

Your Voice Your Choice

Report

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Údarás Náisiúnta Míchumais
National Disability Authority

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Preface

I am pleased to present the Report of the consultation process, **Your Voice Your Choice**, which the National Disability Authority hosted at the request of the Minister for Disability, Equality, Mental Health and Older People in June 2012.

Your Voice Your Choice was organised as a consultation where individuals with disabilities could have their say on issues that matter most to them. **Your Voice Your Choice** brought together individuals with disabilities, parents of children and young people with disabilities, and advocates to have a constructive dialogue guided by their experiences in their daily lives. It provided a space to hear about what the challenges are and what supports are needed in daily living. It gave people an opportunity to have their say about what they see are the priorities and to capture this important information to guide policy and service development.

This Report captures the views and experiences of about 250 people who participated in the event on the day and through the online facility which was available to those who would have liked to be there but could not attend. It reflects what people with disabilities said is important to them when it comes to key issues like:

- Being treated equally
- What it means to reach one's potential
- Being able to participate in the community
- Living independently

It is important that these views have been captured to help inform and shape the development of the new implementation plan for the **National Disability Strategy**. The plan provides for a whole of Government approach through most government departments and agencies in improving the lives of people with disabilities over the next 3 years. This Report is a significant contribution to this process and will be submitted to the Minister and circulated to government department officials in that regard.

On behalf of the National Disability Authority I want to thank everyone who took the time to share their views and experiences at the event and through our online facility making this Report possible.

Peter McKevitt

Chairperson – National Disability Authority

Acknowledgements

The success of **Your Voice Your Choice** was primarily due to the participants who engaged with the process in significant numbers and made extensive and insightful contributions. The rapporteur, facilitators and note-takers were another important component part of the seminar. Their diligence in carrying out their role ensured that matters were given appropriate time and discussion and that the information was recorded and comprehensively collated.

Executive summary

Opening of Your Voice Your Choice by the Minister

The Programme for Government 2011 – 2016 contains a commitment to draft an implementation plan with achievable timescales and targets for the **National Disability Strategy**. The National Disability Strategy Implementation Group which is developing and will monitor the plan is chaired by the Minister for Disability, Equality, Mental Health and Older People. The Group comprises representatives from government departments, the National Disability Authority, local authorities and disability stakeholders (including disability groups and individuals).

To inform that Plan, the National Disability Authority organised the **Your Voice Your Choice** consultation exercise to hear from people with disabilities on the ground what their concerns and priorities were.

The event was launched by Ms Kathleen Lynch T.D. Minister for Disability, Equality, Mental Health and Older People, who spoke of the need to hear the voice of people with disabilities in developing any policy or services that impact on their lives:

‘This event is about genuinely listening to the voices of people who often don’t get an opportunity to have their voice heard and air their concerns and experiences’.

Participants expectations of the Your Voice Your Choice event

For participants the range of expectations can be summarised as follows:

- Optimise the opportunity to speak, present viewpoints and input into strategy
- Provide an opportunity to highlight the lack of action to date on many disability issues and to identify areas of necessary action
- Contribute to addressing cuts to services which make life difficult or unbearable for people with disabilities
- Seek to improve existing services, make them more coherent, responsive and consistent
- Advance the disability rights agenda through legislative, administrative and procedural means that will ensure equality, promote respect, improve accountability and enable independent living

Key themes

The framework for the **Your Voice Your Choice** consultation was based on the central themes of the draft **National Disability Strategy Implementation Plan**- namely equality, independent living, choice, participation and maximising potential. These themes also find synergy with the intent and aims of the **United Nations Convention on the Rights of Persons with a Disability** and the objectives of the **National Action Plan for Social Inclusion 2007 – 2016**. The following is a summary of the key issues and discussion that took place.

Attitudes

Campaigns to bring attitudinal change have been successfully deployed to raise awareness and to force cultural alterations in the past. Similar campaigns need to be renewed to address, such things as, the perception of a growing intolerance by parents to integrated schooling arising from the competitive nature of schooling in Ireland.

Schooling is seen as the point at which awareness should be embedded to bring about the level of responsibility and acceptance in society that will ensure greater equality into the future.

Awareness training that instils equality values should be a core part of training for health and education professionals. This could contribute to the required attitudinal change in services provision over time.

Education

Integrated schooling is a positive measure only if it is flanked with supporting measures. Special Needs Assistants are a key support for children with disabilities. A key concern among parents of children with disabilities is the potential impacts that funding cuts to this service will have on the outcomes from education and it could lead to reinforcing inequalities that arise from educational disparities. If this service is not economically viable then alternatives need to be investigated.

