INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Citizens Assembly

On how we best respond to the challenges and opportunities of an ageing population

May 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 contribute to the Citizens Assembly's discussions on how we best respond to the challenges and opportunities of an ageing population. It is most welcome that the Citizens Assembly is considering this issue as it is one of the most important issues facing Irish society and one that impacts on all sectors of society.

We know from the available data that Ireland has an ageing population and that there is a strong link between disability and ageing. As the population of people over 65 increases, we can expect to see an increase in the numbers of people with disabilities as they acquire disabilities with age.

1.1 Profile of the ageing disabled population

- While the population increased by 7% between 2007 and 2016, the number of people over 65 increased by 33%[1]
- 10% of people in their 20's have a disability; over 70% of people over 85 have a disability[2]
- 29% of people with a moderate, severe or profound intellectual disability were aged 35 or over in 1974. 49% were aged 35 or over in 2015[3]
- Disability is more common in boys and men in many age groups. However, this is reversed among older people with disabilities, with more women than men in the older age brackets.

Those who have had a disability all their lives, such as people with intellectual disabilities, may need a greater level of support than those who acquired a disability through ageing. For example, they may have had less opportunity to build up economic assets during their working lives. They are less likely to be married or have children, and so cannot rely on these social supports as they age, as many other older people do.

It is important to stress the diversity of the ageing population and of the ageing experience itself - each person ages in a different way and at different times. However, many of the issues that affect people with disabilities throughout their lives are similar to those that impact on people as they age. The importance of autonomy, rights, choice, independence, accessible environments, participation and inclusion are key themes in both disability and ageing policy.

1.2 Planning for an ageing society

The prevailing narrative on ageing focuses mainly on the challenges of an

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[1]Department of Health (2016). *Health in Ireland. Key trends 2016.*

[2] CSO (2012). *Census 2011.*

[3] Figure relates to the number of persons with an intellectual disability registered on the Health Research Board's National Intellectual Disability Database, 1974-2015.

ageing population, and in particular the budgetary challenges associated with the cognitive changes, increased risk of physical and mental ill health, social changes and economic changes that often accompany ageing.

While this is a significant factor, people living longer than they ever did before is a hugely positive development and is something to celebrate. There is a wealth of demographic data on ageing available to guide policy and practice. If we plan now and put the right supports in place, we can create a society that values, respects and supports all older people, including those with disabilities.

1.3 A vision for older people with disabilities

To create a disability and age friendly society, Inclusion Ireland proposes the following high level outcomes. Achievement of these outcomes would go a significant way towards ensuring quality of life for older people with disabilities and indeed all older people in Ireland:

- People are supported to live in a home of their choosing

- People have the best physical and mental health possible

- People have the economic resources to sustain a decent standard of living

- Physical and social environments are age and disability friendly

This rest of this submission sets out some of the issues that need to be addressed if we are to achieve these outcomes. Inclusion Ireland asks the Citizens Assembly to consider these issues in its recommendations to the Houses of the Oireachtas.

We also urge the Citizens Assembly to consult directly with people with disabilities to ensure that their voices are heard. In reflecting our own values as an organisation, Inclusion Ireland engaged with people with

disabilities in compiling this submission. Their views on key issues are dispersed throughout this paper.

2. Older people with disabilities are supported to live in a home of their choosing

Supporting people to live in their own home is a key policy objective of both the disability and older people's sectors. The UN Convention on the Rights of Persons with Disabilities (UNCRPD), Article 19, reaffirms the right of people with disabilities to choose where and with whom they live on an equal basis with others.

In a recent comment, the UNCRPD Committee repeated the requirement for "States parties to take measures to eradicate practical barriers to the full realization of the right to independent and community living, such as inaccessible housing, limited access to disability support services, inaccessible facilities and services in the community and prejudices against persons with disability"[4].

