reducing poverty and promoting social inclusion" were updated to make room for community based care. In this respect, a long term care strategy was adopted to create conditions for independent and dignified life for the elderly and people with disabilities by improving access to social services and their quality, expanding the network of those services in the country, deinstitutionalization and promotion of the interaction between health and social services, as well as providing comprehensive support to families who care for people with disabilities and the elderly¹⁰⁵.

¹⁰⁴ UNICEF, *Deinstitutionalisation Of Children In Bulgaria - How Far And Whereto? Independent review of progress and challenges*, June 2014

¹⁰⁵ Republic of Bulgaria, Initial Report to the CRPD Committee, 4 December 2014, CRPD/C/EU/1, pg 19

The social services that were outlined under the National Programme for the Development of the Republic of Bulgaria: Bulgaria 2020 strategy were: Personal Assistant, Social Assistant and Home Assistant. According to the state party report, projects implemented under the laws and strategies mentioned resulted in 376 social services for adults with disabilities¹⁰⁶. There is no data on whether the legal reforms had an impact on the number of institutions¹⁰⁷.

The Government of Bulgaria approved amendments to the Social Assistance Act by-laws, which regulate the placement of disabled children and adults in need of constant medical care in family-type residential centres¹⁰⁸. These changes came with the Government decision to close down eight residential institutions for children aged 0 to 3, which was Bulgaria's commitment under the Direction: Family Project implemented by the Ministry of Health and funded by the 2007 – 2013 Human Resources Development Operational Programme of the Ministry of Labour and Social Policies¹⁰⁹. Most stakeholders agreed that Foster Care Project was successful with the numbers of foster carers in the country increasing to over 1000 and a total of 1943 children being

Outcomes of the Plan for Implementation of the National Strategy: Vision for the Deinstitutionalisation of children in Bulgaria

This plan has been successful because it was run in partnership with a wide range of stakeholders thus ensuring inclusivity and documentation of the process. For example: the European Commission Bulgaria and the Bulgarian Ministry for Labour and Social Welfare, asked Lumos to assist them in transforming the Vision into a National Action Plan. Lumos assisted the government to:

- Facilitate an inter-ministerial and inter-agency planning process that put in place a plan to end institutionalisation of children by 2025
- Negotiate with the European Commission to allocate more than 100 million Euros to the deinstitutionalisation programme
- Develop and implement assessment processes for children in institutions
- Develop management mechanisms at national and regional level to oversee the implementation of the plan culminating in the closure of the Krushari Institution for children with severe intellectual and physical disabilities in January 2016.

*Lumos, Ending the Institutionalisation of Children: A summary of progress in changing systems of care and protection for children in Moldova, Czech Republic and Bulgaria, 2014

Another example of the outcomes is the strategic partnership with the Cedar Foundation and the National Network of Children which resulted in the complete closure of the Gorna Koznitsa institution for children with intellectual disabilities in April 2010. The organisations applied a 5 step process starting with:

1. Situational analysis to identify key stakeholders and municipalities that would collaborate with them on the project.
2. Planning for change
3. Preparing the children, families and key stakeholders for change including training of staff on person centred planning and provision of community based services.
4. Moving children out of the institution and documentation of the process.
5. Assessment of the project focusing on outcomes and sustainability.

*Lindsay Saltsgiver, Margarita Parakova and Irina Papancheva, Creating New Horizons: Sharing the Experience of the Cedar Foundation in the closure of the Institution for children and youth with Disabilities in Gorna Koznitsa, 2012.

¹⁰⁶ Ibid, pg 21

¹⁰⁷ Republic of Bulgaria, Initial report on the implementation of the commitments under the Convention on the Rights of Persons with Disabilities within the meaning of Art. 35 of the Convention. Period: 2012 – 2013

¹⁰⁸ Interview with Margarita Parmakova, Cedar Foundation on 20 November 2015.

¹⁰⁹ European Network on Community Living, Re-Institutionalisation Continues in Bulgaria August 21, 2015 available at <http://www.enil.eu/news/re-institutionalisation-continues-in-bulgaria/>

cared for in foster care by the end of 2013¹¹⁰.

The Plan to deinstitutionalise children has been largely successful making Bulgaria a good practice example. Since 2010 the number of children in institutions has reduced by 54% especially since the Bulgarian **government decided to start deinstitutionalization with the most vulnerable children – young babies and children with multiple complex disabilities**¹¹¹. Bulgaria has set itself the target of 2025 to end institutionalisation. If the political will can be sustained, and EU funding continues to be channelled towards changing systems of care, it is likely that the target will be achieved much earlier¹¹².

Hungary

According to the World Health Organisation, as at 2011 there were 799 mental health outpatient facilities, 29 day treatment centres and 3 mental hospitals with a total of 7,202 psychiatric beds. There is no information on the number of community residential facilities¹¹³. NGO reports puts the figures at approximately 15,000 people with intellectual disabilities and 8,000 people with mental health conditions living in institutions in Hungary¹¹⁴. Government records as at December 2014 show that 8,775 person with disabilities live in psychiatric homes and 15812 in temporary homes for handicap adults¹¹⁵. A further 12,890 person with mental disabilities receive support services outside of institutions¹¹⁶. It is not clear what support they receive though a significant proportion of all people with disabilities live with their families, isolated from the rest of the society. The support services available are regulated by the Social Act of 1993, however access to these services is rather limited¹¹⁷. In 2006 Hungary spent 9, 6% of total social benefit expenditure on disability benefits with the largest part of disability allowances covers pensions¹¹⁸. A legal framework has been established in the last decade to promote integration and equal treatment of disabled persons.

Deinstitutionalisation of large institutions is a vital issue in Hungary. There are more large institutions than group homes, with majority of the existing group homes forming part of larger institutions¹¹⁹. Hungary has been in the lime light of mental disability rights because of; the large number of children living in institutions situation faced by

¹¹⁰ UNICEF, *Deinstitutionalisation of Children in Bulgaria - How Far and Whereto? Independent review of progress and challenges*, June 2014, pg 28

¹¹¹ Lumos, *Ending the Institutionalisation of Children: A summary of progress in changing systems of care and protection for children in Moldova, Czech Republic and Bulgaria*, 2014
<https://wearelumos.org/sites/default/files/Ending%20Institutionalisation%20of%20Children.pdf>

¹¹² Lumos report.

¹¹³ World Health Organisation, *Mental Health Atlas 2011*.

¹¹⁴ Mental Disability Advocacy Center, *Legal Capacity in Europe*, 2013, pg 54

¹¹⁵ Hungarian Statistics Office, *Residents in Long and short term residential institutions* available at https://www.ksh.hu/docs/eng/xstadat/xstadat_annual/i_fsi001.html

¹¹⁶ Hungarian Statistics Office, *Number of Recipients of Disability Support* available at https://www.ksh.hu/docs/eng/xstadat/xstadat_annual/i_fsg006.html

¹¹⁷ Tamás Gyulavári – Zita Éva Nagy, *ANED country report on the implementation of policies supporting independent living for disabled people*, 2009, pg 4

¹¹⁸ *Ibid*

¹¹⁹ Zsolt Bugarszki, Orsolya Eszik, Ágnes Soltész and István Sziklai, *One step forward, two steps backwards: Deinstitutionalisation of large institutions and promoting community-based living in Hungary through the use of the Structural Funds of the European Union*, 2010, pg 5

persons under guardianship where a decision on institutional care is made by the guardian rather than the person him/herself, and guardians are authorized to give consent to mental health care services¹²⁰. In addition was the (now repealed) Act CLIV of 1997 on Healthcare which allowed for subjecting persons with disabilities whose legal capacity is restricted to medical experimentation without their free and informed consent, as consent may be given by their legal guardians¹²¹.

Legal reform on deinstitutionalization in Hungary started with Act XXVI of 1998 on the Rights and Equal Opportunities for Persons with Disabilities which envisioned deinstitutionalisation of social institutions providing nursing and care for people with disabilities with a capacity exceeding 50 beds in line with the requirements of Article 19 of the CRPD. This led to the development of the Deinstitutionalization Strategy which aimed to deinstitutionalise institutions with a capacity for at least 1,500 people with disabilities and people with mental health problems with EU co-financing by 31 December 2013¹²². Unfortunately, the legal adaptation of alternative housing is wanting. Article 57 recognises three types of housing services: "a flat or house designed for up to 6 people, a flat or house designed for 7-12 people, and flats or an ensemble of buildings designed for a maximum of 50 people which resemble institutions. According to Article 75 of the Hungarian Social Act, supported living includes housing services, case management that promotes independent living, accompanying support which takes into account the living conditions of the person who receives care, the individual's complex needs assessment and an optional support services in the area of meals, nursing care, development and participation in the social life of the community¹²³.

