



## The CRPD and Older Persons with Disabilities: The Transition to Community-Based Long-term Care Services

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### **Executive Summary**

*This paper examines the barriers to the development of community-based services for older persons with disabilities in Europe as provided for in Article 19 of the CRPD.*

*The CRPD is an important human rights convention in Europe, of which Article 19 has been a key focus. The European Disability Strategy 2010-2020 committed the EU to promote the use of EU Structural Funds to assist Member States in the transition from institutional to community-based services though success in achieving this objective has been mixed and there is a risk that the efforts being made to support persons with a disability to transition to community-based care may not be seen as relevant for the lives of older persons with an acquired disability.*

*Overall bed numbers in residential care settings/institutions providing for older persons in need of long-term care have risen in all countries since 1995 and community-based services remain under-developed throughout Europe. As such, many older persons have no choice but to enter an institution. There is a need for greater recognition of the relevance of the CRPD and Article 19 for OP with disabilities by all stakeholders and greater investment by States Parties in the development of high-quality community-based services.*

### **Introduction**

The entry into force of the United Nation Convention on the Rights of Persons with Disabilities (CRPD) in 2008 is widely regarded as having created a dynamic new disability rights paradigm that empowers persons with disabilities. In particular, Article 19 ('Living independently and being included in the community') is the first international treaty provision to explicitly provide the right to community living for individuals with disabilities. However, older persons with disabilities often don't have access to a range of long-term care services that allow them to live independently in their own home or community. This paper examines the barriers to the development of community-based services for older persons with disabilities in Europe.

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## The CRPD and the Right to Independent Living

At its heart, the CRPD is based on the facilitation of persons with disabilities' right to self-determination, participation and inclusion. Article 19 seeks to offer persons with disabilities choice and control over their living arrangements, access to services provided to the general public and, if needed, individualised support by stipulating that persons with disabilities have the right to choose their place of residence and access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community. In facilitating individuals to realise this right, the nature of support is key; governments must enable individuals with adequate support "to live the life that they choose and to be included in their local community".<sup>1</sup> One of the key aims of Article 19 is therefore to ensure that persons with disabilities are facilitated to transition from living in institutions to community-based services.<sup>2</sup>

## The Implementation of Article 19 in Europe: Younger Persons with Disabilities

The CRPD is an important human rights convention in Europe, not least because it made the EU the first supranational government to ratify a human rights treaty in 2010. Article 19 has been a key focus of both the European Commission and European civil society organisations advocating on behalf of persons with disabilities. The European Disability Strategy 2010-2020 committed the EU to promote the use of EU Structural Funds to assist Member States in the transition from institutional to community-based services.<sup>3</sup>

Available evidence of the outcome of these policies in providing persons with disabilities a greater choice to live in the community is limited. Although one report found that nearly 1.2 million persons with disabilities lived in institutions in 2007, a rate of approximately 2.8%,<sup>4</sup> the absence of more recent data limits information on the

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<sup>1</sup> UK Joint Committee on Human Rights, 2012, *Implementation of the Right of Disabled People to Independent Living*, <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/257/257.pdf>

<sup>2</sup> Any residential care spectrum for older persons, regardless of its size or model, can be considered an institution if it exhibits the characteristics of an institutional culture, namely where residents are isolated from the broader community and/or compelled to live together; where residents do not have sufficient control over their lives and over decisions which affect them; or the requirements of the organisation itself tend to take precedence over residents' individualised needs, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, 2009, [ec.europa.eu/social/BlobServlet?docId=3992&langId=en](http://ec.europa.eu/social/BlobServlet?docId=3992&langId=en).

<sup>3</sup> European Commission, 2014, *Staff Working Document: Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*, [http://ec.europa.eu/justice/discrimination/files/swd\\_2014\\_182\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf)

<sup>4</sup> 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*. [https://www.kent.ac.uk/tizard/research/DECL\\_network/documents/DECLOC\\_Volume\\_2\\_Report\\_for\\_Web.pdf](https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf)

progress made in reducing the overall number living in institutions in the intervening nine years. Reports show that opportunities and support for people with intellectual disabilities to live independently vary widely throughout the EU, with several barriers still prevalent, including a lack of (financial) support for daily living, institutional regimes and stigmatisation and discrimination.<sup>5</sup>

Indeed, it is evident that EU Structural Funds (ESF) have actually continued to be used to build institutions for persons with disabilities in a number of countries.<sup>6</sup> Thanks in large part to awareness-raising work by national human rights institutions (NHRIs) and civil society organisations, the European Commission has put in place better monitoring and oversight measures to ensure that ESF are no longer spent on developing institutions to house persons with disabilities.<sup>7</sup> However, as outlined below, there is a risk that the efforts being made to support persons with a disability to transition to community-based care may not reach, or be seen to be relevant, for the lives of older persons with an acquired disability.

## **Article 19 and Older Persons with Disabilities in Europe**

Although ESF have also been used to build residential care settings for older persons, there has not been the same intensive lobbying by disability organisations as occurred for younger people with intellectual or psychosocial disabilities. It is also challenging to find data on how many institutions providing for the long-term care of older persons have been built using ESF.