The availability of appropriate housing in Ireland is already at crisis point. By 2019, the remaining two to three thousand people currently living in congregated settings across Ireland will need to be accommodated in suitable, community based accommodation, in line with the HSE policy, Time to Move on from Congregated Settings. Residents in congregated settings are an aging population - 20% were over the age of 60 and 50% were between the ages of 40-60 at the time the report was published more than 6 years ago[5].

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[4] Committee on the Rights of Persons with Disabilities Draft General Comment No. 5 (2017). *Article 19: Living independently and being included in the community*

[5] HSE, Working Group (2011). *A Time to move on from congregated settings-a strategy for community inclusion.*

All people with disabilities, whatever their age or the level of support they may require, should have an opportunity to live in an inclusive community of their choosing. As people age, they may require a higher level of supports. There is a danger that if we do not plan now to provide appropriate housing supports in the community, that older people with more complex needs may return to institutional settings.

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Housing – What people said

- "People with disabilities should be supported to live independently in their homes and not be sent to a nursing home. There are people who have lived in institutions for years, who now live in the community and who do not want to go back to living in an institution in their old age"

- "We would like to see housing planning place more of a focus on providing buildings with greater accessibility for older people and those with disabilities. We want there to be input from those with disabilities when houses are being planned and constructed"

- "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".

Views of participants at Inclusion Ireland consultation, April 2017

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Personal Assistance is a vital support to enable people to live independently in their own homes and to access the community. The right to supports such as this is also enshrined in the CRPD, which states that people with disabilities should have "access to a range of in-home, residential and other community support, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community".

Full commencement of the Assisted Decision Making (Capacity) Act 2015 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 (Capacity) Act 2015 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.

2.1 Supporting those in caring roles as they age

People with a disability are living longer and as a consequence their carer's are also an aging population. While not all are caring for people with a disability, there are 24,746 carer's over the age of 65 according to the most recently available census data[6].

The National Intellectual Disability Database (NIDD) counts the numbers of people receiving a service and as a result is an underestimate of persons with a disability. However, it is a useful source of data to inform planning. Of the 28,000+ registered on the database, 4,039 people with an intellectual disability over the age of 35 are living at home with their aging parents[7].

Through Inclusion Ireland's advocacy work we are aware of a case of a man in his 90's with an acquired physical disability caring for his daughter with an intellectual disability in her 50's. Inclusion Ireland has also been made aware of a carer with dementia caring for her daughter in her 50's. As family members age, it is vital that the necessary supports are in place to address their needs and to enable the people they are supporting to continue to live as independently as possible. Supporting people with disabilities and family to engage in future planning would help to negate the crisis effect that people experience as they and their family members

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[6] Census (2011)

[7], Health Research Board (2016). *Report of the National Intellectual Disability Database 2015*

age. This must be accompanied by rights based legislation to ensure that people can access the services and supports they require.

Focus on: Short breaks

In order to sustain the caring relationship into the future, quality, regular, flexible short breaks (respite) is seen by many carer's as an essential support. Short breaks also provide the care recipient with a break from the home routine and an opportunity to socialise with others outside the family unit. During the recent times of austerity, short breaks was one of the disability services that was hit hardest for funding cuts.

Family Carer's Ireland monitor the implementation of the National Carer Strategy which aims to "promote a range of person centred and flexible respite options". Each score card from Family Carer's Ireland rates performance in the provision of short breaks as regressive. Respite places are being used as residential, are being closed for not complying with HIQA standards and are not available at weekends due to cost constraints.

It is commonly assumed that people with disabilities are care recipients only, with support and care provided by non-disabled carers. However, there is increasing evidence that people with intellectual disabilities also provide care and support to ageing family members and contribute in many ways to sustaining the household, such as through carrying out practical care tasks and providing emotional support and companionship[8].

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[8] Brennan, D. , Murphy, R. , McCallion, P. et al (2016). Understanding family strategies that enable long term and sustainable environements for older people with an intellectual disability. Dublin: TCD.