The outcome of these laws can be summarised in the establishment of the National Body on deinstitutionalization. This body is tasked with the preparation of 3 year Action plans on deinstitutionalization to guide the use of EU financial resources, develop and define assessment methodology and supported living, organize training for professionals in the education, medical and social services field as well as awareness rising. There is very little data on the impact the laws have had on the number of institutions.

One of the main conclusions of this research study is that in Hungary, despite the signed international agreements and the relevant domestic legislation in this field, smooth implementation of deinstitutionalisation is not secured.

In 2009, several laws and policies were adopted (then later stopped by the Supreme Court) that had an impact on deinstitutionalization. First was the adoption of the National Programme of Disability Affairs (2007-2013) and the Governmental Resolution 1062/2007. (VIII.7) whose main impact was to mainstream disability in a number of

¹²⁰ UN CRPD Committee, Concluding Observation on Hungary, 22 October 2012, CRPD/C/HU/CO/1, Para. 21, 27, 29

¹²¹ Ibid

¹²² Zsolt Bugarszki, Orsolya Eszik and Zsuzsanna Kondor, Deinstitutionalisation in Hungary 2012-2013, Pg 8

¹²³ Ibid, pg 9

other government policies¹²⁴. With regards to deinstitutionalization, there are several legislations that guide the Hungarian government;¹²⁵

- Act XXVI of 1998 on the Rights and Equal Opportunities of People with Disabilities:
- Act CXXV of 2003 on the Equal Treatment and Promotion of Equal Opportunities
- UN Convention on the Rights of Persons with Disabilities (Act XCII of 2007)
- Government Decision 1257/2011. (VII.21.) on the strategy and the implementation of governmental tasks of the replacement of large social institutions providing nursing and caring for persons with disabilities in community based settings.

The outcome of these laws can be summarised in the establishment of the National Body on deinstitutionalization. This body is tasked with the preparation of 3 year Action plans on deinstitutionalization to guide the use of EU financial resources, develop and define assessment methodology and supported living, organize training for professionals in the education, medical and social services field as well as awareness rising. There is very little data on the impact the laws have had on the number of institutions. In Addition, the New Hungary Development Plan (UMFT) that defined the directions for development for the period 2007-2013, explicitly mentioned replacement of residential institutions as a goal and led to the creation of flat-homes¹²⁶ for children¹²⁷.

In conclusion Hungary is still in the initial stages of deinstitutionalization and developing community based alternatives to institutionalisation with majority of persons with disabilities still living in institutions¹²⁸. The process is highly centralised and controlled by the National Government hence little information on progress. Also there are findings that the government is using EU structural funds to build or improve institutions instead of developing community based services¹²⁹. Thus Hungary cannot be deemed as a good practice example.

Challenges

The move by the European Union and several countries to anchor deinstitutionalization in the law is a good practice. In that, this gives the individual the power to contest their right to live in the community or access to community services should the government fail to put in place measures. In addition, anchoring deinstitutionalization in the law makes it easier to measure impact through policy analysis and outcomes. However, the one challenge that stands out is in the implementation of the said policies as is the case in Bulgaria and Hungary where there are no clear outcomes of the policy. For instance in

¹²⁴ UN Convention the Rights of Persons with Disabilities Committee Concluding observations on Hungary, 22 October 2012, CRPD/C/HUN/CO/1, par. 6

¹²⁵ Miklos Szentkatolnay, *Experience of the transformation of social services in Hungary*, presented at Deinstitutionalization: The Way forward Conference, Prague, 14-15, 2013.

¹²⁶ Similar to group homes.

¹²⁷ Zsolt Bugarszki, Orsolya Eszik, Ágnes Soltész and István Sziklai, One step forward, two steps backwards: Deinstitutionalisation of large institutions and promoting community-based living in Hungary through the use of the Structural Funds of the European Union, 2010, pg 5

¹²⁸ Skype Interview with Magdi Birtha, Hungarian Civil Liberties Union, 11 December 2015.

¹²⁹ Camilla Parker and Ines Bulic, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transitions from Institutional Care to Community Living* (Budapest: European Network on Independent Living – European Coalition for Community Living, December 2013)

the case of Bulgaria's Family Project done in partnership with civil society; project partners complained that the state had no clear vision of how to support parents and families. Instead, the current situation was that sanctions and penalties to parents are the most used tools of the state when working with them resulting in the fact that the number of "children raised by the state" was not decreasing, even though there is a deinstitutionalisation process going on.¹³⁰.

Secondly is the use of archaic language in the law which then affect the implementation of the policy. For example, the Law on Integration of Persons with Disabilities and Social Assistance Act of Bulgaria, where disabled population is treated as beneficiaries of social assistance and users of services who need special protection (as opposed to citizens with equal rights who need support to participate in the life of communities by their individual choice)¹³¹.

Thirdly is the issue on stakeholder engagement and consultation in passing laws. Where stakeholders and in particular civil society and DPOs are left out of a discussion, the laws or policies passed may not be reflective of the needs of persons with disabilities. For instance, Hungarian government has been mentioned in several reports for delaying deinstitutionalization by refusing to consult with civil society especially in the use of structural funds which have been used to expand institutions rather than development of community services.¹³²

3.2. Choice and Control

The issue of choice and control links Article 12 of the CRPD to Article 19. When analysing country practices on choice and control with regards to independent living, the paramount consideration should be the individual will and preference of the person and not the best interest of the person. This is important as most states implementing de-institutionalization have implemented deinstitutionalization programs based on the best interest principle. In addition, family members have been known to use guardianship laws to institutionalise persons with disabilities under the best interest principle. However Article 19 envisions the will and preferences of the person over where to live, who to live with supports required and safeguards in place to protect the choice of the person. Individuals have a right to make decisions about their lives and to have control over the support they receive thus access to information, advice and advocacy should be provided so people are able to make informed choices about the support they want¹³³.

The UN General Comment on Article 12 links the issue of legal capacity to independent living and deinstitutionalization. There is a clear link between guardianship and choice. Historically, guardianship laws have been used to institutionalize person with mental

¹³⁰ National Network for children, 91% of Bulgarian parents believe that state policy is inefficient for families, 9 October 2015, <http://nmd.bg/en/91-of-bulgarian-parents-believe-that-state-policy-is-inefficient-for-families/>

¹³¹ Kapka Panayotova, *ANED country report on the implementation of policies supporting independent living for disabled people*, 2009

¹³² Judith E Klein, *Time for leadership in Hungary*, January 14, 2011 available at <https://www.opensocietyfoundations.org/voices/time-leadership-hungary>

¹³³ Michelle Murdoch, *Better for you, Better for Us, Supported Living in Community*, Executive Directors and Chairs Network, July 2013, pg 9

disabilities. Thus the General Comment gives clear interpretation of what choice and control in independent living is:

“(40) To fully realize the rights provided for in article 12, it is imperative that persons with disabilities have opportunities to develop and express their will and preferences, in order to exercise their legal capacity on an equal basis with others. This means that persons with disabilities must have the opportunity to live independently in the community and to make choices and to have control over their everyday lives, on an equal basis with others, as provided for in article 19.

(41) Interpreting article 12, paragraph 3, in the light of the right to live in the community (art. 19) means that support in the exercise of legal capacity should be provided using a community-based approach.

(42) (...) widespread denial of legal capacity to persons with disabilities, which allows others to consent to their placement in institutional settings. The directors of institutions are also commonly vested with the legal capacity of the persons residing therein. This places all power and control over the person in the hands of the institution. In order to comply with the Convention and respect the human rights of persons with disabilities, deinstitutionalization must be achieved and legal capacity must be restored to all persons with disabilities, who must be able to choose where and with whom to live (art. 19). A person’s choice of where and with whom to live should not affect his or her right to access support in the exercise of his or her legal capacity.”¹³⁴.

The concept of legal capacity and its link to liberty/institutionalization was discussed by the European Court of Human Rights in its 2008 judgment of *Shtukaturov v Russia*. The Court noted that 'as a rule, in such a complex matter as determining somebody's legal capacity, the authorities should enjoy a wide margin of appreciation. The extent of the margin will depend on 'the nature of the issues and the importance of the interests at stake' and 'the quality of the decision-making process'¹³⁵. In conclusion the court ruled that a mental illness cannot be the sole reason to justify deprivation of legal capacity and that such deprivation is not a ground to deprive a person of their liberty.¹³⁶

Choice and control over living space has largely been influenced by guardianship laws. It is not surprising to find families using guardianship laws to institutionalise person with mental health conditions. Thus Article 12 of the CRPD is important in that person with mental health conditions need to have their legal capacity restored in order to move and stay put of institutions.

