



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Committee on the Rights of Persons
with Disabilities on the draft General Comment on the
right of persons with disabilities to live independently and
be included in the community (article 19)

June 2017

This document is written in font 12 Verdana in line with Inclusion Ireland
plain English guidelines.

1. About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

2. Introduction

Inclusion Ireland welcomes the opportunity to make a submission to the United Nations Convention on the rights of Persons with Disabilities (UNCRPD) Committee on Article 19 which is about Living independently and being included in the community.

We note that the committee has established the core elements of community living and we propose to address our submission primarily under those heading with a few additional categories examined.

The Committee has established that the core elements are:

To have legal capacity to decide where and with whom and how to live is a right for all persons with disabilities, irrespective of impairment;

The right to choose where to live requires a realistic option of accessible housing to choose from;

The right to live independently does not entail dependence on informal support from family and friends;

To have access to basic personalised and human rights-based disability specific services;

To have access to basic mainstream community-based services and support on an equal basis with others; and

The possibility of living independently must not be negatively affected by measures taken to respond to economic constraints.

There are other areas that can adversely impact on a person with a disability's right to community living and we propose to address this in addition to the core areas and will include commentary on social exclusion, hate crime, attitudes, disaggregated data and the cost of disability.

3.1 Legal Capacity

It is very welcome that the Committee has considered the recognition of legal capacity as a key aspect of community living.

Legal Capacity is recognition that all persons have a right to make decisions and have those decisions recognised regardless of disability.

In Ireland the Lunacy Regulation (Ireland) Act 1871 remains on statute. This Act refers to people as 'idiot', 'lunatic' and 'unsound mind' and there are currently over two and a half thousand people in Ireland who are Wards of Court under this act on account of age, intellectual disability, mental illness or brain injury.

The Lunacy Act can be seen as a barrier to owning or renting property. Individuals who have difficulty making decisions are not entitled to formal support under Irish law. A person with a disability may be made a ward of court if they are in possession of property and cannot manage this 'estate'. People with disabilities are also discriminated against in relation to leases, mortgages and other financial products because of an inadequate legal infrastructure.

Ireland introduced the Assisted Decision-Making Act at the end of 2015 but has, to date, only commenced two parts of the Act. If commenced the Act would allow a person to get the support required to make a particular decision rather

than a blanket loss of decision-making capacity. Commencement of the Act is also required to support people with intellectual disabilities to live in the community and to enter into the kinds of arrangements that this entails, such as tenancy and mortgage agreements. The Assisted Decision-Making Act also provides a mechanism for people to live in their own home as they age by providing structures to support people to make decisions relating to property, other than Ward of Court or the Fair Deal scheme.

Inclusion Ireland, along with other produced 'Essential Principles of Legal Capacity' in 2012. This document sets out that legal capacity legislation should ensure the person's right to dignity and self-determination should remove all barriers to people with disabilities exercising their legal capacity, should have adequate support from the State to exercise their will and preference and that decisions being made by a representative should be strictly as a last resort.

3.2 Accessible Housing & Choice

In Ireland many people with disabilities live in residential institutions or at home with their families and there is an historical lack of options for people with disabilities.

Homelessness has soared in Ireland in recent years. People with disabilities are more likely to experience homelessness than non-disabled people. While people with a disability constitute around 13% of the population as a whole, 42% of the homeless population had one or more disabilities in 2011. Census 2011.

In 2015, there were 4,039 people with intellectual disabilities aged over 35 living at home with aging parents. Of this number 734 were aged over 55 and living at home with their parents.¹

The Irish policy for the closing of institutions is 'a Time to Move on from Congregated Settings – a Strategy for Community Inclusion' which was published in 2011. The policy set a target of closing all institutions in 7 years (by 2018). At the time there was slightly over 4,000 people living in institutions².

¹ Annual Report of the National Intellectual Disability Database Committee 2015, Doyle, A & Carew, A., Health Research Board, 2016.

² A time to move on from congregated settings – a strategy for community inclusion, HSE working group, 2011.