There is a need to examine the prevailing narrative that people with intellectual disabilities are the recipients of care only and to provide accessible information and supports to this group of people.

Recommendations:

- Provide person centred, community based housing for people with disabilities to meet identified need. There must be choice for the person with a disability in where and with whom they live. A priority must be given to situations where the person's carer is aging

- Provide a range of supports such as Personal Assistance, short break services and home care to support people to maintain their independence and inclusion in the community

- Fully commence the Assisted Decision Making (Capacity) Act 2015 and provide appropriate resources to the associated Decision Support Service to ensure that people are supported to make their own decisions

- As identified in the National Carer Strategy, a range of flexible, person centred short break (respite) options must be made available to carer's and persons with a disability

- There is a need for information and supports tailored to the needs of people with intellectual disabilities in caring roles.

- Accessible information is vital to enable people with disabilities to participate in decisions affecting their lives. Information on housing and housing supports should be provided in a range of formats including plain English, easy to read, ISL and videos.

3. Older people with disabilities have the best physical and mental health possible

The Irish Longitudinal Study on Ageing (TILDA) and its intellectual disability supplement (IDS-TILDA) provide a wealth of information on health outcomes for older people and how people with intellectual disabilities age compared with the general population.

The IDS - TILDA reported some significant findings concerning people with disabilities and aging. According to the study, as they aged people with disabilities were more likely to experience:

- Vision and mobility challenges

- Chronic constipation

- A higher prevalence rate for falls

- A higher incidence of mental health and emotional health issues

- A higher incidence of polypharmacy (using 5 or more medications).

According to IDS TILDA research, depression in older adults with intellectual disabilities was 3 times more common than in the general population of older people. Prevalence of dementia is also much higher among older people with Down syndrome[9]. In the three-year period since the first IDS-TILDA study was conducted in 2010, the prevalence of dementia has nearly doubled in people with Down syndrome - from 15% to just under 30%.

9 McCarron, M; Swinburne, J; Burke, E; McGlinchey, E; Mulryan, M., Andrews, V., Foran, S., McCallion, P. (2011). *Growing older wiht an intellectual disability in Ireland 2011: First results from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.* Dublin: School of Midwifery adn Nursing, TCD.

Older people with disabilities in Ireland are also more likely than others to experience social exclusion and loneliness, which can have negative effects on psychological well-being and quality of life. The study found that around 50% of respondents experienced some degree of loneliness and 15% reported that they felt lonely most of the time. People living in institutional settings and community group homes were more likely to report feeling socially excluded than those living in family homes or independent situations[10].

Inclusion – what people said

- "We would like to see a community support network for older people so that they do not become isolated".

Views of participants at Inclusion Ireland consultation, April 2017

One of the primary reasons for social exclusion and loneliness amongst older persons with intellectual disabilities in Ireland is a lack of access to community supports and facilities together with the poor levels of social participation and connectedness.

Older people with disabilities are also more likely to be single and without children or grandchildren, a key social support for many older people.

The IDS-TILDA findings also show a gender dimension to ageing with older women with disabilities more likely than men to experience social exclusion, loneliness, cardio-metabolic disease, eye conditions, pain, or be overweight or obese.

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[10] Ibid

Recommendations:

- Health and social care services should make use of the available data to plan for the appropriate type and level of supports needed to cater for the growing population of older persons with disabilities

- Public health information programmes and awareness campaigns should be made accessible to people with disabilities and targeted supports should be made available to groups of people with disabilities that are particularly at risk. Information should be provided in a range of formats including plain English, easy to read, ISL and videos.

- Supports should be provided to access health screening programs for conditions prevalent among older people with disabilities. Publication of disaggregated data on uptake of screening would help to inform policy and practice in this area.

- Person-centred supports need to be provided to older people with disabilities to protect against social exclusion and loneliness and to ensure that they are included in the community as they age. Particular attention needs to be paid to the support needs of those leaving institutional settings

- People with intellectual disabilities should be supported to engage in relationships, if they wish to do so.

