

# NATIONAL FEDERATION OF VOLUNTARY BODIES

*Providing Services to People with Intellectual Disability*

## Opening Statement at Joint Committee on Health, 17 May 2017

Mr. Brian O'Donnell,

Chief Executive, National Federation of Voluntary Bodies

*Opening thoughts about the universal good things in life. ..*

### Definition of Disability

*“Disabilities is an umbrella term, covering **impairments, activity limitations, and participation restrictions**. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.*

*Thus disability is a complex phenomenon, reflecting an **interaction between features of a person's body and features of the society** in which he or she lives.”*

(World Health Organisation - <http://www.who.int/topics/disabilities/en/>)

If we take the example of a person with cerebral palsy who wishes to use the library, for instance, we can see that the **impairment** is their diagnosed condition of cerebral palsy, which may then lead to **activity limitations** such as reduced mobility requiring the use of a wheelchair. As this person approaches the library, however, it is the presence or absence of a ramp and accessible doors which affects their ability to enter, **participate** and access the facilities of their community. With a ramp in place the person can fully participate - and in relation to this very simple example of using the library, their impairment or activity limitations are no longer a barrier. Similarly for a person with Down Syndrome, whilst their impairment (an intellectual disability) means that they may learn differently or less quickly than their peers (activity limitation), the provision of appropriate supports in mainstream school, for instance, means that they can participate, learn with their peers at a pace appropriate to their ability and learning style, and live a fuller life more included in their community.

Too often, discussions are focused on the first two elements of this definition of disability (the impairment and activity limitations). However, the UN Convention on the Rights of Persons with Disabilities provides us with a clear framework to focus on the ways in which Government and society must ensure that participation restrictions are identified, addressed and removed and therefore people with disabilities can be afforded their human right to live inclusive lives in the community as fully active and participating citizens.

The UN Convention on the Rights of Persons with Disabilities (2006) enshrines the principles of respect for the inherent dignity and individual autonomy of persons with disabilities (*article 3 paragraph a*); respect for difference; and acceptance of persons with disabilities as part of human

diversity and humanity (*article 3 paragraph d*). The Convention recognises the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities (*Preamble, paragraph m*).

I will briefly touch on ways in which the principles of the Convention are relevant at all stages of the life-course of an individual with a disability. But first, I want to share with you a very brief outline of the life story of one person - as an embodiment of the potential of the full ratification and implementation of the Convention. At the National Federation, we work closely with a self-advocate, Martin Dooher. Martin has an intellectual disability, health difficulties and uses a wheelchair. He has given his permission for us to share his story with you.

When Martin was a child, his parents were told – as was the practice of the day – that the best option for his life and that of his family was for him to live in an institution, and so he was moved from Ballina in Mayo to live in Cork in a congregated setting at the age of 9. For a number of years he lived in various institutions - none of them close to his family, and in his 20's he began living in bungalows on congregated settings lands, followed by group homes in the community, and then an apartment that belonged to the service provider. Finally, at the age of 65, just before Christmas last year, Martin became a **tenant in his own apartment**, which he secured through mainstream social housing and with the supports he needs in place from the Supported Independent Living Programme with the Brothers of Charity.

For Martin, the universal 'good things in life' – living where he chooses, with security of tenure, maximising his potential for independent living with supports in place as required – have become a reality. He is enabled to make valued contributions in the wider life of the community as an advocate, a neighbour, a pet owner, a friend, an uncle. He can have his family come to stay in his own home. These things happen when the services and supports that are offered are tailored to the individual choice and needs of the person, with the various Government Departments taking up their appropriate roles. For Martin, his housing is provided by an Approved Housing Body through the Local Authority whilst supports are in place via a voluntary service provider funded by the HSE. And fundamentally, the natural supports that come about through being part of a community are growing and developing.

Returning to the UN convention:

### ***From the earliest stages in life - Informing Families of their Child's Disability***

Over the past number of years, the National Federation has provided a particular focus on the value of the UNCRPD in relation to the very first stage in life – when a family is informed that their child has a disability. This can take place before the baby is born, at birth or in an evolving diagnosis which can occur over time.

Within the context of promoting the value, dignity and rights of people with disabilities as enshrined in the UN Convention on the Rights of People with Disabilities, the initial communication of a child's disability can become the first opportunity for professionals to make real the 'recognition of the inherent dignity and worth and the equal inalienable rights of all members of the human family, including those with disabilities' [*UN Convention Preamble (a) and (c)*]. Positive, realistic and hopeful messages from the professionals supporting the family can help to ensure that parental expectations positively influence the developmental opportunities afforded to the child - whereas low expectations modelled by authoritative sources at times when parents are likely to be particularly vulnerable can have a detrimental impact on the family's outlook.