¹³⁴ UN Convention on the Rights of Person with Disabilities, General Comment on Article 12.

¹³⁵ *Shtukaturov v Russia*, judgment of the European Court of Human Rights, Application No. 44009/05, 27 March 2008

¹³⁶ *Shtukaturov v Russia*, judgment of the European Court of Human Rights, Application No. 44009/05, 27 March 2008.

Canada

In the 1980s, guardianship laws came into focus in Canada. Civil society and self advocates brought the issue of forced institutionalization into the lime light. In 1984, the Canadian government prompted by anticipation that much of existing mental health legislation was susceptible to possible challenge under the *Charter*, a “Uniform Mental Health Act” was developed by a working group established under the Uniform Law Conference as a model for provincial mental health legislation. The working group consisted of a lawyer and a senior mental health official from each participating province and territory. The Uniform Mental Health Act was adopted by Uniform Law Conference representatives in 1987. The ensuring principles form the essence of the proposed Uniform Mental Health Act:

- A system that promotes voluntary admission and treatment with informed consent is preferred to compulsory services;
- Where there is no alternative to involuntary detention and treatment which limit a person’s liberty or right to make decisions, these limitations must conform with the *Charter*;
- A range of appropriate treatment options, including the least restrictive and intrusive alternatives, are offered and explained to the person;
- The duty of confidentiality of information in the medical file/record is heightened by the vulnerability of mentally-ill persons and the potentially severe consequences of improper release of such information;
- The patient has the right to view, for purposes of accuracy, documents gathered for the purpose of his/her medical treatment;
- If a person’s rights and freedoms are affected by legislation, an independent body or a court can review the decision to determine whether or not the decision was reached fairly.

Canada is one of the pioneer countries that started deinstitutionalization and community based care for persons with disabilities. Deinstitutionalization in Canada began in the 1950s and 60s which saw the closure of almost 80% of beds in psychiatric hospitals. However, there was no corresponding shift towards community based care which lead to homelessness and trans-institutionalization. Change began to occur in the 80s with the publication of reports such as the Graham report which shifted focus from the medical model to community based care. The report emphasised the need for personalised services in community care provision in order to move persons from institutions to the community. In addition was the development of the Putting People First Report of 1993 which outlined a 10-year plan to prioritizing the needs of people with serious mental illness, and recommended that, by 2003, the Ministry of Health and Long-Term Care commit 60 percent of mental health funding to community services and the remaining 40 percent to hospital care.

Along with funding was the issue of housing and employment. Homelessness and trans-institutionalization was linked to lack of supported housing and poverty. Thus the regional governments were tasked with creating deinstitutionalization plans which included supported housing and employment opportunities for person with mental disabilities to ensure that they can live and support themselves in the community.

Although the Uniform Mental Health Act was never implemented as such in each province and territory, many jurisdictions have enacted legislation which conforms to its fundamental principles. There remain, however, significant differences in the provisions of the relevant mental health statutes among the various jurisdictions. At present, the federal government has no comprehensive framework for mental health, mental illness and addiction federally or nationally. While several witnesses pointed to

the fact that Canada stands alone among similar G8 countries in not having a national mental health policy reaching across the applicable jurisdictional boundaries, others noted the absence of an integrated framework even at the federal level with its responsibility for the provision of mental health services and addiction treatment to specific groups¹³⁷.

In Canada, both supported decision-making and substitute decision-making regimes exist under Legislation in appropriate circumstances and in accordance with the law. Canada's reservation to Article 12 of the CRPD allows the use of substitute decision-making arrangements in appropriate circumstances and subject to appropriate and effective safeguards. Unlike the American case where safeguards are only afforded through litigation, in Canada, safeguards relating to the exercise of legal capacity are subject to regular review by an independent and impartial authority or judicial body, while others are subject to a review or appeal mechanism¹³⁸. With regards to Article 19 and the right to choice and control, Canada has entrenched this right in the Canadian Charter of Rights and Freedoms.¹³⁹ Persons with disabilities' are guaranteed mobility rights and individual liberty to choose a place of residence on an equal basis with others.¹⁴⁰

There has been wide debate on the need for institutionalization for person with severe disabilities. The basis of this was that the disabilities may require extensive supports that may not be adequately provided for in the community. The conclusion was that should a person remain in an institution, it should be based on his/her personal choice and not perceptions of disability¹⁴¹. This received judicial recognition in *Gray v. Ontario* [2006] where the court found as follows:

I accept that these residents are severely developmentally delayed and are no doubt very vulnerable individuals. However, it does not follow and the evidence does not establish that their needs cannot be met in community placements. On the contrary, the evidence establishes that individuals with this level of developmental disability have been placed successfully in community settings since the mid-1980. There have been no new admissions to the three remaining institutions for nearly 20 years¹⁴².

In addition, Canadian Association on Community Living has established a set of guiding principles on what choice in independent living looks like. While most countries look at independent living as the home, Canada considers aspects of employment, support services/programs and the family as part of independent living. Thus a deinstitutionalization plan must ensure that people have:

1. The right to choose where they will live, and with whom;

¹³⁷Parliament of Canada, Report on Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, available at

<http://www.parl.gc.ca/content/sen/committee/381/soci/rep/report1/repintnov04vol1part3-e.htm>

¹³⁸ Initial State Party Report of Canada, 7 July 2015 CRPD/C/CAN/1, Par. 14

¹³⁹ Sections 6, 7 and 15 of Schedule B of the Constitution Act 1982

¹⁴⁰ Initial State Party Report of Canada, 7 July 2015 CRPD/C/CAN/1, Par. 66

¹⁴¹ Daniel Rempel, *Review of Social Science Evidence concerning the Deinstitutionalization of Persons living with Mental Disability*, Public Interest Law Centre 2007, pg 17

¹⁴² *Gray v Ontario* [2006] O.J. No. 266 D.L.R. (4th) 717

2. Services/programs that are directed and controlled by the person and that are respectful of that person's right to make choices and take risks;
3. The right to individualized living arrangements and control over the required individualized funding;
4. The necessary disability related supports needed to fully participate in the community;
5. Support, as necessary, from friends/family/advocates to assist in decision making (supported decision making);
6. Services that meet all of their needs and are of high quality, portable and accessible¹⁴³.

Each individual must be empowered to choose where and with whom to live and the resulting living arrangement must truly be that person's home— not a facility, not a workplace and not a place where arbitrary rules or the needs of staff or others come first.

Choice and control in independent living includes making decisions over the choice of support one needs. There has to be a variety of options available or an opportunity to allow the person to make an informed decision as well as participate in making a decision. For example, one may want to move out of an institution but there is only one support option available that the person may not be comfortable with. The alternative is that there could be various alternatives to institutions but another person gets to determine what supports are required by the persons. To ensure the will and preference of the person is respected, there has to be a variety of supports available for the person to choose from.

For example, Canada's National Strategy of Equalization of Opportunities for Persons with Disabilities 2007– 2015, the Plan for Deinstitutionalization and Transformation of Social Welfare Homes provides various alternatives for person with disabilities. At national level, this includes the option of supported living, group homes, employment quota obligations, adoption of supported decision making models, disability benefits such as respite care amongst others. The primary mode of care available to persons with mental disabilities is respite care, out-patient care and short term hospital stays¹⁴⁴. In addition the government funds NGOs to provide community based services and deinstitutionalization programs to ensure that person with disabilities have a wide alternative of choices¹⁴⁵. Though service delivery is through the local municipalities and each county¹⁴⁶ can expand on the services being provided, the minimum choices have to be maintained.

As of fiscal 2001-2002 there were 948 care facilities for people with intellectual disabilities in Canada with 19 facilities housing 100 or more people and 70% of

¹⁴³ Joint Task force on deinstitutionalization, *The right way: A guide to closing institutions and reclaiming a life in the community for people with intellectual disabilities*, 2010, pg 9

¹⁴⁴ Janet Dumbrack, *Respite for Family Caregivers- An Environmental Scan of Publicly funded programs in Canada*, February 2003 available at http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2003-respite-releve/index-eng.php#a3_10

¹⁴⁵ Canadian Government, *Federal Disability Reference Guide*, 2013, available at http://www.esdc.gc.ca/eng/disability/arc/reference_guide.shtml

¹⁴⁶ Equivalent of Municipalities in Latvia and Sweden.

institutions housing between 4-9 persons¹⁴⁷. Large facilities with 100 or more beds decreased from 4% of all facilities for people with intellectual disabilities in 1986 to 2% from 1990 afterwards¹⁴⁸. Currently there are still challenges in deinstitutionalization and community living in Canada. An estimated 900 people with intellectual disabilities still live in institutions, 12,000 living in a health related facility with most people with intellectual disabilities living in group homes¹⁴⁹.