Employment

Accessing employment continues to be extremely problematic, and has been made worse because of the perceived failure of employment inclusion strategies in the public service. The introduction of the employment embargo has worsened this situation. In addition, people with disabilities are unable to get onto established pathways to employment that seamlessly connect education to training and employment. Thought should be given to the development of joined-up pathways towards employment for people with a disability.

Environment – local authorities

Streetscapes have improved, but clutter from signage, bollards, and poor road dips, for example, continue to make physical access awkward. Many buildings are not accessible and there is considerable frustration that building regulations are not being enforced.

The fragmented nature of local administration affects the implementation of access remedies and needs to be addressed. In most European countries key public services like public transport; education; and roads are all within the remit of local authorities. The absence of this in Ireland requires the establishment of coordination structures that bring agencies together to address physical environment; transport; and information access issues.

Living in the community

The commitment to moving from institutional or centralised care regimes towards community settings has not made sufficient progress, despite the obvious advantages and economies that could be achieved. Moving closer to communities enables independent living to be more realisable and draws in a range of community supports that would not be otherwise available. These community interfaces also have a cumulative effect in generating community development activity, which in turn enhances independence, personal development and collective attitudinal change.

Having choice and control; being able to socialise; access options; conduct a socially interactive life; and get a job; are core requirements for people with disabilities that cannot be addressed through a single action. The ideal was expressed as:

‘Living independently, with a house close to the job’.

Many of these matters are related to awareness and attitudinal change, but there are also institutional and structural changes that will hasten matters along. Moving services closer to the community; strictly enforcing planning and building regulations; insisting on integration as a requirement in all local services and public provision, would all contribute to independent living.

Quality services

Access to quality services is highly problematic. Services are disjointed, inconsistent and some felt often administered in a less than respectful manner. Information on entitlements is complex, located with different providers and needlessly bureaucratic. Access to both services and information is often dependent on the resilience of the person or the advocacy that can be mustered to pursue the matter. Parents, in particular, spoke of enduring battles being

undertaken to get basic entitlements for their children. It is clear that effective complaint procedures need to be enhanced and information on same more widely available.

Services need to be better coordinated and seamless in delivery. Many services should be regionalised with inconsistencies of quality ironed out through the implementation of national standards. Shifting control of the funding towards the individual would enhance the power of the recipient and bring about improvements and efficiencies.

There is a widespread concern about the failure to develop a system of services that are fit for purpose and capable of delivering on the objectives outlined in the National Disability Strategy. Greater transparency about funding and value for money is required before this failure can be properly addressed. Value for money concerns relate both to statutory and NGO providers, but there is a particular concern about the percentage of spend getting through to the user in non-governmental organisations.

Social exclusion

Inability to access employment and welfare dependency leave people vulnerable to poverty and social exclusion. This leads to isolation and separation from the social networks that sustain people in living their life. Families are central in maintaining social inclusion and, therefore, need to be supported. It is unfair and disempowering to solely rely on families. The State needs to revise existing payment schemes in order to guarantee an adequate floor of income provision that facilitates social inclusion and protection from poverty.

Ultimately, social inclusion is dependent upon a critical level of demand from those experiencing marginalisation. This will only occur if there is sufficient investment in community level organisations to enable their effective interface at the policy and delivery level. Although there is a substantial NGO infrastructure in place it is mainly focused on service provision rather than advocacy and is insufficiently inclusive and empowering of people with disabilities themselves.

Transport

Public transport has become more accessible but some felt that there has been little improvement in the availability of accessible trains despite Irish Rail transitioning its train fleet in recent years. The level of access to and availability of public transport in rural areas is a fundamental factor in disadvantaging people trying to access services, employment or conduct a social life.

Access to information on public transport remains a problem with insufficient use made of modern communications technologies to provide basic information on times, destinations and so forth.

Taxis are often the only appropriate means of transportation for people with disabilities but carry no subsidy to make them affordable.

UN Convention on the rights of persons with a disability

Ratification of the **UN Convention on the Rights of Persons with a Disability** would help to further secure rights and equality for people with disabilities in a number of areas.

Overview

About the report

This report is an outcome of the National Disability Authority's consultation **Your Voice Your Choice** held on the 19th of June 2012 in the Royal Hospital, Kilmainham, Dublin to facilitate people with disabilities to have their say about issues that matter most to them in living with a disability.

This report has been compiled from the views, insights and experiences of people with a disability and their parents/carers as expressed through the consultation process. It includes elements from the three core parts of the consultation exercise, the morning plenary, the afternoon workshops and the post-seminar online facility but it is primarily an account of living with a disability from the perspective of people with disabilities themselves.