This target will not be met by 2018 and in 2016 in a clear admission of the failure of the policy, Government set a new target of reducing the amount of people living in institutions by 1/3 by 2021.³

At the new proposed rate of moving people it will take a further 15 years to move all people out of institutions. At present there are 2580 people with disabilities living in large institutions in Ireland⁴.

Over a 6 year period (2011-2017) the amount of people living in institutions has reduced by almost 1,500. Not all of these people moved to community settings. In 2015, 123 people moved to a community house, 27 moved to a nursing home and 121 died.⁵

In a backward step, 41 people moved into a large institutional setting in 2015⁶ and 35 moved into a large institutional setting in 2016.⁷

The CRPD comment that “neither large scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals can be called independent living or community living arrangements” as in Ireland, of those that moved in 2015, 53.4% moved to a home with 4 or more other people with a disability. Less than 10% of people moved into their own accommodation.

Movements, such as the ones we have seen in Ireland creates a risk of establishing of mini-institutions in the community and indicates a lack of choice for people when moving out of institutions.

3.3 Independence & Informal Support

People with disabilities are often dependent on family for support. As mentioned in the previous section a significant percentage of persons with intellectual disabilities live at home with family.

Inclusion Ireland’s believes that that persons with disabilities have a right to their own home in the community. Supports should be available to sustain

³ A program for partnership government, 2016.

⁴ Answer to PQ 5585/17, HSE, 2017.

⁵ HSE, Progress report on the implementation of Time to Move on from Congregated a strategy for community inclusion, Annual Report for 2015, 2017.

⁶ *ibid*

⁷ HSE documentation.

this, whether they are disability specific supports such as, Personal Assistance, home support, nursing care if appropriate or mainstream community supports.

Our Self Advocacy Committee told us “We want there to be proper supports in place for people with disabilities as they get older, so that they can live as independently as possible. We want this especially for those whose carers have passed away and may need extra supports.”

The role of carer often falls to families and subsequently siblings because of a lack of resources.

Ireland has an underdeveloped advocacy service. Independent advocacy can be a crucial tool for enabling people with disabilities to enjoy their rights and entitlements and can be a significant support for people living in the community.

In Ireland, the National Advocacy Service provides a representative advocacy service to people with disabilities. However, demand for the service is high and waiting lists can be long. The Personal Advocacy Service, as provided for under the Citizens Information Act 2007, has yet to be introduced. This Personal Advocacy service was envisaged as having statutory powers, currently in Ireland professional advocates do not have these powers.

Besides the National Advocacy Service (NAS) there are many organisations throughout Ireland providing advocacy supports but many do not provide a representative advocacy service and similarly they do not have statutory powers. Often the NAS cannot gain access to vital information because there is no compulsion to cooperate with them. Independent advocates must have appropriate powers.

Currently, funding for advocacy for people with a disability, including self-advocacy, representative advocacy and peer advocacy, is provided by different Government departments. There is a need for a consistent, joined-up approach. A broad range of advocacy services and supports should be available to people with a disability and advocacy should be co-ordinated by a central, national focal point.

3.4 Personalised Services

Inclusion Ireland welcomes the recognition of the CRPD Committee in the draft comment that "personal budgets do not necessarily allow persons with disabilities to have access and control over community support services".

Personalisation of services is an important element of community living. Individuals having choice and control over the services they receive means that they can be empowered to live self-directed lives. Inclusion Ireland has prepared a document on the essential principles of personal budgets and consider the following to be the bedrock of a personal budgets system

- A. Personal Budgets should be available to all persons with disabilities regardless of age or complexity of needs.
- B. Personal Budgets should be cross-departmental and joined-up and not placed simply in departments of social protection or health. Other areas such as transport and environment are crucial to the working of personal budgets.
- C. The focus should be on achieving personal outcomes. The outcomes should be identified by the person with the disability and the outcomes used to assess the effectiveness of the operation of the budget.
- D. Values should underpin a Personal Budgets system. Inclusion Ireland proposes the values of dignity, democracy, social justice, autonomy and inclusion.
- E. A Human Rights and Equality Based Approach should be adopted
- F. Personal Budgets should be flexible and responsive, changing as circumstances change through the lifespan.
- G. People should have choice about how they receive a Personal Budget, be it through a third party, broker or as a cash payment.