Czech Republic

According to statistics from 2013, there are 418 institutional care homes for persons with disabilities in the Czech Republic housing about 16,017 people with 1,045 being children¹⁵⁰. Mental disorders are the second most common reason for people becoming eligible for a disability pension. There are 20 psychiatric hospitals with a bed capacity of 9,000. Institutional care is also provided by psychiatric wards in hospitals with a total capacity of approximately 1,400¹⁵¹.

A new Civil Code (Supportive Measures for Decreased Legal Capacity) was adopted in 2012 which abolishes plenary guardianship in the Czech Republic. In its place was the adoption of supported decision making where a person with mental disability can enter into a contract with a support person for information sharing, communication and advice¹⁵². This is a good development as the practice was that people with disabilities with restricted legal capacity could be placed in an institution by their guardian who can sign a contract thereof; or placed into social care institutions by the

The process of deinstitutionalization in Czech Republic was influenced by two key periods. The first period was the socialist period of 1948-1998 when Czech Republic was under communist rule. During this period, centralized authority and large-scale institutions were introduced and key forms of substitute care, foster care, family settlements, and kinship care were effectively abolished¹. As a result, the number of institutions and the number of children in them grew dramatically throughout this period, with 166 institutions housing 10,752 children in operation in 1947 and 760 Institutions housing 45,058 children in 1962.

The second period begins from 1960-1990 when decentralization started in the republic and professionals in the field voiced concerns. Scholars such as Zdenek Matejchik published studies exposing the negative consequences of institutional care leading to introduction of reform measures such as foster and kinship care as viable alternatives to residential care*. However, institutional care remained the dominant care model for children with disabilities who would end up growing in institutions.

*Victoria Schmidt and Jo Daugherty Bailey, Institutionalization of Children in the Czech Republic: A Case of Path Dependency Department of Social Work,

¹⁴⁷ Cameron Crawford Residential Care Facilities in Canada for People with Intellectual Disabilities: Numbers and Trends (Technical Paper), 2002

¹⁴⁸ Cameron Crawford Residential Care Facilities in Canada for People with Intellectual Disabilities: Numbers and Trends (Technical Paper), 2002

¹⁴⁹ *First of Canada (PFC) and Canadian Association for Community Living (CACL) Task Force*, available at <http://www.institutionwatch.ca/about>

¹⁵⁰ Source: Ministry of Social Services Czech Republic, *Manuál transformace ústavů*, MPSV 2013

¹⁵¹ Jan Bodnar, *Reform of Psychiatric care in the Czech Republic, presented at Deinstitutionalization: The Way Forward* 14-15 February 2013 Prague

¹⁵² Section 45, Czech Civil Code (03/2009) Supportive Measures for Decreased Legal Capacity Mental Disability Advocacy Center (MDAC, *Legal Capacity in Europe*, 2013, pg 49

municipality, if they are viewed as lacking capacity and do not have a guardian¹⁵³. Most of the users of institutional services have none or limited capacity to legal acts, which is quite disproportionate to their real capacities. Care-takers (both family and public caretakers) had insufficient knowledge of the legal dispositions and factual issues on legal capacity. Thus are unable to assist the individual with social integration of the people with disabilities, their departure from an institutional facility to a protected or individual housing, the conclusion of an employment contract, their life with a partner, the utilization of user's own financial resources in order to pay for shopping, recreational activities etc¹⁵⁴. Thus by including supported decision making in the law, Czech Republic protects the rights of persons with disabilities to make independent decisions.

In practice however, there is still guardianship based on partial restriction. Though a person can raise complaints to the court on guardianship, experience is there still needs to be allot of awareness creation within the court system especially on the implications of the Civil Code¹⁵⁵. In addition, persons with disabilities living in the community do not have required support from community based services; they don't have enough money to cover support essential to an independent living. New institutional care services are being built and there is significant increase of places in so called "homes with special regime" (locked-up institutions with money from EU funds¹⁵⁶. For this reason, Czech Republic is not a good example of good practices in deinstitutionalization.

Challenges

In choice and control over independent living, the challenge of implementation is anchored on legal capacity. Guardianship laws are still enforced in most countries even where various models of supported decision making have been adopted. Various countries have tried to balance guardianship laws by putting in safeguards to guard against forced institutionalization. However the best approach would be to put in safeguards to ensure that supported decision making models are not abused. In addition, more effort should go towards making choice and control over independent living sustainable. This includes well established transition plans which prepare persons with disabilities to make decisions on their own or with appropriate supports.

3.3. Personalized Services

For inclusion and community based services to be realised, services for persons with mental disability have to be personalized. There are a variety of conditions associated with mental disability covers a wide array of conditions including psychosocial and

¹⁵³ Mental Disability Advocacy Center (MDAC), European Disability Forum, League of Human Rights (LIGA), NGO information to the UN Human Rights Committee For consideration of the Third Periodic Review of the Czech Republic under the International Covenant on Civil and Political Rights, Submitted on 14 June 2013, pg 8

¹⁵⁴ Difficulties in the transformation of institutional care Elaborated on the basis of experience acquired by the providers of various types of social services JUDr. Dana Kořínková Quip – Society for a Change, 2008

¹⁵⁵ Interview with Dana Kořínková, Legal Officer, QUIP on 26 January 2016.

¹⁵⁶ Prague, 21 April 2015 JDI – jednota pro deinstitutionalizaci – We are a wide group of ex-users of institutional care, people with disabilities, organizations and experts motivated, experienced and ready to help with the transition from institutional to community based care. Contact person: Terezie Hradilková, Threats to the process of transition from institutional to community based care in the Czech Republic <http://www.podporatransformace.cz/?p=277>

intellectual disability thus there cannot be a blanket application of services. Various models have been developed to ensure choice and control in independent living. This includes the use of person centred planning in transition from institutions to community based care, and use of personal budgets. These models take into consideration the individual needs, preferences and will thus the process more personalized. The most common personalised service is the personal budgets/individualised budgets. Though each country has a different name and approach to what can or cannot be covered under a personal budget the concept remains the same.

United Kingdom

In the UK, the Community Care (Direct Payments) Act 1996 enabled local authorities to provide direct payments to disabled people to allow them to commission their own services. The Welfare Reform Act 2009 introduced the Right to Control, while the Health Act 2009 introduced personal health budgets, both of which would extend disabled people's choice and control over their supported services.¹⁵⁷ The Government's 2005 cross-departmental report, *Improving the Life Chances of Disabled People*, set a goal that by 2025 "disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society". In particular, it aimed to help "disabled people to achieve independent living by moving progressively to individual budgets for disabled people, drawing together the services to which they are entitled and giving them greater choice over the mix of support they receive in the form of cash and/or direct provision of services."¹⁵⁸ One of the recommendations of this report was

In England and Wales, the Hospital Plan in 1962 predicted the closure of half of all psychiatric hospitals by 1975. A Government Paper on Hospital Services for the Mentally Ill, in 1971, proposed the complete abolition of the mental hospital model with all services being delivered by general hospitals in close collaboration with primary care and social services. Alongside these developments there was a shift towards the provision of other community-based services, such as supported accommodation, day services and community based multidisciplinary mental health teams (Killaspy, 2007). Over the last 50 years there has been much further investment in community based mental health services, with the National Service Framework for Mental Health (Department of Health, 1999) being the most obvious recent example. It detailed the national implementation of further specialist community teams (over 200 assertive community treatment teams, 50 early intervention services and 300 crisis resolution/home treatment teams) across England, working alongside community mental health teams and local inpatient mental health units. Other policies have supported the integration of health and social care services and the provision of a range of supported accommodation by both statutory, independent (private) and voluntary sector providers. Over time the models of supported accommodation have recognised the real potential of service users to gain and regain independent living skills and there is increasing investment in less "institutional" models (such as residential care homes) and more time-limited supported tenancies and "floating outreach" (non building based) support to people living in a permanent tenancy. More recent policy has refocused attention on the importance of the interface between primary and specialist mental health care for the treatment of common mental disorders, access to psychological therapies, attention to the physical health care needs of those with severe mental disorders and on the use of the Recovery approach (Department of Health, 2008; 2011).

* Caroline Glendinning, Long Term Care Reform in England: A long and Unfinished Story, 2013

¹⁵⁷ House of Lords Joint Committee on human Rights, Report on Implementation of the Right of Disabled People to Independent Living, Twenty-third Report of Session 2010-2012.