Low expectations can create negative, self-fulfilling outcomes and limit the developmental opportunities that will be provided for the children with disabilities. Acknowledging the dignity and worth of the child as an individual, includes celebrating the birth of a child with disabilities. It means acknowledging and respecting the child first and the disabilities as secondary in all communication, and providing messages that are not disproportionately negative when compared with the visions for the future expressed for children without disabilities. As one father put it during our research, when describing the difference in communication at birth for a child with a disability and without:

*“... if you had an ordinary child, they don’t give you a book saying, look, he’s going to rob a car and he’s going to get a girl pregnant or he’s going to fail his exams. So you have to live life as it goes by. They don’t tell you that with the ordinary child.”*

In his experience, professionals felt compelled to list all possible negative outcomes in a worst case scenario approach for a child with a disability at the time of diagnosis, in sharp contrast with optimism expressed at the time of a child’s birth who does not have a disability.

Appropriate communication at the time of diagnosis of a child with disabilities can be seen as providing recognition of the dignity of all children, and gives voice to the provisions of Article 8 of the UN Convention (*paragraphs 1a, b and c*) in raising awareness of the dignity of persons with disabilities; combating stereotypes and prejudices; and promoting awareness of the capabilities and contributions of persons with disabilities.

The National Federation developed evidence-based guidance to support professionals in the sensitive communication of the news of a child’s diagnosis to the family, and we are currently engaged in a national roll-out programme in close collaboration with the HSE and the Department of Health. Internationally, a range of other countries have begun using the Irish guidance – with the materials having been translated into Finnish and Bulgarian, and work is beginning on the Swedish version. This work is evidence of how the application of the principles of the UNCRPD in action can be transformative for families and professionals. It may not have been imaginable to the professionals who informed Martin’s family about his disability 65 years ago that he would one day live independently with supports, with his own tenancy – and so it is very important that we imagine what is possible for children who are diagnosed today and think about what we have learned in terms of the potential and the ‘good life’ possibilities for individuals, when we support families from the outset.

**As we move through the life cycle, the range of Government Departments who have significant responsibility for maintaining the vision of life lived to its full potential in line with the UN Convention grows. As children reach school age, for instance,** the National Federation warmly welcomes the implementation of a new policy for allocation of special needs teaching resources in mainstream school settings which will come into effect in autumn 2017 - as a wonderful example of the potential of Government Departments to influence positive change. The focus of this policy moves from a deficit-based approach that provided resources based on the diagnosis of a child, to a system based on the profiled educational needs of each school. This will address the unfairness that existed in the previous system, whereby many parents were struggling to access assessments in order to quality for educational resources, which had a particularly negative impact on children from disadvantaged areas.

Similarly, as young people move into the transition from school to post-school options, the **Comprehensive Employment Strategy** provides a framework which must be implemented in order to ensure that a range of Departments meet their responsibilities to enhance inclusion and develop the potential of individuals to access work, and that of employers to recognise the value of people with disabilities as employees. The 2011 Census provides stark evidence of the extent to which people with disabilities are currently much less likely to have employment than other people of working age, and for people with intellectual disabilities this is even more acute. The National Federation strongly advocates for the implementation of the Comprehensive Employment Strategy through cross-departmental collaboration to ensure that current barriers to employment are removed so that the vision of the Strategy - that people with disabilities are supported to maximise their potential and enabled to have jobs, earn a living, and make a contribution; is fully realised in line with the State responsibilities set out in Article 27 of the UNCRPD.

### **Living in the Community**

Article 19 of the UNCRPD unequivocally recognizes *‘the equal right of all persons with disabilities to live in the community, with choices equal to others’*, and places responsibility on States to take *“effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.”*

Very positive work has taken place under the **National Housing Strategy for People with a Disability**, which is a joint strategy of the Department of Health and the Department of Housing Planning, Community and Local Government - to mainstream the assessment and allocation of housing resources to meet the needs of people with disabilities. Under the Strategy, pathways for people with disabilities to access mainstream housing options through funding schemes such as the Capital Assistance Scheme, the Capital Advanced Leasing Facility, and the HAP payment have been improved, and Housing and Disability Steering Groups have been established at Local Authority level to ensure an ongoing cross-sectoral focus on the meeting of the housing needs of people with disabilities.

