

The Right to Live Independently and be Included in the Community

Written Comments to the UN Committee on the Rights of Persons with Disabilities in response to its Call for Submissions to the Day of General Discussion on 19 April 2016

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Background

1. MDAC uses the law to secure equality, inclusion and justice for people with mental disabilities worldwide in a manner that recognises the multiple and aggravated forms of discrimination they face. This submission seeks to assist the CRPD Committee in developing a general comment on Article 19 of the CRPD. It draws on MDAC's experience using law and justice systems in around fifteen countries, and focuses on one of the main issues globally that remains a chronic human rights crisis, namely the segregation of children, adults and older people with psychosocial or intellectual disabilities in institutions. We recognise that universal human rights may look different in law and in practice depending on the specific country and context. Enabling all persons to exercise and enjoy their rights requires changes in laws, policies, budgeting and practice in many domains including education and health care systems, the justice system, social and public services, banking services, workplaces, international development and other sectors.
2. Millions of people with intellectual or psychosocial disabilities around the world live out their lives in institutions, by which in this context MDAC means any place in which people are isolated, segregated and/or congregated on the basis of an actual or perceived disability (including a mental health diagnosis). An institution is any place in which people do not have, or are not allowed to exercise control over their day to day decisions, subject to rules and routines defined and controlled by others. An institution is not defined merely by its size. The Committee is familiar with the "unspeakable horrors" (Commissioner for Human Rights of the Council of Europe, 2012) that take place in institutions, and relevant materials are listed in the Appendix.

What does this right require in law and practice?

3. The right to live in the community is not a revolutionary concept, but has evolved rapidly in international human rights law. Based on its experience with litigation, review of literature and policy advocacy, MDAC respectfully recommends that the Committee provide practical, policy-oriented and feasible guidance to States. This submission draws on MDAC's fifteen years of legal and policy experience internationally to provide the Committee with information it for consideration in an eventual general comment on Article 19.

Access to justice, monitoring and public awareness – Articles 8, 13, 31 and 33

4. Governments should enact in domestic law a right for people with disabilities to live independently and be included in the community. This right must apply to everyone, irrespective of age or irrelevant characteristics such race or ethnicity, and irrespective of the type of severity of impairment. This speaks to the operative verb in Article 19 which is the obligation on States to "recognize" the right. Sub paragraphs (a), (b) and (c) in the Article all flow from this primary obligation of law reform, in conjunction with Articles 4(1)(a) and (b).

5. Effective and independent complaints mechanisms should be made directly to people with disabilities where their right to independent living in the community has been breached. This includes complaints about the failure to provide individualised services or community-living options, and failure to make mainstream services accessible. Legal remedies must be made available directly to people with disabilities where independent complaints mechanisms have failed. The initiation of legal proceedings must never be determined by relatives, carers, guardians or other substitute decision-makers.
6. Governments should collect comprehensive disaggregated data - including statistical and research data - to ensure evidence-based policy and action by government authorities in advancing independent living in the community. The data collected should comply with the requirements of Article 31 of the CRPD and should be published on an annual basis, and identify:
 - a) Numbers of people with intellectual or psychosocial disabilities, by age and gender breakdowns;
 - b) Numbers and types of accommodation they live in (institutional and community-based);
 - c) Full list of institutions, their size and capacity, breakdown of funding (including funding sources), admissions, and lengths of admissions and discharges;
 - d) Types of individualised services available, their geographical scope, funding, and how many people access them; and
 - e) Analysis of the numbers of people with disabilities who access mainstream services (including education, healthcare and employment assistance), and analysis of the funding of reasonable accommodations.
7. The criminal law should be amended to classify the targeting of a victim on the basis of their disability as a hate crime. Data should be published annually on the prevalence of hate crime against people with disabilities, the investigation of allegations and their disposal.

Choice and Control - Article 19(a)

8. Legislation must be adopted without further delay to abolish all forms of guardianship in line with Article 12. Legislation should also provide recognition for supported decision-making models based on relationships of trust and giving primacy to the will and preferences of persons supported.
9. Governments should adopt an immediate moratorium on new admissions to social care institutions in order to stop filling up vacancies. Instead, local governments should be required to find alternatives for each person on the waiting list. States should urgently take steps to end the placement of children, especially under the age of 3 years, in residential institutions, and ensure family-based care (Committee on the Rights of the Child, 2015).
10. There should be coordination at national and regional levels on deinstitutionalisation and the abolition of guardianship through the designated Article 33(1) government focal point, and publish annual reports on progress with disaggregated data (Article 31) speaking to an internationally-agreed indicator set.
11. Plans for financing to maintain, renovate or expanding existing institutions should be abandoned. Instead, use available funding to develop individualised community-based support services to the maximum extent possible. And effective disability-positive health interventions should be available across the lifespan to foster the social cohesion and community support for people with complex disabilities to live a good life in the community.