3.5 Economic Constraints

The focus on rights over resources is fundamental.

In the inquiry of progress in the UK, the UNCRPD Committee⁸ stated that even in the context of limited resources; the state should ensure that

⁸ Ref: CRPD Committee (2016) Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention

budgets “Take into account the rights of persons with disabilities, that sufficient budget allocations are made available to cover extra costs associated with living with a disability and that appropriate mitigation measures, with appropriate budget allocations, are in place for persons with disabilities affected by austerity measures”

Also that that any budget reforms should be “rights-based, upholds the human rights model of disability and does not disproportionately and/or adversely affect the rights of persons with disabilities to independent living”

In Ireland, economic constraints have had a significant effect on housing for all member of the population. A June 2017 media report⁹ illustrated that housing stock had plummeted and that almost 8,000 homes could not be used due to neglect.

In a recent report, the Office of the Children’s Ombudsman (OCO) noted that homeless children with disabilities are not afforded any additional priority in the allocation of social housing. On launching the OCO annual report, Nuala Ward, director of investigations noted: “children with disabilities were struggling living in inappropriate housing, while children with disabilities or medical needs who are homeless were not always being prioritised for housing”.

As the economy is recovering, the numbers being de-institutionalised have decreased partly due to a lack of housing options and in spite of monies being made available for the process. The Department of Health and the Health Service Executive made €100 million available in capital funding over a 5-year period to purchase houses in the community. These funds are directed towards a small number of institutions (10) that have been failing to meet basic standards of inspection by the Health Information and Quality Authority (HIQA). HIQA is the agency with statutory powers to inspect and regulate residential services for people with disabilities.

The Department of Housing, Planning, Community and Local Government made €10 million available to purchase houses to move people out of institutions in 2016. Only €2 million of this fund was drawn down.

To assist with transitioning people out of congregated settings into ordinary homes a Service Reform Fund has been established. The fund has €27m

⁹ The Times June 13 2017

available to services over a 3-year period. Despite being announced in June 2015¹⁰, no money has been allocated from this fund as at May 2017.

Despite significant funds being made available to move people out of institutions in 2016, less people moved than in 2015 when dedicated funds were not available. In 2016, only 52 people moved to community settings.

In the previous 4 years the HSE has set a target for people to move from institutions to community settings. The targets have never been met.

In the last two years (2015 & 2016) there has been a greater likelihood of passing away in an institution (216) than moving to a home in the community (185).

3.6 Additional Areas to consider

Social Isolation

A recent survey¹¹ estimated that people with disabilities were twice as likely to be at risk compared with others (18% vs. 9%). Compared with non-disabled respondents, those with disabilities being classified as at risk of social isolation specifically from friends (26% vs. 17%) and family (19% vs. 12%), were significantly higher.

One in four persons with a disability reported a restriction on their participation in community life as compared to non-disabled people. 34% of people with disabilities reported a restriction in socialising as compared with 7% non-disabled.

Hate Crime

Hate Crime can be a serious block to people moving to the community or remaining there. The perception of hate crime, fear of crime or risk can also be a barrier. Concern with risk and a perceived need to 'mind' those with complex needs in particular, was also shown to act as a barrier to community participation for those living in residential settings. in interviews

¹⁰ Lynch welcomes collaboration with The Atlantic Philanthropies on service reform fund, press release, June 16th 2015, available at www.merrionstreet.ie

¹¹ National Disability Authority Survey on Attitudes 2011

with service providers, there was an acknowledgement there can sometimes be a tendency towards 'catastrophic thinking' which limits openness to supporting people to engage in community activities.¹²

Fear may be held by the person with a disability themselves or by their family member or other support. The fear of crime can also be a soft barrier to individuals making a move to the community.

There is a growing trend of recording 'disability hate crimes' throughout the Europe and Ireland is one of the few EU member states without hate crime legislation. Civil Society organisations have developed a bill called the Criminal Law (Hate Crime) Amendment Bill 2015.