Participants

The purpose of **Your Voice Your Choice** was to ensure that the perspective of people with disabilities informs the development of an implementation plan for the National Disability Strategy. This is the first time this event was held. People from around the country, drawn from a range of ages and from a variety of people with different disabilities – ranging across physical, mental health, sensory, autism and intellectual disabilities – participated in the consultation seminar. People with rare conditions also participated, as did parents of children and young people with disabilities. Personal Assistants and Carers, many of whom were family members of participants, also attended and were helpful to participants in conveying their experiences, views and priorities. Many people came long distances at considerable difficulty in order to participate. Others chose to use the online survey on the National Disability Authority's website to address the questions posed in the workshops or to add additional perspectives and viewpoints. All of the material generated has been used in the compilation of this report.

Your Voice Your Choice event

The morning plenary session focused on daily living - the everyday issues that matter most to those living with disability. This session provided an opportunity for participants to convey a sense of their daily life, the challenges faced and what and how things could be improved. The format was tables of approximately eight people with a facilitator and note-taker addressing the following questions:

- What's the most important support you have for daily living?
- What's the biggest challenge that you face every day?

- What's good in your daily life but could be made better for you?
- If you are the Minister and could fix one thing – what would that be?

The afternoon workshops took the same table format, focusing on the four themes of Equality, Independence and Choice, Participation and Maximising Potential. Everybody was given their first preference choice. Participants were asked to address the themes as follows:

- **Being treated equally...** what is important to you in being treated equally, including things like attitudes, having accessible public services, access to information and public buildings, protection from abuse, mental health legislation and other laws, the **UN Convention on the Rights of Persons with Disabilities**
- **Living the life I choose...** what is important to you in having choice and independence to live your life, including things like advocacy, independent living, personalised budgets, having quality in services that support you; moving from institutional settings to a place that suits you
- **Participating in the community...** what is important to you in being able to participate in the life of the community, including things like accessible environments, transport, communications, inclusive communities, participating in sport and cultural life
- **Becoming who I want to be...** what is important to you in making the most of potential, including things like education and learning, health and well being, the world of work
- **The online questionnaire** enabled people to input in the consultation after the event. In particular, it enabled those who expressed an interest in workshops other than the one they attended on the day to input on the other themes. Material submitted after the event and the results of the questionnaire are incorporated into the report and the questionnaire is included in full as an appendix to the report

I. Equality

Being treated equally means receiving fair treatment, being positively regarded and having access to a range of services and opportunities. In the case of people with disabilities, equal treatment often means providing a measure of different treatment, so that people can have a truly equal outcome. Guaranteeing equality requires the formulation of enabling legislation and the creation of mechanisms to provide protection from abuse.

People were aware, that in terms of equality, the current status of people with disabilities is at a relatively low level and they were also pragmatic in recognising that it will take time to achieve parity of treatment with the rest of the population. They believe that equality can be achieved on a graduated basis, even in unfavourable times, and wish to see continuous progress in meeting the equality goals set out in disability policy and service delivery strategies.

Access to buildings

There was a strong view that despite improvements, physical access to buildings is still a problem for people with disabilities, with older buildings; amenity venues; public spaces like football grounds; and even some doctor's surgeries; being specifically mentioned. Some of the problems identified included access difficulties in social venues, such as, restaurants and pubs, due to poor arrangement of furniture and fittings and the impossibility of utilising low/moderate cost accommodation due to a lack of accessible rooms in hotels, hostels and guesthouses.

Toilet facilities still pose a major problem with most people in agreement that the provision of accessible toilets would remove a major barrier to mobility and social interaction. The majority of pubs do not have wheelchair accessible toilets and where there are accessible toilets, these are frequently too small for the wheelchair. This raises issues about the specifications within the regulations and the need to take account of modern motorised chairs which are bigger.

Many people felt that workplace access has improved but that more needed to happen:

'In my job I have a swipe card that will unlock a door, but I'd like if it automatically opened it too and I'd like an accessible parking space at work'.

Those with cars felt that access to public and private car spaces could also be better. Often an accessibility feature will not be available because of a safety requirement, for instance, placing temporary bollards at accessible parking spaces.

There was a strong view that, at this stage, it is a realistic expectation that all public services and new homes and buildings should be accessible. Many people were of the view that **Part M** of the **Building Regulations** was not being enforced and that complaint mechanisms to ensure compliance are too bureaucratic. Part 3 of the **Disability Act 2005** places an obligation on public bodies to make their buildings and services accessible but people's experience points to continuing failures and inconsistencies in carrying this out.