4. Older people with disabilities have the economic resources to sustain a decent standard of living

4.1 Cost of disability

People with disabilities experience greater levels of poverty and deprivation than the general population. The latest data from the Survey

on Income and Living Conditions (SILC) indicates that 35% are at risk of poverty (their income is below a certain threshold). This is more than double that of the population as a whole.

Consistent poverty (where people's income is below a certain threshold and they lack two or more basic necessities) rose from 14% in 2014 to 22% in 2015 among those with disabilities, compared to 9% among the general population[11].

However, standard measurements of poverty based on income underestimate poverty among people with disabilities since for a given income level, people with disabilities have additional costs not taken into account. These costs include specialist disability aids, home adaptations and therapeutic supports, higher energy costs or an increased need for taxis where accessible public transport is not available.

There is evidence that the additional costs of having a disability can place a household at significant risk of poverty and deprivation. A report by Cullinan et al found that the estimated cost of disability is equal to 35 to 55% of average weekly income[12]. Older people with a disability face greater levels of poverty due to their age and their disability with older people living alone being the worst affected[13].

Having less opportunity to build up financial assets through their working life is another factor contributing to poverty among older people with disabilities. The Commission on the Status of People with Disabilities recommended in its 1996 that a 'Disability Pension' should be established to compensate older people with a disability for loss of income associated with work. They also recommended that a cost of disability payment

[11] CSO (2017). Survey on Income and Living Conditons 2015.

[12] Cullinan, J., Gannon, B. and Lyons, S. (2010). *Estimating The Extra Cost of Living for People with Disabilities*. Health Economics.

[13] Cullinan, J. (2014). *The economic cost of disability for older people.* Health Economics.

should be established to meet the additional costs associated with disability[14]. Neither of these recommendations have been implemented to date.

4.2 Wills and inheritances

Like all older people, older people with intellectual disabilities are at a stage in their lives where having a will reflecting their wishes is of utmost importance. However, from Inclusion Ireland's experience, the majority of people are unaware of the importance of having a will or how to go about making a will.

Currently the process of making a will is inaccessible to many persons with an intellectual disability. The legalities and procedures associated with making a will and the inaccessibility of language and formats all act as barriers.

With the enactment of the Assisted Decision Making (Capacity) Act 2015, a person is presumed to have legal capacity. This also applies in the context of making a will. Therefore, a solicitor must presume that a person with an intellectual disability is capable of expressing his/her wishes in a will like anyone else.

Further training for legal professionals is required around the Act and on intellectual disabilities. From our advocacy work, Inclusion Ireland is aware of cases where solicitors have requested a GP's assessment of a person's capacity without determining a person's capacity for themselves.

Inclusion Ireland also receives numerous queries from concerned parents and siblings in caring roles regarding the consequences of inheritance for their disabled family member. The main concern for people with disabilities in relation to inheritance is how any monies they benefit from in a will can negatively affect their entitlement to Disability Allowance

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[14] Commission on the Status of People with Disabilities (1996). *Report of the Commission on the Status of People with Disabilities*

under the means test. Unknown to some family members that leave sums of money or property behind to individuals with disabilities in their will, the rate of Disability Allowance is affected by any benefit over €50,000 on a sliding scale basis.

On a more general note disabled persons can be overlooked in terms of inheritance as family members do not acknowledge them as being capable of managing money or having a monetary need. This is a societal perception regarding individuals with intellectual disabilities and what they can and cannot do for themselves.

Money matters – What people said

- "We want people with disabilities to have enough money to live independently and be comfortable financially"

- "We want people with disabilities to be supported to make a will if they want to".

Views of participants at Inclusion Ireland consultation, April 2017

Recommendations:

- Establish a Cost of Disability Commission to identify the extra costs of having a disability and to make recommendations around necessary reforms.