Limited views on what constitutes disability appear to play a role in why the relevance of Article 19 for older persons with disabilities is not more widely recognised by states parties and civil society organisations for persons with disabilities. In many European countries, legislation can often define disability in a narrow way, with the result that older persons in need of long-term care are not considered to have a disability,<sup>8</sup> even

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<sup>5</sup> [http://fra.europa.eu/sites/default/files/choice\\_and\\_control\\_en\\_13.pdf](http://fra.europa.eu/sites/default/files/choice_and_control_en_13.pdf)

<sup>6</sup> European Network on Independent Living - European Coalition for Community Living, (ENIL-ECCL), 2015, *Briefing on the use of European Structural and Investment Funds to support the transition from institutional care to community living for people with disabilities*, [http://www.enil.eu/wp-content/uploads/2015/05/ENILECCL\\_Briefing\\_SF\\_300415.pdf](http://www.enil.eu/wp-content/uploads/2015/05/ENILECCL_Briefing_SF_300415.pdf)

<sup>7</sup> Commission Staff Working Document, 2015, *Reply of the European Union to the list of issues in relation to the initial report of the European Union on the implementation of the UN Convention on the Rights of Persons with Disabilities*, <http://ec.europa.eu/social/BlobServlet?docId=14142&langId=en>

<sup>8</sup> For example, *Concluding Observations on the Initial report of Austria, Adopted by the Committee at its tenth session, 2-13 September 2013* [www.ohchr.org/Documents/.../CRPD/.../CRPD-C-AUT-CO-1\\_en.doc](http://www.ohchr.org/Documents/.../CRPD/.../CRPD-C-AUT-CO-1_en.doc), *Concluding observations of the Committee on the Rights of Persons with Disabilities Spain, 2011*, [www.ohchr.org/Documents/HRBodies/CRPD/.../CRPD.C.ESP.CO.1\\_en.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/.../CRPD.C.ESP.CO.1_en.doc)

if it is an age-related disability that falls under the definition of disability set out in Article 1 of the CRPD.<sup>9</sup>

This exclusion subsequently carries over into research on disability. For example, the 2007 report on institutionalisation rates in Europe showed that many countries did not record the age of those living in institutions.<sup>10</sup> More recently, a report by the EU Fundamental Rights Agency which studied 225 persons with disabilities' experiences autonomy, inclusion and participation only included 2 persons aged 66 and over in its sample.<sup>11</sup> This side-lining of older persons with disabilities is problematic, given that the rate of institutionalisation of older persons with acquired disabilities is significantly higher than for younger persons with disabilities (6-7%, rising to between 30-50% for those aged 90 and over, in contrast with 2.8%).<sup>12</sup>

Although the majority of older persons (70%) in receipt of long-term care in Europe are cared for in their own homes rather than in institutions, overall bed numbers in institutions have increased in all countries bar Sweden since 1995.<sup>13</sup> As such, home- and community-based care services remain under-developed relative to residential care in many countries throughout wider Europe.<sup>14</sup> This means that older persons in many countries with high caring needs have no option but to enter an institution because of the absence of care services in the community.<sup>15</sup> Even in countries with well-developed community services, poorly developed respite and rehabilitation community-based services, inadequate personal budgets and inadequate support for informal (family) caregivers can limit older persons from having adequate choice and control over their own lives, even if they remain living in their own homes.<sup>16</sup>

Population ageing may further limit the choice of long-term care services available to older persons. With the population of older people in Europe expected to almost double from 87.5 million in 2010 to 152.6 million in 2060, policy-makers throughout Europe are generally agreed that it will not be financially possible to increase the

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<sup>9</sup> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others,

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

<sup>10</sup> Mansell et al, op. cit.

<sup>11</sup> EU Fundamental Rights Agency, 2012, *Choice and control: the right to independent living*, [http://fra.europa.eu/sites/default/files/fra\\_uploads/2129-FRA-2012-choice-and-control\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2129-FRA-2012-choice-and-control_EN.pdf).

<sup>12</sup> Grammenos, S. 2013, *European comparative data on Europe 2020 & People with Disabilities*. <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1569&context=gladnetcollect>.

<sup>13</sup> European Social Network, 2008, *Services for Older People in Europe*, [http://ec.europa.eu/health/mental\\_health/docs/services\\_older.pdf](http://ec.europa.eu/health/mental_health/docs/services_older.pdf).

<sup>14</sup> Ranci, C. and Pavolini, E. 2015. *Not all that glitters is gold: Long-term care reforms in the last two decades in Europe*. *Journal of European Social Policy*, 25(3), 270-285.

<sup>15</sup> Ibid.