Many believed that these matters will only be addressed by monitoring compliance and applying penalties. Some people felt that consideration should be given to the introduction of the type of regulatory power afforded the HSE, Health and Safety Authority and the Fire Service. Others were of the view, that forcing coordination at local level through obligatory working protocols and other collaborative arrangements could also advance progress.

Most people felt that greater participation in planning processes would remedy lots of problems in the social sphere; the services sector; and the built environment. Many articulated the need for people with disabilities to be included in the planning processes associated with the built environment because professionals involved, such as planners and architects, are usually able-bodied people and disability is beyond their familiar experience. Recognising the need to get the balance right between accessibility and other requirements was important. For instance, the 'kissing gates' along the canal are intended to prevent motorbike access but present a problem for wheelchair or hand-cycle users. Various suggestions were made about consultation structures, but all were based on participation and equalising provider-user influence.

Access to information

Information opens up possibilities to reduce inequalities. Knowing what information and services are available and making this information accessible is a prerequisite to better service delivery. Yet, many people spoke about access to welfare information on entitlements and entry points continuing to be difficult, with some people having to invest an extraordinary amount of time and effort to get information about available services and supports. Overall, many people felt that information on entitlements is complex, located with different providers and needlessly bureaucratic.

Many people complained about government communications rarely being in a format that is accessible. Sending printed material to people with visual impairments was an example:

‘Why post it when it could be emailed (and enlarged), which would be better and cheaper?’

On the positive side, most people felt that access to information was better for those with literacy skills, and the assistive services of intermediary organisations, such as, Citizens Information Service and Money Advice and Budgeting Service were highly regarded. There was a strong view that website information, especially interactive websites, can help make services easier to access. More localised public services were also positively regarded, with specific mention of the library system for its accessibility and accommodative staff.

People were strongly of the view that a comprehensive and coherent information resource that addresses the problems people have in knowing their entitlements and options should be part of more general changes to bring quality services. Currently, the number of agencies and service organisations providing services is baffling and

‘It’s nearly impossible to know what you are entitled to and too difficult to get it when you do know.’

Access to public infrastructure/services

Physical accessibility was recognised, by almost everybody, as central to making life better. Being able to transit independently from point to point in urban areas, without seeking help unless required, was regarded as a reasonable expectation. There was a widespread consensus that access to the built environment, when combined with accessible information and interactive websites, creates the conditions that allow people to avail of services, often without any further assistance.

Many people felt that given the sheer scale of the changes required, the objective of creating an accessible environment has been advanced to a considerable degree, although, there are significant disparities between regions. Despite these improvements most people felt there is plenty of room for improvement.

Many felt that accessibility in Dublin is getting better but still doesn’t compare with other cities in Europe and America. People identified poor town layouts, although all were agreed that sloping kerbs were a great development and that more are needed. Many people complained about poorly designed crossing points, paths that are not dipped or only dipped on one side of the road, hazardous paving, manholes that are slippery when wet and pedestrianised areas

too dangerous to walk in. Tactile paving for the visually impaired were identified by many as difficult for wheelchair users and make walking difficult for those using crutches or sticks.

Pavement clutter was mentioned by many people as representing a particular hazard for people with visual and hearing issues, who spoke about the difficulties in negotiating an environment that changes almost every day:

‘You might walk down the same road but there are always new street signs/furniture forcing people to push through narrower spaces.’

In addition, some people felt that universal design principles have not been inclusive of the needs of the visually impaired.

Many people spoke of narrow roads in cities and towns which make it difficult for wheelchair users getting in or out of cars as well as impeding traffic. Many felt that there is a need for more accessible parking, properly dished pavements and with enough space to get in/out of the car, which would also assist those with other medical or age related conditions. A number of people spoke of the need to challenge abuse of disability parking spaces.

Access to services

There was strong support by almost everybody for direct payments to the individual which would enable the matching of services to different levels of disability.

Many people spoke of the difficulties they experience in accessing their right to and of constantly having to fight to get entitlements. The fear of being labelled as a ‘malcontent’, with consequent sanctions, was a theme articulated by some people, who spoke of their experience of complaining to the HSE and feeling that the HSE tried to wear them down through the complaints process. Many people contrasted this with the Canadian system which is child/person centred, non-legal, accepting of fault and committed to seeking agreement on needs within an acceptable timeframe. Many felt that an effective complaints procedures needs to be introduced in order to maintain and improve the quality and level of services.

Many welfare applicants spoke of having to repeatedly give a case history and of the failure of agencies to acknowledge the limiting factors of people with intellectual disabilities. Many also complained of inaccessible formatting and lack of provision for those with hearing problems.