- Introduce a universal cost of disability payment based on individual needs, to offset some of the extra costs that people with disabilities face to attain the same standard of living as non-disabled people

- Full implementation of the Assisted Decision Making (Capacity) Act and associated structures is needed to support older people with

disabilities to make financial decisions. An awareness campaign aimed at all people with disabilities as well as other stakeholders should also be implemented

- Accessible information should be provided to families and persons with disabilities around inheritance and its potential impact on social welfare payments and other State entitlements.

5. Physical and social environments are age and disability friendly

5.1 Accessible communities

The Programme for Partnership Government made a commitment to "support people with disabilities in maximising their potential, by removing barriers which impact on access to services, education, work or healthcare[15]."

People with disabilities experience many physical barriers to their full enjoyment of the community. Older people with intellectual disabilities have reported that street signage and feeling unsafe are barriers to community inclusion. Those with more complex support needs identified footpath design, surfaces and building accessibility as the greatest barriers[16]. Many of these are the same barriers experienced by the general population of older people.

Universal design refers to designing and building environments that can be accessed, understood and used by all people to the greatest extent

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[15] Programme for Partnership Government (2016)

[16] McCarron, M; Swinburne, J; Burke, E; McGlinchey, E; Mulryan, M., Andrews, V., Foran, S., McCallion, P. (2011). *Growing older wiht an intellectual disability in Ireland 2011: First results from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.* Dublin: School of Midwifery adn Nursing, TCD.

possible regardless of their age, size or disability[17]. It is a fundamental condition of good design rather than a special consideration for a minority of people. The principles of universal design should be incorporated at all levels of Ireland's planning strategy.

5.2 Changing Places

Currently in Ireland, many people are excluded from towns, cities and communities through a lack of fully accessible toilet facilities. Standard disabled toilets do not meet the needs of all people with disabilities or indeed older people as some people need extra facilities to use the toilet.

Changing Places facilities are different from mainstream accessible toilets in that they include both a hoist and a height-adjustable changing bench. They have been designed to put health, safety and dignity concerns of the person to the fore.

As it currently stands, there are only a small number of fully accessible toilet facilities in Ireland including Trinity College Dublin, Dublin Airport Áras an Uachtaráin and The Lime Tree Theatre in Limerick.

Some work has already started at Government level around rolling out Changing Places toilets around Ireland. The Office of Public Works (OPW) has made a commitment to carry out appraisals of tourist centres Farmleigh House, Dublin Castle, Glendalough Visitor Centre, the National Gallery and Clonmacnoise Heritage Centre to incorporate fully accessible toilets. The OPW unveiled the first of this series of installations at Áras an Uachtaráin in May 2016.

Access to public toilet facilities is a basic requirement for people to be able to participate in the life in the community. An expansion of Changing Places facilities across the country would benefit both disabled and older people.

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[17] The Disability Act 2005

5.3 Transport

Accessible transport is vital to enable people with disabilities and older people in general to get around their community and across the country, to attend work and to generally participate in the life of the community. It is a key driver of inclusion in the community.

Findings from the IDA-TILDA indicate that the majority of older people with intellectual disabilities are dependent on others for transport to participate in community life. Participants reported that this was the biggest barrier to participating in social activities[18].

The need for accessibility in transport encompasses the whole journey experience – from accessible timetables and information to accessible public transport infrastructure, disability aware staff and accessible parking.

Recent figures indicate that more than one in four people with disabilities do not use public transport due to accessibility reasons; nearly half of Bus Éireann's fleet is not deemed accessible and only 5% of licensed vehicles were deemed accessible in 2015[19]. The Workplace Relations Commission published a ruling in May 2017 upholding the requirement for disabled passengers to give 24 hours' notice to Bus Éireann should they wish to travel. In their statement, the WRC argued that "is reasonable and proportionate and fulfils the objective of ready accessibility for the generality of passengers with a disability who need to avail of the service" [20].