However, at this time there are very significant barriers which mean that many people are not enabled to access the opportunity to live in community settings, in line with the UNCRPD. There has been a lack of provision of funding for residential supports in the community over the past 8 years which means that even with the mainstreaming of housing options, the funding for *the supports* to enable people to take up these options is currently severely limited. The numbers of people with disabilities requiring support and the increased age of carers is leading to built-up emerging need. In just one of our member organisations for example, there are there are 285 people living in their childhood home with family support in which the primary carer is over 71 years of age; 98 of whom are over 80 years of age. Additionally in this one service provider organisation, there are 205 carers in the 61-70 age range – and these represent significant emerging need for residential support to come.

Due to the lack of residential supports available, most people who access new residential support at this time present as emergencies – which often leads to decreased availability of respite support for families, since respite places are then taken up in addressing emergency need. Meeting residential support needs in this crisis-driven model does not allow for the kind of freely chosen, planned life that we heard about Martin accessing earlier. At this time, the only new residential support that the HSE can provide within the funding envelope provided, to people currently living as adults within the family home, is provided on an emergency basis.

The evidence is clear that people with all levels of disability can live in the community and benefit greatly from the exercising of their right to do so. The *'Time to Move on From Congregated Settings Report'* provides clear evidence of the need to support people currently living in institutional settings to move to inclusive community-based living, however implementation of this report is currently behind schedule. In the context of supporting people with disabilities to live in the community, it is essential that the changing needs of older adults with disabilities are factored into planning and resourcing. It is essential that resources are put in place to ensure that the fundamental driver of a fulfilling life – living in a place that you are happy in, with people you have chosen to live with – is available to people with disabilities on an equal basis as for all citizens.

### **Decision Making**

In relation to all of the life stages we have touched on, Article 12 of the UNCRPD upholds the overarching rights of persons with disabilities to recognition everywhere as persons before the law. It indicates that *"States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life"* and *"shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."* Clearly, there is an urgent need for prompt commencement of all sections of the Assisted Decision Making (Capacity) Act 2015, to ensure that individuals with disabilities in Ireland are fully supported in exercising their right to make decisions on a 'will and preference' basis. Central to the success of these measures is the establishment of the Decision Support Service and the provision of the appropriate funding to enable the implementation of arrangements that support individuals exercising their right to make decisions.

### **Budget 2018**

Achieving the exciting aspirations set out in the UNCRPD will require significant resourcing. After the years of austerity during which there was little investment and substantial funding cuts there are now worrying waiting lists for Residential Supports, Day services, therapeutic supports and Respite care. Emergency cases arise on a daily basis and as people with disabilities grow older their support needs are changing. Many families are in crisis as carers also grow older. **What is required as a matter of urgency is a commitment by Government to a Multi-Annual Investment Programme commencing with Budget 2018.** We have clear evidence that accessing the human rights set out in the UNCRPD to live in the community, to be seen as a contributing member of society and to reach one's full potential is transformative in the lives of people who have had an opportunity to do so already. **We look forward to the day when all citizens with disabilities in this State are given the opportunity to reach their full potential and access their human rights as set out in the UNCRPD** and as exemplified by the inspiring life story of Martin Doohar.



## References

Central Statistics Office (2012). *Our Bill of Health*. Dublin, Stationary Office.

Government of Ireland (2016) *Comprehensive Employment Strategy for People with Disabilities 2015-2024*. Dublin: Government of Ireland.

Harnett, A., Tierney E., & Guerin, S. (2009) *Convention of hope – Communicating positive, realistic messages to families at the time of a child’s diagnosis with disabilities*. *British Journal of Learning Disabilities*, 37, (7), 257-264.

Harnett A., Dolan B., Guerin S., Tierney E. & Walls M. (2007) *Informing Families of their Child’s Disability – National Best Practice Guidelines; Consultation and Research Report*. Galway: National Federation of Voluntary Bodies. (ISBN 978-0-9557833-0-2)

Health Services Executive (2011) *Time to Move on from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*. Dublin, Health Service Executive.

National Council for Special Education (2014) *Delivery for Students with Special Educational Needs A better and more equitable way. A proposed new model for allocating teaching resources for students with special educational needs*. Meath: National Council for Special Education.

National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (2007) *Best practice guidelines for informing families of their child’s disability*. Galway: National Federation of Voluntary Bodies

World Health Organisation - <http://www.who.int/topics/disabilities/en/> . Accessed on 9 May 2017.

UN General Assembly (2007) *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007 A/RES/61/106*