The Irish Central Statistics Office (CSO) crime figures recently demonstrated an increase in the number of recorded sexual offences against mentally impaired persons¹³ increased from 12 in 2014 to 22 in 2015. An increase of 83%.

Recorded sexual offences rarely lead to convictions. Of the 144 recorded sexual offences against mentally impaired persons between 2003 and 2012, only six lead to convictions (a conviction rate of 4%).

Attitudes

Societal attitudes can be a significant barrier to people with disabilities living in the community. There remains a paternalistic view of people with disabilities and this is borne out by various attitudinal surveys.

In a national survey of public attitudes to disability in Ireland¹⁴ 98% said that they believed that people with disabilities should have the opportunity to live as normal a life as possible. This figure drops however, when more specific questions are asked about attending local primary school (88%), living independently (85%), marrying (80%) and managing own money (76%). Although these figures are relatively high, it is a clear demonstration of a perception among some parts of society that, people with disabilities

¹² Brennan D., McCausland D., McCallion P., McCarron M., (2016). Understanding the contributors to better integration and community participation by persons with severe and profound intellectual disability, Dublin

¹³ Under section 5 of the Criminal Law (Sexual Offences) Act, 1993, "mentally impaired" means suffering from a disorder of the mind, whether through mental handicap or mental illness, which is of such a nature or degree as to render a person incapable of living an independent life or of guarding against serious exploitation.

¹⁴ Inclusion Ireland 2008

living 'as normal a life as possible' does not involve enjoying the things the rest of us enjoy.

Disaggregated Data

Article 31 of the CRPD requires States to collect "appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the ... Convention". The information should be "disaggregated" and "used to help assess the implementation of State Parties' obligations" and to "identify and address barriers faced by persons with disabilities in exercising their rights."

Following ratification of the CRPD in Ireland, the Committee will need disaggregated data to monitor progress on community living in Ireland.

Comprehensive national data is currently difficult to obtain. Information on the numbers of people with intellectual disabilities living in different residential settings is available from the NIDD. However, data is required on the specific support needs of those leaving institutional care as well as those living in other residential settings in order to plan and support them to live independently.

Disaggregated data is required so that the experiences of different groups of disabled people, such as women, those with complex needs or ethnic minorities, can be examined to ensure that all people with disabilities are being supported to live in the community.

A report by the European Expert Group on the Transition from Institutional to Community-based Care, identified the need for data on those conditions that often lead to institutionalisation such as mental health issues and behaviour that challenges.¹⁵

Crucially, qualitative data is needed on the experiences of people with disabilities themselves and what they need to live independent lives in the community.

Cost of Disability

Persons with disabilities are more at risk of poverty and experience greater rates of deprivation than the general population. In the Department of Social

¹⁵ <http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf>

Protection and the ESRI report entitled 'Social Risk and Social Class Patterns in Poverty and Quality of Life in Ireland' it was found that 55% of adults with a disability experienced multiple quality of life challenges – more than any other societal group.

Additionally persons with disabilities are less likely to attend further education or be in employment. If they do have a job, they are likely to have lower earnings. This 'earnings handicap' is the indirect cost of disability.

As well as income disadvantage, persons with disabilities generally have extra costs associated with having a disability; costs such as home adaptations, higher costs for energy & transport, higher medical costs and disability aids. These are the direct costs associated with disability.

In the UK, the Extra Costs Commission pronounced simply "life costs more if you're disabled"¹⁶

Conclusion

During a consultation with self-advocates we heard that "We would like to see more people living in the community, and out of institutions. It is important that people meet new people and learn to do new things independently."

There are many different strands to be brought together to make community living a reality. It is not just the bricks and mortar of houses, although adequate housing is a substantial issue.

Infrastructure often needs to be dismantled and put back in place in order to ensure a right-based approach to community living.

Access to adequate income and choice and control over budgets is an important enabler of community living and likewise, correct support around decision-making, personal assistance and community connections is a vital part of sustainable community living.

¹⁶ Driving down the extra costs disabled people face Progress review October 2016