Families with autistic members spoke of the difficulties they experienced in accessing services. One person said there were no respite supports available in

her area. Others spoke of having to pay for respite with no allowances from the State.

Many felt that there are lots of acts and regulations that you have to know your way around before you receive supports. Those affected by autism said that lots of services don't deal with their condition.

One person spoke of difficulties with services provided by banks. An example given was of a person with a hearing impairment losing their bank cards and having no alternative to the telephone as an emergency notification process.

Access to rights

There was a widespread belief that people with disabilities are gradually gaining their voice, which will allow them to exercise their rights, but progress is slow. Others were of the view that, even though the visibility of people with disabilities is increasing, they are still unable to get equal access to employment, services, and education.

Most people felt that more awareness about disability among all services providers, as well as employers, and the general public, needs to happen in order to create the conditions for the achievement of equality and rights.

Many people gave examples of human rights infringements, especially for people with mental health conditions, some of whom have virtually no rights, for example, being unable to retain home ownership during mental illness and over-medication were cited in this respect. Many people, especially those with intellectual difficulties, spoke about being excluded from the processes that impact heavily on their lives, like not being listened to on important matters, being excluded from meetings and decision-making processes. A number of people were of the view that a rights-based approach would include provision for trustees to be appointed for people with intellectual disabilities, as happens in the United Kingdom.

Considerable frustration was expressed by many people about suggestions put forward through consultation and advocacy channels that could make life better, but never get acted upon. Many said they would like policymakers to listen more, rather than making presumptive decisions. A considerable number of people felt that fora like this consultation are good, where people are listened to, and which the Minister has promised will inform the implementation of policy.

A number of people felt that the assumption that children's rights can be safeguarded by the constitutional protection afforded to the family was proven to be flawed in recent years and that this needs to be reflected in relation to children with disabilities within the proposed referendum on children's rights.

Attitudes /awareness

There was widespread agreement that general awareness about disability, especially in relation to mental health, has improved, largely as a result of media coverage, campaigns and the activities of the community and voluntary sector. However, most people felt that there is still a considerable way to go before people are treated with the dignity and respect due, even within provider organisations.

Almost everybody felt that breaking through public prejudices and stigma and trying to get societal acceptance remains a substantial challenge. People spoke of how prejudice can present itself as disapproval, physical abuse and bullying or in seemingly benign ways, such as being patronised or ignored. People with forms of autism must cope with a form of social dyslexia that compels them to 'best guess' situations and are thus especially prone to rejection and bullying because of a lack of understanding in educational, social and work settings.

Dealing with attitudes to sexual relationships was also identified as a form of prejudice and a barrier to social development, illustrating the need to improve the supportive environment around boyfriend/girlfriend relationships. Attitudes towards disabled couples trying to do normal things, such as having a baby, underlined the need to combat deeply rooted prejudices.

Some people spoke of the considerable communications deficit that exists between people with a disability and the general population which needs to be targeted in a comprehensive awareness campaign focusing on conveying a sense of **ability** rather than **disability**. The need for a media campaign to project people as members of the community, as active participants in education and potential employees was suggested by many.

There was an overall view that disability awareness in early schooling provides the best opportunity to embed a positive culture in society over time and to contribute to changed organisational cultures in the schooling system itself. However, this will require disability to be a core part of the teacher training curriculum. Many people were in agreement that innovative whole-school approaches, often cost neutral, can turn attitudes around in a relatively short time period.

Some people felt that, more immediately, annually updated awareness training for all public officials and medical staff would enhance and copperfasten equal treatment by administrators and professionals.

Community organisations play an important role in promoting inclusion at local level when discrimination is present. It was strongly felt that greater participation

by people with disabilities in civil society organisations and politics, initially supported through investment in leadership training and community development, would enhance and develop this role.

A number of people thought that assisting community groups to be more aware of people with disabilities within their community by ensuring they operate out of accessible buildings would help to integrate people with disabilities into community activity and community life. There was a supporting view by others that community organisations provide essential activities, often on a shoe string, and need to be given greater support which, in turn, would assist them to be more inclusive. This would increase activities and facilities in the community and encourage non-family members to become involved with people with disabilities.

In terms of promoting social contact some people thought that the cost of activities, such as, swimming need to be subsidised, which is difficult when most amenity provision operates out of a semi-market model. A number of people felt that the centrality of the Gaelic Athletics Association to social life was positive and believed that the Gaelic Athletics Association, and other local organisations, should continue to be encouraged to be inclusive in their programmes and processes.