¹⁵⁸ Ibid, pg 37

the setting up of the Office for Disability Issues and the establishment of a body, Equality 2025, to advise the Government on how to achieve the aims of the report by 2025.

Though service delivery is through devolved government structures¹⁵⁹, the Independent Living Strategy guides how the different levels of government implement all projects across the UK but are at liberty to create their own strategies of implementation¹⁶⁰. Through the Community Care (direct Payments Act), Welfare Reform Act and Health Act, a variety of personal budgets models have been made available to assist persons with disabilities to live independently in the community. There is a slight distinction in the use of terms under the Acts. A personal budget refers mostly to funds aimed at providing social services under the Direct Payments Act. Individual Budgets refer mostly to a stream of funds envisioned under the Welfare reform Act and Health Act that cater for social services, education and health needs. Thus, in summary, these two acts lead to the creation of three types of personal budgets; direct payment, council managed or individual service fund. Thirdly, since social services are funded by local authorities the amount received by the persons is dependent on the needs and income level. That is, where a person has a source of income/wealth, that will be put into consideration in determining the amount of the personal budget being received from the local council¹⁶¹

In most cases, recipients of the funds would be expected to go through a needs assessment, a planning process where the views of the person and caregivers are included and continuous monitoring and reporting once the personal budget is approved. It must be noted, in the UK, personal budgets are used for health care, social welfare and education needs. Persons with disabilities are expected to work with a supporter, carer/family or council appointed persons to manage and monitor the use of their personal budgets. The needs assessment would be used to determine how much money is available to the person. The next step is for the person along with supporters to plan and determine how the funds would be used. Personal budgets can be used in a variety of ways. First, the person could use the funds to pay for a personal assistant, housing related support, equipment and adaptations and domestic care. The Council however determines the limits of what fits within the requirements. The second alternative is the person could pay back the funds to the local authority to purchase services on the user's behalf and as agreed in the planning process.

The most recent personal budget survey showed that 78.9% of beneficiaries were more independent, and 82% felt dignified in the support they received¹⁶². 68.8% of carers felt that the process was inclusive and had better outcomes in quality of life and self-esteem¹⁶³. Based on the outcome of the model, one can deduce that this is good practice.

¹⁵⁹ The UK is made up of several Kingdoms which then form the devolved Structure. In this paper use of the term Local Authority refers to the Government of Scotland, Government of Wales, Government of England and Government of Northern Ireland.

¹⁶⁰ House of Lords Joint Committee on human Rights, Report on Implementation of the Right of Disabled People to Independent Living, Twenty- third Report of Session 2010-2012, pg. 32.

¹⁶¹ Caroline Glendinning, *Long Term Care Reform in England: A long and Unfinished Story*, 2013, pg 181

¹⁶² Christ Hatton, and John Waters, *National Personal Budget Survey: Summary of Main findings and next steps*, Lancaster University, 2013.

¹⁶³ Ibid, pg 11

Sweden

In Sweden just like the UK, the care regime is highly decentralized under the Social Services Act. The Social Services Act (SSA) regulates home-based care services and residential care including nursing homes. The SSA guarantees a general right to claim support “if the needs cannot be met in any other way,” so that the individual can have a “reasonable level of living.” The legislation does not specify “needs” but there is a right to appeal to court if the individual is not satisfied with a decision¹⁶⁴. Secondly under the Act, municipalities have primary responsibility for organizing publicly funded care services, both home-based and residential. Municipalities also have the substantial taxing powers required to fund much of the total public budget for formal care for older people (85 %) and for people with disabilities (around 70 %). Municipalities are also free to decide on the distribution of different types of care (for example, between homecare and residential care in eldercare services) and between services that meet the needs of different social groups (for example, eldercare, childcare, and disability services). The National government plays a role in funding (up to 10% of the national budget), legislation and regulation; financial incentives; and oversight and guidance¹⁶⁵.

Secondly, the Swedish Personal Assistance Act guarantees each and every person the right to personal assistance irrespective of income/wealth¹⁶⁶. Personal Assistance budgets are prepared based on a needs assessment report though service provision may vary. Assistance needs in terms of the number assistance hours needed are assessed by case managers at the tax-funded Social Security Fund. Each month recipients get an amount that corresponds to the costs of these hours. Budgets are not dependent on the financial situation of the state nor on recipients’ and their families’ income or property nor on whether one buys services from a provider or employs one’s assistants¹⁶⁷. Payments for basic services, specialized services, health care needs etc are paid by the user. Users pay wages at going market rates for this type of work and the use of funds has to be fully accounted for. The budgets also allow for payment of provider’s administrative costs thus, private companies have an incentive because they can cover their expenses and make even profits¹⁶⁸.

The Compulsory Psychiatric Care Act outlines the conditions under which a person may be committed to involuntary treatment. As care is not normally to be given without the individual’s consent, compulsory treatment may only be ordered for patients who object to care, but are suffering from a serious psychiatric disturbance. This care is only to be provided in instances where “due to their psychiatric condition or personal circumstances”; an individual needs psychiatric treatment that will only be effective if

¹⁶⁴ Gabrielle Meagher and Marta Szebehely, *Long-Term Care in Sweden: Trends, Actors, and Consequences*, 2013, pg 57

¹⁶⁵ Ibid

¹⁶⁶ European protection systems in the areas of childcare and long-term care: Good practices and lessons learned Stefania Ilinca, Kai Leichsenring, Eszter Zólyomi and Ricardo Rodrigues Vienna, November 2015 European Centre for Social Welfare Policy and Research, pg 33

¹⁶⁷ Adolf Ratzka, *Personal Assistance: Key to Independent Living as illustrated by the Swedish Personal Assistance Act*, presented at Colloquium “CRPD and EU Structural Funds: The way ahead for Independent Living”, United Nations Human Rights, Office of the High Commissioner, Europe Regional Office, Brussels, 7 May 2012

¹⁶⁸ Kenneth Westberg, *Personal Assistance in Sweden*, Independent Living Institute, 2010

the patient is admitted to an inpatient psychiatric care facility¹⁶⁹. In addition, persons with certain functional impairments are entitled to certain specific forms of assistance, such as counselling, daily activities, personal assistance, housing with special services or personal companions and contacts.¹⁷⁰

The outcomes of the impact of these two Acts have been clear. By the 1980s residential institutions had been phased out in Sweden except for group homes where 4-5 persons live together in a house or large apartment with common staff¹⁷¹. Compared to what it would have cost to provide the same number of hours through municipal home helpers direct payments for personal assistance have saved the Swedish taxpayer some € 3 billion and at considerably higher service quality. In addition, official government reports show that personal assistance users consume less healthcare, special transportation and other local government services¹⁷².

3.4. Access to Community Services

Community based alternatives to asylums were first developed in the 1920s and 1930s in Italy and France. Globally, it was only by the 1950s, as patient numbers continued to increase and unacceptable standards of care in asylums came to the fore, that community alternatives were considered more seriously by professionals and the public. A community mental health team, with a multidisciplinary team, is a core component of community mental health services. Social care services are an important part of any community mental health service given the range of non-health support needs someone with a severe mental illness often has. Good community-based services are organised on the basis of certain principles¹⁷³:

1. They are *person-centred*. That is, they are tailored to the individual's needs, wishes and aspirations, providing assistance in whatever way best helps the person achieve their own goals and adapting the kind and level of support as required over time.
2. They *support family and community life*. They provide extra help to the person, their family and friends to enable them to live in and be part of their community, augmenting their resources rather than displacing or disrupting them.
3. They adopt *a social model of disability*. They recognise that the experience of impairment is mediated by social structures and processes and address these.
4. They *address all of people's lives*. They provide whatever help is needed to overcome the effect of impairment and disability to enable people to have a good quality of life. They do not pretend that people can manage without extra help.

¹⁶⁹ Bolling, J., Rosenberg, D., Kawesa, V. (2009) "Mental health study – Sweden" European Union Agency for Fundamental Rights (FRA)

¹⁷⁰ Tuori, T., Gissler, M., Wahlbeck, K., and the Nordic reference group (2007) "Mental health in the Nordic Countries. In: NOMESCO: Health Statistics in the Nordic Countries 2005, pages 149-211; Nomesco, Nordic Medico-Statistical Committee 80, Copenhagen

¹⁷¹ Adolf Ratzka, *Personal Assistance: Key to Independent Living as illustrated by the Swedish Personal Assistance Act*, presented at Colloquium "CRPD and EU Structural Funds: The way ahead for Independent Living", United Nations Human Rights, Office of the High Commissioner, Europe Regional Office, Brussels, 7 May 2012

¹⁷² Initial State Party Report for Sweden, 18 September 2012, CRPD/C/SWEDEN/1

¹⁷³ Mansell J, Knapp M, Beadle-Brown J and Beecham, J, (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report*. Canterbury: Tizard Centre, University of Kent.