<sup>16</sup> Ilinca, S., Leichensring, K. and Rodrigues, R. 2015. *From care in homes to care at home: European experiences with (de)institutionalisation in long-term care*, [http://www.euro.centre.org/data/1449741582\\_83911.pdf](http://www.euro.centre.org/data/1449741582_83911.pdf)

supply of formal long-term care services in Europe in line with expected demands. Instead, service planners are being encouraged to develop policies to support active ageing and support family carers to step into the breach.<sup>17</sup>

## **Requirements on the Transition from Institutions to Community-Based Care for Older Persons with Disabilities in Europe**

At a systemic level, the greatest driver towards de-institutionalisation for older persons with disabilities in Europe is a greater recognition that the CRPD also applies to older persons with disabilities, who must also be afforded the right to live independently in the community. This requires greater investment by states parties in the development of high-quality community-based services, along with a cultural change that allows older persons with disabilities to participate in the development of national policies in this area, as well as to participate at the micro level in decisions affecting their care and daily lives.<sup>18</sup> Individuals with complex caring needs will require access to multidisciplinary care teams, and a high level of contact with trained care staff to enable them to carry out activities of daily living and participate in community life.

Evidence from a number of studies shows that such care is achievable and can still be more cost-effective than care provided in a residential setting, particularly when care is well co-ordinated.<sup>19</sup> As noted by the *Independent Expert on the Enjoyment of all Human Rights by Older Persons*, ageing at home also requires innovations in the housing sector, including alternative forms of housing for older persons, such as mixed and designated communities and age-adapted homes, or flat-sharing concepts that promote intergenerational interaction.<sup>20</sup> There is also a need for the CRPD Committee to systematically seek information from states parties on the progress made in implementing Article 19 (and all other articles) for older persons with disabilities.

At the individual level, research suggests that it is possible for older persons, even if they have multiple co-morbidities, to transition successfully from residential care back to the community, once they receive adequate support. This includes the provision of informal and formal community supports in the discharge process, proactively addressing physical environment needs, and assisting individuals and their family

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<sup>17</sup> European Commission, 2013, *Staff Working Document : Long-term care in ageing societies - Challenges and policy options*, ec.europa.eu/social/BlobServlet?docId=12633&langId=en

<sup>18</sup> Ilinca et al., op cit.

<sup>19</sup> The King's Fund, 2014, *Providing integrated care for older people with complex needs Lessons from seven international case studies*, [http://kf-staging.torchboxapps.com/sites/files/kf/field/field\\_publication\\_file/providing-integrated-care-for-older-people-with-complex-needs-kingsfund-jan14.pdf](http://kf-staging.torchboxapps.com/sites/files/kf/field/field_publication_file/providing-integrated-care-for-older-people-with-complex-needs-kingsfund-jan14.pdf)

<sup>20</sup> *Report of the Independent Expert on the enjoyment of all human rights by older persons*, Rosa Kornfeld-Matte, [www.ohchr.org/EN/HRBodies/HRC/.../A\\_HRC\\_30\\_43\\_ENG.docx](http://www.ohchr.org/EN/HRBodies/HRC/.../A_HRC_30_43_ENG.docx)

members in managing physical and mental health conditions.<sup>21</sup> As with younger persons with disabilities, there needs to be a focus on legal capacity and supported decision making, which remains problematic and contentious in Europe.<sup>22</sup>

It is also important to remember that Article 19 of the CRPD does not prohibit care in residential settings, but seeks to ensure that individuals with a disability have a choice as to where they live and receive the care and/or support to participate in their community. As such, older persons themselves must also have access to high-quality residential care if they so wish. The human rights, including the autonomy, of older persons must be respected when they are living in a residential care setting.

## **Conclusions**

The CRPD has made great strides in ensuring that the human rights of persons with disabilities are protected and promoted. However, there is a need for governments and other stakeholders to remember that 45% of people with disabilities in Europe are aged 65+. At present, the organisation of long-term care services for older persons with disabilities in Europe is highly variable and a number of barriers exist that limit the choice and control older persons have over their lives, including an over-reliance on residential services as well as under-developed community-based services and supports for informal caregivers. The ageing of the European population can act as a great opportunity for the development of community-based long-term services for older persons with disabilities, not simply as a way of meeting increased demand at a low cost, but in guaranteeing the full enjoyment of their human rights.

## **About ENNHRI**

The European Network of National Human Rights Institutions (ENNHRI) aims to enhance the promotion and protection of human rights across the wider Europe region. National Human Rights Institutions (NHRIs) are independent bodies with a constitutional or legal mandate to promote and protect human rights. They are a key element of a strong and effective national, regional and global human rights framework. ENNHRI supports European NHRIs to be effective on the national level and to promote and protect human rights across wider Europe. For more information about ENNHRI please visit [www.ennhri.org](http://www.ennhri.org).

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<sup>21</sup> Leedah, S. et al., 2015, *Successful Strategies for Discharging Medicaid Nursing Home Residents With Mental Health Diagnoses to the Community*, Journal of Social Service Research, 41(2), 172-192; O'Keeffe, S. 2001, *Autonomy vs welfare? Anatomy of a risky discharge*, Irish Medical Journal, 94(8), 234-236.

<sup>22</sup> FRA, 2015, *Implementing the United Nations Convention on the Rights of Persons with Disabilities (CRPD) An overview of legal reforms in EU Member States*, [http://fra.europa.eu/sites/default/files/fra-2015-focus-05-2015-crpd\\_en.pdf](http://fra.europa.eu/sites/default/files/fra-2015-focus-05-2015-crpd_en.pdf)