Equality

Many people with disabilities said they did not feel equal, but did acknowledge the advances that have been made in progressing equality. They believe that everyone has the right to be treated equally and point to the overwhelming evidence that equality is both beneficial to individuals experiencing inequality and to the broader society.

Some people felt that an increased incidence of treating people with disabilities equally was heartening and put down an important expectation marker. There was a shared recognition that changing attitudes and countering the poor status afforded people with disabilities needs to be driven by those with power and demanded by those affected.

Considerable frustration and anger was expressed by many people about the pace of change in implementing equality measures for people with disabilities. There was a shared view by many people that the political will for change just isn't there and there was a strongly expressed conviction that the **UN Convention on the Rights of Persons with Disabilities**, if ratified, would provide a catalyst for attitudinal and institutional improvement. They felt that this could lead to universal design being mainstreamed and facilitate a strengthening of rights-based legislation. Many felt that this is the only way that funding will be made available for people to live independent lives.

A considerable number of people felt that rights-based legislation can underpin equality for all regardless of ability. They felt that attitudinal change that allows real social inclusion will only take place if legal instruments provide the initial impetus for change and are then followed by awareness campaigns. There was a strong view that proactive measures can complement legislation. For instance, promoting inclusion should be part of the programme guidelines for public media and it should be encouraged in the private media

Most people regarded existing disability legislation as generally good, but the complaints mechanism needed tightening up and that the legislation did not adequately cater for children with disabilities. Some people called for the implementation of equality/disability proofing of all legislation. Disability awareness training should be part of induction training on the Equality Legislation, which is a normal requirement in many organisations. This would counter preconceived ideas about the employment capability of people with disabilities.

Equality issues were also raised by many carers, mainly family members, a substantial number of whom are forced to dedicate their lives substituting for the service deficits of statutory providers. Many of these carers also felt compelled by necessity to be advocates without the supporting information and network infrastructure of a fully funded National Advocacy Service.

Most people were conscious of the need for a genuine guarantee of equality and fairness that ring-fenced rights and forced effective implementation. Others felt that this would only come about by addressing flaws in the representative model of democracy, which denied people with disabilities their rightful say as citizens in developing policy and influencing policy decisions.

Some people said that the provision of supports for people with disabilities to complete courses in third level education was a significant factor in sustaining this inequality, although it was acknowledged that supports provided by an organisation, like the Association of Higher Education Access and Disability (AHEAD), have contributed to improved participation in third level.

2. Independent living and choice

Independence doesn't equate with self-dependence or total autonomy, but it does mean being able to access opportunities, make choices and pursue personal goals and being able to access the means, supports and assistance that enable independent living. Having choice and control, being able to conduct a socially interactive life and get a job are core requirements for people with disabilities that cannot be addressed through a single action. Many of these matters are related to awareness and attitude change, but at its core it is institutional and structural factors that make independent living possible. Having quality services that are readily accessible, accommodating and respectful is most important for people with a disability. Moving these services as close as possible to communities and ensuring universal standards are applied across regions and areas contributes significantly to independent living.

Home and housing

Many people expressed the desire to have their own home with inbuilt supports to maximise independence and participation. People felt that having a house or apartment with some support services allows one to meet and interact with others and to get involved in a range of everyday activities. They felt that participation and independent living begins from this starting point and should be the primary policy stance taken by agencies, rather than working from the assumption that the person cannot live independently. Others said that living with parents may also allow people to participate in social activities and sporting opportunities. A number of people pointed to the need to have an income, and control over that income, being strongly linked to gaining independence.

Having an accessible home was important to many people but waiting for accessible housing was also an issue for some. Others expressed a willingness to pay for the security of sheltered housing, were it available to give them addition security of tenure:

'There are different activities where I live (sheltered housing) and I would like to be able to pay for it!'

There was a strong view that appropriate housing for people with disabilities in the community should be a planned provision rather than something provided as an add-on to the edge of estates.

Many people expressed a need for more purpose built homes for independent living. However, the fragility involved in having a home was illustrated in instances where parents fitted out their home but upon their death no agency was

prepared to continue to support their son/daughter to continue living independently in the home, preferring residential care.

The fear of going back into residential care was a concern for some people with intellectual disabilities who are living independently. Having greater independence was a shared desire, with many people expressing the need:

‘To be able to go out with friends, without staff’.

People spoke about the importance of having their own space, of being able to manage daily housework, but would also like to be able to reach out further in key areas like travel to work and going on holidays.

The ‘loophole in housing’ was referred to by some people whereby those who bought a house before becoming a person with a disability now needed an accessible house. One person outlined her problem:

‘...Because I own a home and I am in negative equity I don’t qualify for a council house. I can’t afford to sell my house and buy/build an accessible house’.