5. They ensure these principles are expressed in the day-to-day assistance provided to the individuals they support.

Croatia

In Croatia civil society organizations and local governments have developed a range of community based alternatives to institutions. The sustainability of the process is enshrined in how the person is prepared for deinstitutionalization. These programs provide quality care to their participants, allow participants to choose the programs that are best for them, and promote interaction between participants and the community to ensure excellent alternatives to institutions. At the beginning of the deinstitutionalization process, clients are prepared to leave the institutions through training on self advocacy and self-determination. Over time clients form groups that meet regularly to learn and discuss their rights, responsibilities and how they would like to be supported to live in the community such as supported housing and improvement of service delivery.¹⁷⁴ In addition, staff and parents have been trained to understand person centred approaches rather than best interest principles. Though largely driven by civil society organizations, the Croatian government provides safeguards through monitoring and awareness creation on supported living. A person leaving the institution has a variety of community based alternatives offered by the government to choose from. These include:

1. Supportive and Independent Community Living Environments: these homes provide individuals with apartments, support and care in the community, outside the grounds of institutions). Such assistance, including help buying groceries, cooking, house cleaning, personal grooming, and finding employment, is based on individual needs and requests. For persons with psychosocial disabilities, it might also include access to mental health care, if requested. Sometimes called “organized housing” by the Ministry of Health and Social Welfare, these programs also include some facilities otherwise classified as “family homes” or social welfare homes called Homes for Independent Living.

**Ministry of Social Policy and Youth,
Deinstitutionalization of children and adults: Social
Protection System Modernization Project-
Component IV**

As at 2013, in Croatia, there are:

1. 90 homes and other legal persons providing social welfare services without being established as homes, which offer accommodation services (44 state-run homes, 15 non-state homes and 8 other legal entities as well as 23 family homes)
2. there was a total of 8,311 beneficiaries placed in institutional accommodation in the Republic of Croatia
3. 6,757 beneficiaries accommodated on a long term or weekly basis in 2013, of which:
 - 2,781 children and adults with physical or intellectual impairments
 - 600 children with developmental difficulties
 - 2,181 adults with disabilities
 - 3,976 adults with mental impairments

* Zvezdana Bogdanović, and Dubravka Marušić, Head of Department, Ministry of Social Policy and Youth,

¹⁷⁴ Judith E Klein, *Deinstitutionalization in Croatia: A Summary of Open Society Support*, 2014.

2. Day Centres and Temporary Accommodations: These programs provide day or overnight accommodations and support at a facility outside the individual's home, often to offer a respite to primary caregivers. Participation in these programs requires that individuals have their own permanent place to live, or are able to live with family.
3. Family-based support: Individuals can live with their family, and primary caregivers in the family can receive a stipend for providing necessary support¹⁷⁵.

According to the World Bank report on Croatia (2014) the Plan for Transformation and Deinstitutionalization of Social Welfare Homes and Other Legal Entities Providing Social Welfare Services in Croatia for the period 2011-2016 (2018) provides for the following goals by 2016¹⁷⁶

- to change the ratio of institutional and non-institutional care so as to have 20% of beneficiaries in institutional forms of care and 80% of beneficiaries in non-institutional forms of accommodation for children and youth without adequate parental care
- to deinstitutionalize 40% of children and youth with behavioural problems, who are currently accommodated in homes
- to reduce the total number of adults with disabilities placed in long-term or weekly accommodation in homes and other legal entities providing social welfare services by 30%

Like many European countries, Croatia has been badly affected by the global financial crisis. As a result, it has experienced significant cuts in government spending, which have likely contributed to the slow pace of reform. However financial crisis did threaten to affect provision of services but the government did not reduce funding towards deinstitutionalization projects.¹⁷⁷ However, at the heart of Croatia's failure to live up to its pledge is not lack of money but lack of leadership concerning the process of deinstitutionalization. This includes the need to create a plan for deinstitutionalization and the prevention of institutionalization and to develop viable alternatives such as supportive and independent community living programs¹⁷⁸.

¹⁷⁵ Human Rights Watch, *Once you Enter you never leave: Deinstitutionalization in Croatia*, 2010, Pg 23

¹⁷⁶ Zvezdana Bogdanović and Dubravka Marušić, *Deinstitutionalization of children and adults Social Protection System Modernization Project-Component IV*, 2015.

¹⁷⁷ UN Committee on the Convention on Persons with Disabilities, Concluding observations on Croatia, 15 May 2015, CRPD/C/HRV/CO/1, para. 4,

¹⁷⁸ Human Rights Watch, *Once you enter, you never leave*, 2012

United States of America

Institutions were introduced to the US from Europe by Samuel Howe around 1860¹⁷⁹. However by 1866 Howe, who had been a leading and influential figure in introducing the institutional care model, grew concerned that they were failing to achieve his vision and that they were taking on some very undesirable characteristics. In a speech at the laying of a cornerstone of a new institution in 1866, Howe warned:

“Grave errors were incorporated into the very organic principles of our institutions... which make them already too much like asylums; which threaten to cause real asylums to grow out of them, and to engender other evils.” all such institutions are unnatural, undesirable, and very liable to abuse.” “We should have as few of them as possible, and those few should be kept as small as possible.” “Such persons [with disabilities] (...) should be kept diffused among sound and normal persons¹⁸⁰.”

The US is a signatory to the CRPD but has not ratified it. Research has been done in America to determine how the CRPD differs from American disability law. The results of these studies have varied to a degree, but the findings of these studies have been that American disability law and the CRPD are harmonious.

In the US, there are two factors to take into consideration. Whereas the federal government may guide minimum standards on community based services, implementation and diversification of services is at the sole discretion of the states.

Nonetheless, institutions were built at increasing rates until reaching a peak in 1970, when about 280 institutions were operating in the U.S. Families were convinced that institutions were the best place for persons with intellectual disabilities given their limited potential for normal development, and the 'burden' that care would impose on families and communities. When Howe spoke his warning words, the total U.S. population experience of institutional life consisted of one or two thousand people. By 1970, that number reached 187,000 and by the year 2000 it would plummet to 43,000, with 125 institutions closed or slated to close¹⁸¹. In the 1980s, activism against institutionalization of persons with intellectual disabilities compounded with strategic litigation began the process towards gradual closure of institutions. Currently, nine U.S. States and the District of Columbia have closed all of their public institutions¹⁸².

Deinstitutionalization and access to community based services was mostly driven by litigation against forced institutionalization. The landmark case *Olmstead v. L.C.*¹⁸³ involved two women, Lois Curtis and Elaine Wilson, who had mental illness and had voluntarily been admitted to a state run psychiatric hospital. After treatment the health

¹⁷⁹ James W. Conroy, *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities*. Final Report on 3 years of Research and Analysis (Narberth, PA: Center for Outcome Analysis, 2002) [Outcomes] at 3.

¹⁸⁰ *Ibid*, pg 3

¹⁸¹ Multiple authors, “Trends in institution closure” in “Community for All” Tool Kit: Resources for Supported Community Living, online at http://thechp.syr.edu/toolkit/Community_for_All_Toolkit_Version1.1.pdf. (Syracuse: Human Policy Press, 2004) [Tool Kit] at 70.

¹⁸² James W. Conroy, *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities*, (Narberth, PA: Center for Outcome Analysis, 2002).

¹⁸³ *Olmstead v. L. C.* 527 U.S. 581 (1999)

professionals recommended them to move to community based programs but they remained institutionalized for several years after the recommendation. They filed suit under the Americans with Disabilities Act (ADA) for release from the hospital. On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity¹⁸⁴."

The *Olmstead* Case set the ground for disability activists and state governments to set up systems on community based services. After *Olmstead*, the lawsuits that followed slowly defined the contours of the decision including that *Olmstead* applied to individuals living in the community who were at risk of institutionalization¹⁸⁵. In addition the United States Justice Department made *Olmstead* rights a priority of its Civil Rights division through taking up complaints, giving advisory opinions and pursuing cases and settlements against states that are yet to comply with the ruling¹⁸⁶. A good example of the department's involvement in deinstitutionalization is the case of *Lane v. Brown*¹⁸⁷ which questioned the civil rights of individuals with intellectual and developmental disabilities who are unnecessarily segregated in sheltered workshops, or at risk of such unnecessary segregation. 3,944 private individuals working in sheltered workshops sued the State of Oregon alleging that that the State's employment service system over-relied on segregated sheltered workshops to the exclusion of integrated alternatives, such as supported employment services, and placed individuals, including youth, at risk of entering sheltered workshops¹⁸⁸.