Individualised community supports – Article 19(b)

12. Governments should establish in law an enforceable right for people with disabilities to receive social services in the community. Provide for a range of community based services – such as in-home support, personal assistance, personal budgets, financial and practical support to families and carers – and ensure that these services are accessible for all people with disabilities regardless of their age or support needs. Community-based services should be rolled out so as to inform national budgetary priorities, moving resources from institutions to the development of individualised support services. Everyone with disabilities and their families should be able to access specialised support and funding, including personal budgets, to purchase professional, individualised support where such services are not provided by government.
13. MDAC's experience is that restrictive eligibility criteria regulating the provision of social services are a barrier that deny people tailored services. For example, in Slovakia there is no law mandating local governments to provide in-home services for children. In a case MDAC supported, local government refused services to a 4-year-old girl with profound multiple disabilities, saying that she should go to a social care institution and in-home support are available only to adults. A court disagreed, ordering the local authority to provide home care. If there were a law mandating this, families would not have to resort to litigation.
14. Some Governments justify their inaction by hiding behind the economics of Article 19. The CESCR Committee has clarified that the phrase “progressive realisation” (which appears in Article 4(3) of the CRPD), “should not be misinterpreted as depriving the obligation of all meaningful content” because it “imposes an obligation to move as expeditiously and effectively as possible” towards the full realisation of the rights in question (CESCR, 1991, para. 9). The principle of progressive realisation requires more of States than to simply refrain from taking measures that may negatively impact on rights holders. It includes an obligation to, “take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities.” The CESCR Committee has stated that this will almost invariably entail use of additional resources and a wide range of specially tailored measures (CESCR, 1995, para. 9).
15. Under Article 19(b) of the CRPD, States must progressively introduce *more* in-home, residential and other community support services specifically for people with disabilities. They must progressively increase access to existing services through, for example, expanding their geographical scope and putting in place accessibility measures. Failure to take positive action breaches the CRPD. MDAC's view is that Articles 19(b) and (c) of the CRPD require at a minimum: access to essential primary health care (including mental health care), food and water, basic shelter and housing (outside institutions), basic inclusive primary and secondary education and basic support services to facilitate community living (see OHCHR (2014), para. 41).
16. The general comment should emphasise two additional legal points. First, that international human rights law requires health and social care to be available, accessible, acceptable and of sufficient quality (see CESCR 2001, 1995, 1999a, 1999b, 2000, 2008). Second, that progressive realisation does not apply to those elements of Article 19 that are civil and political in nature, such as choice and control, as well as non-discrimination.

Access to mainstream services – Article 19(c)

17. Using Article 9 of the CRPD as a basis, governments should conduct accessibility assessments of mainstream public services (including schools, healthcare and employment support) with a

specific view to identifying barriers for people with mental disabilities. The assessments should inform budgeted plans for reform which should be published. Governments should develop a plan to ensure that people with disabilities can access mainstream community services, including health, education and employment, on an equal basis with others. In achieving this goal, governments should prioritise the accessibility of all services to people with intellectual disabilities.

18. Programmes to increase the employment rate of people with psychosocial and intellectual disabilities and facilitate their access to the labour market should be adopted. And in addition governments should publish a strategy on providing inclusive education which is responsive of the needs of children with disabilities, including through the provision of supports that enable all children to access common learning environments.

Transitions from institutions to the community

19. Governments' deinstitutionalisation strategies often fail to set measurable indicators for progress. They can operate with unreasonably long timelines or exclude certain groups of people or institutions. For example, the Hungarian government adopted a strategy in 2011 with a 30-year implementation period that lacks intermediate measures and excludes children's institutions and institutions for people with psychosocial disabilities.
20. Trans-institutionalisation is sometimes called de-institutionalisation. This occurs when people are shifted from one institution into another, usually smaller and newer, institution but the second institution is always called something other than "institution". Even in the new smaller residential set-up, an institutional culture pervades. In Moldova MDAC is investigating how 14 young adults were transferred from an institution into "community homes" that are houses where the residents receive education and where most of their daily regime takes place in isolation from the community. In Romania civil society has raised concerns about a new governmental scheme that transfers people into "protected homes" where, again, an institutional culture pervades, resulting in human rights breaches.
21. Governments should rationalise the various plans and proposals on deinstitutionalisation of services into an overarching and inclusive Action Plan for all people with disabilities. They must ensure that people with disabilities and their representative organisations have opportunities to be fully included and participate in the development of this action plan (Article 4(3) of the CRPD). The timeframe for completing the process should be limited to five-years. Governments should, in conjunction with academic and civil society experts, develop quantitative and qualitative objectives that advance the end goals of the Action Plan. These should include closing institutions, developing specialised community-based services and accommodation, and improving access to mainstream services. Governments should report annually and accurately against objectives.
22. Governments should make sure that the Action Plan contains a detailed analysis of the way in which state funding is currently spend on disability-based services (including institutions), and reallocate future financing away from institutions and towards community-based services. Annual reports should be made public on the way in which public finances are spent. To coordinate and spearhead the deinstitutionalisation process, the government should appoint an Action Plan Ambassador at central governmental level. This person should ensure that the necessary local leadership is developed to manage the process and solve problems at the institutional and community level (see Article 4(1)(f) of the CRPD).
23. Individualised transition plans for institutional residents should be developed, based on the will and preferences of each resident. The plans should provide genuine options for living in the

community, including private or family accommodation. Plans should identify the required individualised supports, specify how they will be provided, set out how independent living skills will be developed, all within clear timeframes.