Most people felt that this would be avoided if universal building standards were compiled and applied.

A considerable number of people with intellectual disabilities presently live in sheltered accommodation which may be community-based. These were generally regarded by residents as a positive place to live and therefore cutbacks and reductions in staff generated a lot of concern. Similar concerns were also expressed in relation to respite care. Notwithstanding the relevance of community based provision, in terms of supporting people closer to their community, many people with intellectual disabilities wish for further independence, in such things as, loosening the dependence on families; becoming empowered/skilled to participate in everyday life (shopping, banking, transport, education); and breaking free of monotonous eating, sleeping, clothing and door-closure regimes.

Income adequacy

Fear of losing social service payments during the present budgetary crisis was a constant concern for most people. A number of people emphasised the impact of cuts to disability and carer allowances, claiming that this represented a substantial cumulative reduction of their income.

The loss of entitlements when people find work was also identified as problematic for many (no allowance is made for transition) and often resulted in

delays in the return of entitlements, causing untold distress. This is something that people felt could be eradicated with more joined-up systems.

Many people were of the view that there is a need for the introduction of a cost of disability allowance, set at 50% of the average industrial wage, since many necessities for everyday living are very expensive - medical expense being a point in mind. This is related to the desire for independence and the reality that income is a primary determining factor in this quest. Many people expressed a view that they wish to be independent when they're older and don't want to remain at home. A shared view was:

'Don't presume parents want to look after you for the rest of your life'

Domiciliary Care Allowance was seen as important by many parents because it gives parents flexibility in relation to what they can do for their child in the home - speech and language therapy was especially important for many of these people, as was home help with children. However, issues arise in relation to the criteria used in the assessment of **Domiciliary Care Allowance** service, such as, having to demonstrate severe disruption. This could be resolved through the introduction of a more transparent system that was fairer to carers and disabled people.

Independent and community based living

The need for support that enabled people to live independently was widely articulated by people. Ultimately, people don't wish to be dependent. They want to go out by themselves, to go shopping, working and socialising.

The interplay between reliance and liberty was regarded by most people as key to encouraging and achieving independence, and the enabling factor is to have assistance in living an ordinary everyday life. Many people pointed out their reliance on families, friends and services to meet needs, arising from their disability, or to avail of activities and opportunities. One person missed her siblings since they had left home because ordinary things now took a lot of organising.

Most people with intellectual difficulties were acutely aware that they need help at times to do necessary things that they can't manage alone:

'I need to be able to do simple things like going to a hairdresser without having to drag along the occupants of the household because there is only one support worker available.'

Another person described her growing dependence on people - she used to be able to feed herself and now she needed help. For many, the Personal Assistant system is vital for independent living, but improvements in the provision of other types of support would allow people to do more ordinary things such as cooking, going to the pub and socialising.

There was a strongly felt view by many people that independent living is linked to the ability to interact with others to meet needs or get things done; accessing activities and programmes; employment supports; and day services. Supports that provide confidence building, assertiveness training and opportunities to develop life skills, that enable access to local services, were regarded as key in this regard. Skills that empowered people to self-advocate were also regarded as especially important.

Disability is often a shared experience for families. Many family carers regarded the need for a break, a bit of respite over the summer months, as a huge support to them in maintaining some sort of independence.

Many people found that early-diagnosis made life easier, in the sense that it resulted in a care plan which brought organisation, stability and independence to their life, although getting an accurate diagnosis, especially for forms of autism, can be elusive and take many years. Medication, which is particularly important in cases of chronic pain and severe motor impairment, was also regarded as a vital support to daily living.

Maintaining independence was identified by most people as a considerable challenge which is also related to accessibility to the built environment, to transport and information. A number of people pointed to the difference between care and assistance as important in understanding independent living. Controlling one's own life means having the right to make and carry through with decisions - as one person put it:

‘The right to do things that are bad for me if I wish’.

The lack of buddy schemes, sport for girls and the absence of a central fund for communication aids/assistive technology were also cited by some people as presenting challenges in trying to build a more independent and participative life.

People with Aspergers Syndrome said they were very aware of their tendency to overanalyse matters. As a result they often worry too much and as one person put it:

‘ I don’t know how to leave some things alone’.

This brings challenges in learning how to relax, which in turn impacts on the development of an independent life.

Socialising was regarded as important by everyone as a means to establishing independent living. The importance of social contact through friendships, community interaction and peer support groups (of other people with disabilities) was also emphasised in promoting independence.