¹⁸⁴ *Olmstead v. LC: History and Current Status* <http://www.ada.gov/olmstead/index.htm>

¹⁸⁵ *Olmstead v. LC: History and Current Status*. <http://www.olmsteadrights.org/about-olmstead/>

¹⁸⁶ *Olmstead v. LC: History and Current Status* <http://www.ada.gov/olmstead/>

¹⁸⁷ *Lane v. Brown* (*Lane v. Kitzhaber*) – 12-CV-00138 – (D. Or. 2012)

¹⁸⁸ *Ibid*

The case was resolved through a settlement where over a 7 year period, 1,115 working-age individuals with intellectual disabilities who were currently being served in segregated sheltered workshops would have opportunities to work in real jobs at competitive wages. Additionally, at least 4,900 youth ages 14 - 24 years old will receive supported employment services designed to assist them to choose, prepare for, get, and keep work in a typical work setting. Half of the youth served will receive, at a minimum, an Individual Plan for Employment through the State's Office of Vocational Rehabilitation Services. Correspondingly, the State will reduce its reliance on sheltered workshops and implement policies and capacity-building strategies to improve the employment system to increase access to competitive integrated employment and the opportunity for people with intellectual disabilities to work the maximum number of hours consistent with their abilities and preferences.¹⁸⁹

On supported housing, plenary guardianship is applicable in the US, the title II of the ADA makes room for guardianship to be challenged. Whereas each state has its own application of guardianship law, the general rule is that any person advocating must argue in the persons best interest as determined by a court appointed guardian, even if the person disagrees¹⁹⁰. Guardianship laws are still applicable under the American with Disabilities Act though various attempts have been made to include supported decision making. In this regard, courts have used both guardianship laws and supported decision making models to enable persons with intellectual disabilities to move out of institutions. Recent litigation demonstrates this fact. The Jenny Hatch case¹⁹¹, Jenny, a 29 year old with Down syndrome, was under guardianship with her biological parents (the petitioners) who had placed her in a group home. Jenny did not want to live in group home and thus presented the petition to have her guardianship revoked. She wanted to reside with the Talberts (the intervenors in the case) with whom she had been residing with for a year before she was placed in a group home. In addition the Talberts supported Jenny's right

¹⁸⁹ Settlement Agreement, http://www.ada.gov/olmstead/olmstead_cases_list2.htm#lane

¹⁹⁰ In a 2010 decision called *In Re Martel*, the D.C. Court of Appeals

¹⁹¹ *Ross v. Hatch*, Virginia Circuit Courts, 2013 Jenny Hatch Project, Quality Trust for Individuals with Disabilities.

Youth Transition Program: Oregon USA

The Youth Transition Program (YTP) offers a new pattern of services to students with disabilities beginning when they are still in high school and continuing into the early transition years. Since 1990, over 23,000 youth with disabilities have received YTP services.

In each participating school district, YTP services are provided jointly by a Transition Specialist and a local

Vocational Rehabilitation Counsellor. Students participating in the YTP receive

- (a) Individualized planning, focused on post-school goals and self-determination and help to coordinate school plans with relevant community agencies,
- (b) Instruction in academic, vocational, independent living, and personal social skills and help to stay in and complete high school,
- (c) Career development services including goal setting, career exploration, and job search skills, and self-advocacy,
- (d) Competitive employment including connections with local employers, on the job assessments, placement, and training,
- (e) Support services such as individualized mentoring and support or referrals for additional specific interventions, and
- (f) Follow-up support for one year after leaving the program to assist in maintaining positive outcomes in employment or post-secondary settings.

Recent outcome data shows that 80% of YTP participants are engaged in employment or post-secondary training upon completion of the program. These positive outcomes are maintained at 6 month and 12 month follow-up time points.

*European Association for providers for Persons

to supported decision making and freedom from guardianship. The court allowed partial guardianship joint between the intervenors and the petitioners based on the fact that Jenny Hatch had made some questionable financial decisions but this guardianship was to only cover a year. In addition, Jenny Hatch was allowed to make a decision on where to live based on her own will and preference and with supported decision making.

Though guardianship is still applicable in the US, this case goes to show that the system is gradually changing towards the will and preference of the person rather than the best interest of the person. Secondly, litigation can be a safeguard where there are no administrative alternatives to protect the right of the person to make a choice over independent living.

Italy

Deinstitutionalization in Italy was informed by the radical ideas of Franco Basaglia and Italian Psychiatrist who influenced the development of the 1978 Italian Mental Health Law (Italian Law Number 180). Basaglia studied the failure of deinstitutionalization in America in the 1950-60s which resulted in forced re-institutionalization of the mentally ill to form his hypothesis for community based care in Italy¹⁹². Basaglia believed that mental illness was caused by sociological factors and it was a lack of response to these social factors that caused “madness”¹⁹³. Thus by addressing the social needs of persons with mental health conditions, one could address mental illness.

Italian Law Number 180 of 1978 was the reform law that marked the transition from a hospital-based system of care to a model of community psychiatry. The Law specifically looked outside the medical aspect of mental disorders to the “social” components of the factors involved in the origin of the disorders, viewed relational as well as economic and

Summary of the main characteristics of the 1978 Italian Psychiatric Reform based on the research work of Basaglia:

1. Gradual closure of public mental hospitals by blocking all new admissions, with immediate effect (i.e. from 1978), as well as readmissions, two years later (i.e. from 31 December 1980).
2. New community-based services (community mental health centres, day hospitals, and residential facilities) were to be established to provide all types of psychiatric care to the population of a given area. Initially, such services had to be staffed mainly through the relocation of mental hospital personnel.
3. Hospitalization, when necessary, had to take place in general hospital psychiatric wards. These wards were not to exceed 15 beds, in order to avoid an excessive concentration of psychiatric patients, a characteristic of the mental hospital that was considered detrimental to its patients’ well-being.
4. Compulsory evaluation and treatment required in general hospital psychiatric wards. The criteria for involuntary admission were:
 - (a) an emergency intervention was needed,
 - (b) the patient refused treatment,
 - (c) alternative community treatment was impossible.

*Francesco Amaddeo, Corrado Barbui & Michele Tansella, *State of psychiatry in Italy 35 years after psychiatric reform. A critical appraisal of national and local data*, 2012

¹⁹² G. B. Palelrmio, *Italian Mental Health Law- a personal evaluation*, Journal of the Royal Society of Medicine, vol. 84, February 1991.

¹⁹³ Szasz TS, *The myth of mental illness*. New York: Harper & Row, 1974

political.¹⁹⁴ The new system was intended to provide care and support to all types of patients, without back up from the public mental hospital, where only old long-stay inpatients could continue to be accommodated. After more than 30 years of implementation, Law 180 is still unique in the international scenario, considering that Italy remains the only country in the world where traditional mental hospitals are outside the law¹⁹⁵.

In 1978 when the reform law was approved, there were 78,538 residents in Italian mental health institutions¹⁹⁶. All institutions in Italy are now closed. The Basaglia psychiatric reform of 1978 established four principal components¹⁹⁷:

1. the gradual phasing out of Mental Hospitals (MHs) through the cessation of all new admissions;
2. the establishment of General Hospital Psychiatric Units (GHPUs) for acute admissions, with a maximum of 15 beds each;
3. more restrictive criteria and administrative procedures for compulsory admissions; and
4. the setting up of Community Mental Health Centres (CMHCs) providing psychiatric care to geographically defined areas.

The WHO Global Burden of Disease Project estimated that, in Italy in 2001, 2 978 per 100 000 population are ascribable to neuropsychiatric disorders, representing approximately 25% of the overall burden of disease in Italy¹⁹⁸. Mental health services are currently organized through 211 Departments of Mental Health, covering the entire country, each of which is responsible for a geographically defined area.¹⁹⁹ According to the Ministry survey in 2001, 707 CHMCs were operating in 2001 – an average of 1.88 per 150,000 general population. These centres deliver the bulk of outpatient and non-residential care, mainly through a network of 1,107 outpatient clinics, 309 day-hospitals and 612 day-centres²⁰⁰. In 2001, 30,711 workers were employed with unlimited contracts with the National Health Service mental health facilities²⁰¹.

To foster inclusion in the community, Italy carried out two campaigns against stigma on mental health – “Mental health disorders can be cured: more information, less discrimination” – was conducted on April 2006 with the aim of fighting discrimination against people suffering from mental illness and informing the youth about mental health issues²⁰².