24. Governments should treat people who have lived in institutions as victims of torture, inhuman, cruel and degrading treatment or punishment. Such victims are entitled to physical, cognitive, psychological and legal recovery, rehabilitation and social reintegration measures mandated under Article 16(4) of the CRPD, coupled with Articles 25 and 26.

Key issues in realising the right to live in the community

25. MDAC is keen for a general comment on Article 19 to take into account the following problems at the legal and policy coalface. Institutions dress in disguise. Maximal creativity is used in order to conjure up wonderfully euphemistic labels: group homes, protected homes, living centres, shelters, halfway houses, and rehabilitation centres: all of these terms appear in policies, plans and in metal signs hammered to the walls of buildings. All of these establishments can be regarded as institutions, per the definition above and as such they violate Article 19 of the CRPD.
26. Finances are important in implementing Article 19, but so is inspirational leadership. This is the element that is often sorely absent at national and local levels to mandate deinstitutionalisation with needed planning, investments in community alternatives, time-frames and accountabilities.
27. With an aging population, the demand for institutional care is growing. There is inadequate investment in community-based alternatives, thus further entrenching an institutional model. Lack of supports for children with disabilities and their families has led to an institutional model of care for this group, especially for children with more complex needs, creating a long-term demand for this approach and constituting an important part of the supply chain to adult and older people's institutions. A vastly disproportionate investment continues to be made in institutional care in comparison to community supports. Government contracting and regulatory frameworks are largely focused on congregate community care rather than individualised services and supports, and a variety of professional, labour and local political interests sustain this dominant approach.
28. At the community level, service provision for people with disabilities tends to rely on institutional rather than person-centred and person-directed approaches to support. Institutional approaches to care, whether in large facilities or community-based options structure and reproduce negative social and cultural perceptions of people with disabilities. Stereotypes of people as deformed, abnormal, less than fully human and in need of either constant rehabilitation and training or custodial care are used to both justify continued segregation and, through the objectification of people that results, to breed exploitation, violence and abuse. The predominance of institutional approaches combined with persistent negative stereotypes and a permissive legal framework also underlies high rates of systematic detention of people with intellectual and psychosocial disabilities that violates rights.
29. A person's complex health care needs are often used to justify institutionalisation. This trend continues despite the fact that such approaches constitute a violation of Article 19 and the evidence of good practice. There are demonstrated and effective approaches to community-based specialist health services in some jurisdictions to support people to live independently in regular housing in the community.

Appendix 1: Resources

Commissioner for Human Rights of the Council of Europe

“The right of people with disabilities to live independently and be included in the community”, 2012, <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

“Safeguarding human rights in times of economic crisis”, 2013, <https://wcd.coe.int/ViewDoc.jsp?id=2130915>

Committee on Economic, Social and Cultural Rights

General Comment No. 3: The nature of States parties’ obligations, 1991

General Comment No. 4: The right to adequate housing, 1992

General Comment No. 5: Persons with disabilities, 1995

General Comment No. 13: The right to education, 1999a

General Comment No. 14: The right to the highest attainable standard of health, 1999b

General Comment No. 19: The right to social security, 2008

Committee on the Rights of the Child

Concluding observations on the combined third and fourth periodic reports of Poland, CRC/C/POL/CO/3-4, 30 October 2015, para 8 (b), para 33 (a)

Fundamental Rights Agency of the European Union

“Choice and Control: The Right to Independent Living”, 2012, http://fra.europa.eu/sites/default/files/fra_uploads/2129-FRA-2012-choice-and-control_EN.pdf

“Human Rights Indicators on Article 19 of the CRPD”, 2015, <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>

Office of the UN High Commissioner for Human Rights

“Thematic study on the right of persons with disabilities to live independently and be included in the community”, A/HRC/28/37, 2014, www.ohchr.org/EN/HRBodies/HRC/.../A_HRC_28_37_ENG.doc

“Getting a Life”, 2014. http://www.nuigalway.ie/cdip/documents/getting_a_life_art_19_crp_d_and_eu_structural_fund_s.pdf

Jointly with the MDAC, “The Human Rights of People with Mental or Intellectual Impairments in Moldova. http://www.mdac.org/sites/mdac.info/files/moldova_report_2015_english.pdf

Mental Disability Advocacy Centre

My Home, My Choice: Bulgaria, 2014, http://www.mdac.org/sites/mdac.info/files/my_home_my_choice_-_bulgaria_2014.pdf

Open Society Foundations

“The European Union and the Right to Live in the Community”, 2012,

<https://www.opensocietyfoundations.org/sites/default/files/europe-community-living-20120507.pdf>