Two schemes established to support people with disabilities to access transport, the Mobility Allowance and Motorised Transport Grant, were

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[18] McCarron, M; Swinburne, J; Burke, E; McGlinchey, E; Mulryan, M., Andrews, V., Foran, S., McCallion, P. (2011). *Growing older wiht an intellectual disability in Ireland 2011: First results from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.* Dublin: School of Midwifery adn Nursing, TCD.
[19] Disable Inequality (2016). *Transport and Disability Factsheet.*
[20] Irish Examiner (04.04.17). *People with disabilities 'second-class' citizens when it comes to public transport.*

discontinued in 2013. Plans for a new Transport Support Scheme were announced shortly after this but have not been put in place to date.

Transport – What people said

- "We would like to see better infrastructure in local areas so that people with disabilities can avail of public transport and travel with greater ease"

- "We want all buses, trains and taxis in Ireland to have fully accessible wheelchair ramps for people with disabilities"

- "We want all private transport operators to take bus passes in the future as at the moment only public operators and some private ones provide this"

- "We would like to see timetables and transport information being much more accessible and easy to read throughout Ireland's transport network for people with disabilities"

- "We would like to see future planning of transport infrastructure place more importance on people with disabilities and older people, listening to what they have to say"

- "We would like to see a transport scheme in place that could enable older people, and those with disabilities to access their community when they want to".

Views of participants at Inclusion Ireland consultation, April 2017

5.4 Assistive Technology

Assistive Technology can greatly enhance the lives of people with disabilities, older people and those with memory difficulties and is an important tool in supporting people to live more independent lives.

Assistive Technology includes screen reading software that can support people with vision or literacy challenges, voice communication for people who don't communicate verbally and wearable technology that can remind people to take medications or carry out tasks.

Assistive Technology has the potential to support people to access employment, complete their education and live in the community. Research has demonstrated the potential of Assistive Technology in enabling people with complex support needs to communicate. The use of Assistive Technology can support people with complex needs to communicate their will and preference, can enhance their relationships and can promote their inclusion in the life of the community.

Despite the many potential benefits, it is an underdeveloped and underexplored area in Ireland. Enable Ireland and the Disability Federation of Ireland have published a discussion paper entitled 'Assistive Technology for People with Disabilities and Older People' which outlines the benefits of Assistive Technology for the user and for society. The paper calls for a whole of government policy statement on Assistive Technology, the introduction of an Assistive Technology Passport and for a single agency to coordinate a system of supports[21].

Recommendations:

- Planning policy should incorporate the principles of universal design so that housing, public building and public spaces are accessible to both people with disabilities and older people

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[21] DFI and Enable Ireland (2016). *Assitive technology for people with disabilities and older people.*

- A strategy to deliver an accessible and integrated transport system across urban and rural areas is urgently needed

- Work on the new Health (Transport Support) Bill should be progressed as soon as possible to ensure the social inclusion of people with disabilities.

- Changing places, fully accessible toilets, should be installed across the country in both urban and rural areas, with a changing places facility in every major tourist site or civic, social or cultural centre by 2040

- Increased access to Assistive Technology is needed for both people with disabilities and older people

6. Conclusion

Planning for the future should be guided by a vision of the Ireland that we would like to see – an Ireland that acknowledges and values diversity and includes all its people. As a society, we need to develop a shared vision of the kind of place that we would all like to grow old in.

Inclusion Ireland believes that the outcomes and actions identified above are a useful contribution towards developing this shared vision and will go some way towards improving the quality of life of older people with disabilities and the ageing population as a whole.

In developing a shared vision, a broader societal conversation is needed on the negative perceptions and low expectations that exist regarding people with intellectual disabilities and their capabilities.

The voice of persons with disabilities should be included in all such discussions and the diverse ways in which different people communicate should be acknowledged and respected.

The Citizens Assembly has the opportunity to kick-start this conversation. Inclusion Ireland asks the Assembly to consider the issues raised in this submission in its recommendations to the Houses of the Oireachtas.