¹⁹⁴ Giuseppe Bersani , *The Italian Law “180” thirty years after: from the unmet needs of sick people and families the duty of a critical reflection*, 2009

¹⁹⁵ Francesco Amadeo, Corrado Barbui & Michele Tansella, *State of psychiatry in Italy 35 years after psychiatric reform. A critical appraisal of national and local data*, 2012

¹⁹⁶ Giovanni de Girolamo E Mariano Bassi E et al., *The current state of mental health care in Italy: problems, perspectives, and lessons to learn*, Euro Arch Psychiatry Clinic Neurosci, 2007, pg 257:83–91

¹⁹⁷ Ibid, pg 87

¹⁹⁸ Alessia Forti, OECD Health Working Paper No. 71 Mental Health Analysis Profiles (MhAPs) Italy, 7 July 2014, pg 19

¹⁹⁹ Ibid, pg 87

²⁰⁰ Maone A, et al., *Day programs in Italy for persons with severe mental illness: A nationwide survey*, International Journal on Mental Health (2002) :30–49, pg 31

²⁰¹ Maria Benedetta Gambacorti-Passerini, *The Challenge of Educational Work in the Italian Psychiatric Services*, 4th International Conference on Education, Research and Innovation, vol. 81 2014.

²⁰² Alessia Forti, OECD Health Working Paper No. 71 Mental Health Analysis Profiles (MhAPs) Italy, 7 July 2014, pg 32

The reason why deinstitutionalization was successful in Italy is because of the idea of multidisciplinary approach employed by Law 180. The Law attributed meaning to the role of each of the different professional carers involved. Mental health professionals not only took the lead in informing the reform process but also directed the change of attitude with regards to community based care. This dimension of thinking is particularly relevant given the current waning of the political, cultural and ethical spirit of the seventies that inspired the Basaglia coordinators may play a key role by creating conditions for group work that accord space and recognition to each of the professional figures involved²⁰³.

Challenges

Whereas laws and policies are in place to ensure access to community based care, long term institutional care still seems to be the preferred mode of care for persons with mental disabilities. Reports point out that the majority of social service recipients receive long-term social care and social rehabilitation services in institutions with most funding going towards institutions rather than community based care²⁰⁴. This is linked to attitudes and perceptions on disabilities in implementation of projects. For community based care to be a reality there needs to be a change in attitude within the community and amongst policy makers.

Secondly and most important, the biggest challenge to community based care is funding. Whereas various reports have shown that it is cost effective to run community based care facilities rather than institutions²⁰⁵, government funding has been low. In some cases like in the US, budgetary allocations towards community based care have been reducing leading to re-institutionalization²⁰⁶. Access to employment for persons with long standing health conditions vis a vis government social safety nets are very low thus threatening the financial stability and rate of inclusion for persons with mental disabilities²⁰⁷. For article 19 to be adequately realized there needs to be increase funding and budgetary allocations towards community based services.

During the transition responsibility for administering social assistance services has been transferred to municipalities in most countries while responsibility for residential institutions generally has been transferred to regions or remained with the state. This disparity has created the dilemma where in order to reduce expenses, municipalities prefer to place vulnerable individuals in residential facilities financed by other levels of government.²⁰⁸ As the case of Bulgaria has shown, it is actually more effective to move persons with severe disabilities out of institutions first as a cost cutting measure. Person with severe disabilities will always have high financial needs thus if a municipality can

²⁰³ Ibid, pg 49

²⁰⁴ Mansell J, Knapp M, Beadle-Brown J and Beecham, J *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent

²⁰⁵ ZELDA, Accessibility and Costs of Mental health and social care community-based services compared to institutional care in Latvia, 2004-2011.

²⁰⁶ Erica L. Reaves and MaryBeth Musumeci, Medicaid and Long-Term Services and Supports: A Primer, December 15, 2015

²⁰⁷ Eurostat Disability Statistics- Labour Market Access, July 2014 available at http://ec.europa.eu/eurostat/statistics-explained/index.php/Disability_statistics_-_labour_market_access

²⁰⁸ World Bank, *Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union*, 2000, pg 15

provide for them first, then it can cut costs on less severe disabilities based on experience.

4. Conclusions

It is important to note that there is no country in where the goals of independent living and being included in the community have been fully achieved²⁰⁹. Further living and being included in the community means different things in different places. Differences in the socio-economic realities of countries; availability and provisioning of resources; culture and tradition; and the concept and understanding of „living independently in the community” need to be taken into consideration.²¹⁰ Some communities prefer communal living, others prefer an individualized setting. Some communities live with their extended families; other communities prefer nuclear family settings. Article 19 does not provide for a preferred mode so long as the individual can share in those schemes available and utilized by people in that society²¹¹. However, this does not mean that independent living is impossible, but can be adapted to fit the needs of the person. Theory under the social model shows that it is barriers that cause disability hence the need for Article 19 to be flexible enough to adopt to different societies and circumstances. What matters most is that the individual will and preferences of the person are included and that measures insure inclusion of the person in the community.

Secondly from the progressive countries, deinstitutionalization and creation of community based services must go hand in hand in order for Article 19 to become a reality. Each country needs to have a policy or strategy on deinstitutionalization and community based services. Learning from the American and Canadian example, lack of community based services may lead to trans-institutionalization and homelessness. Persons with mental disabilities will need support services in varying degrees. Some may have long term needs while others have short term needs. Thus deinstitutionalization does not mean moving person out of institutions but also ensuring support services are available in their different environment.

Deinstitutionalization is strongly linked to advocacy and political goodwill. In all the country examples, mental health reform came through advocacy and law reform. For example in Italy, it took years of research by Basaglia and finally advocacy through law reform. In Croatia, civil society took advantage of political reform process in order to include the deinstitutionalization agenda as part of the reforms. Therefore in order for deinstitutionalization and community living to become a reality, advocacy and support across all stakeholders has to be part of it.

Coordination across all stakeholders is necessary to make deinstitutionalization a reality. Stakeholders include the government duty bearers, civil society organisations, workers in mental health and social services, families and person with disabilities. Countries with good practice examples have decentralised mental health and social service provision to the regional or municipal governments which makes community

²⁰⁹ Inclusion International, *Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community*, 2012.

²¹⁰ *Ibid*, page 16

²¹¹ Council of Europe Commissioner for Human rights, *The Right of People with Disabilities to live Independently and be included in the community*, Issue Paper, March 2012, pg 4

based care more accessible. In addition there are civil society initiatives that support provision of government services as well as monitoring of processes. Societal attitudes and family have been known to have an impact on deinstitutionalisation. In addition, staff of institutions has been known to create the greatest objection to deinstitutionalisation based on fear of loss of employment. This challenge can only be addressed through coordination both horizontally and vertically – vertically from the national to regional level and horizontally amongst all stakeholders. Additional costs are incurred during the period where two systems are running in parallel – i.e. where community-based services are being established and institutions have not yet closed. There is often limited managerial capacity to plan and implement the change required. Many stakeholders – staff in institutions, politicians, the community, schools and even parents and children themselves – fear the changes and need considerable support. Changes in government mean that professionals, civil servants and NGOs must continuously raise awareness with all politicians to ensure continuity and sustained political will over a long period²¹².

Finally, national governments reflect, enact, and propagate deinstitutionalization in varying degrees. Policies are not only artefacts of nation-states' sovereignty, but they are also signs of support for internationally sanctioned ideologies. The act of adopting a policy allows countries to (re)build their public image and, indirectly, maintain their regional presence²¹³. However, national governments may not be compelled to address the needs of people with severe and chronic mental illness unless they realize the epidemic has a direct impact on the economy²¹⁴. There must be funding towards community based care to ensure sustainability of the deinstitutionalization process. In countries such as Canada, USA and Sweden, the process of deinstitutionalization is at risk and in some cases led to trans-institutionalization because of lack of community alternatives as a result of budgetary allocations. In Eastern and Central Europe, European structural funds have been the subject of discussion because of several EU member states investing the funds in institutional settings rather than community based care. As the case of Italy has shown, the only sustainable method of deinstitutionalisation is by investing in community based care.

²¹² Lumos, *Ending the institutionalisation of children: A summary of progress in changing systems of care and protection for children in Moldova, the Czech Republic and Bulgaria*, 2012

²¹³ Gordon C. Shen and Lonnie Snowden, *Institutionalization of deinstitutionalization: a cross-national analysis of mental health system reform*, 2014.

²¹⁴ World Bank's 1993 *World Development Report*, which highlighted mental disorders as a major contributor to the global burden of disease, but failed to include anything in its recommendations that would address mental health.