There was widespread agreement that the commitment to moving from institutional or centralised care regimes towards community settings has not made sufficient progress despite the obvious advantages and economies that could be achieved. People were convinced that moving closer to communities enables independent living to be more realisable and draws in a range of community supports that would not otherwise be available. Many people spoke about how these community interfaces also have a cumulative effect by generating community development activity, which in turn, enhances the independence and personal development of the individual and attitudinal change within communities.

Some people suggested the provision of a training house where people can explore different options and become accustomed to equipment or make adjustments to their lifestyle would be a cost effective and readily accessible facility.

Maintaining supports and services

Cuts in budgets for support services was a concern expressed by many people, together with an accompanying fear of being thrust into poverty or having to revert to institutional care.

Cuts to personal assistants were felt to be crucial in this regard. Many people pointed out that the social contribution of Personal Assistants was as important as their material assistance by preventing isolation and mental health difficulties and maintaining the quality of people's lives.

The difficulty of getting a Personal Assistant, especially outside the standard 9 to 5 working period was also mentioned by many people. This inflexibility does not accommodate people with a disability who are in employment and require help in the evenings, a particular problem for those people living in rural areas.

Concerns were raised by many parents about maintaining advocacy services that advance the best interest of children.

Others were more accepting of the inevitability of cuts but stressed the need to know exactly what is being spent in each area of provision in order to even out

distribution. How to get the most effective use of money should be the priority preoccupation for many agencies and organisations.

Funding cuts were also a problem for many involved at group level, with many of these groups were struggling to survive. One person said:

‘Our support groups have nearly disappeared’.

Reduction of funding has also resulted in less care workers to help in the various local centres. A call for more volunteers was made by some people alongside a plea to maintain staff. In addition, a number of people felt that at the very time when there is a need for innovative cost effective solutions in social provision cuts in funding continue to undermining innovative projects leading to disappointment and discouragement for participants.

Quality service

Coordination

Addressing the inconsistency in service provision across areas is something which most people felt needs to be prioritised given the overwhelming evidence of significant disparities in provision and the quality of provision. Many people felt that disjointed service-provision results in blocked entry points and complementary services being widely dispersed by location. Case managers not being available to coordinate services across specialists and medical files not being updated regularly were cited as examples. One person felt that maintaining a link between home and hospital for children, and thus establishing a seamless care-regime, could be achieved by designating an incident based contact within the hospital.

In parallel, most people felt that many services should be regionalised, with inconsistencies of quality ironed out through the setting and implementation of national standards. In terms of variations across regions, people felt that the introduction of quality control through an inspectorate, would contribute to improving and evening out the quality of services. This would result in a coherent, affordable joined-up service with appropriate assembled expertise, where all disability services and payments would be coordinated under a single department. Most people also felt that transparency and accountability must precede this part of this equation in order to develop a comprehensible understanding of the unequal distribution of services across both geographic areas and different disabilities.

Part of this reorganisation would result in supports and information on supports being streamlined and made easier to access, including building grants, medication; assistive technology provision and repair; access to physiotherapy;

clinicians; carers and so forth. Many people felt that simply locating case files with a single source would eliminate many difficulties.

Some people believed there are too many organisations and service providers and that many could be combined without any loss of output. Some felt that the introduction of choice in the supply of services would improve matters, while others thought that the use of Personal Outcome Measures in some services has brought about changes and improvements in services. A suggestion to move funding for disability services into the Department of Justice and Equality was also made by one person.

People with rare disorders spoke of finding it difficult to access services on a par with other disabilities because there are issues of organisation and economies of scale that do not readily attach themselves to small numbers. However, many of the issues affecting them, such as transitioning from paediatric to adult care; the requirement for coordinated services; information access and attitudinal change; are exactly the same as other disabilities. For that reason they felt that the development of a National Plan for Rare Disorders should be advanced in collaboration with the development of a national implementation plan on disability.

Many people also felt that greater coherence could be achieved by shifting focus away from systems and towards the user. This would prevent providers choosing the services they will provide and shift their resources towards need. People felt that direct payments would trigger this by enabling choice, allowing people to buy their own services, and thus counter top-down flow. However, they were also aware that individualising budgets would require in-built safeguards and procedures to ensure competitiveness in tendering.

Quality of service delivery

The need for a system that's fit for purpose was uppermost in many people's thoughts about improvements in services. They felt that quality services can only be judged on outcomes. Cutting out administrative bureaucracy was identified as a core requirement to any system improvement.

Overly directive attitudes and less than respectful behaviour by providers brings conflict to the relationship with users, was mentioned by many people. Many people were in agreement that access to both services and information is often dependent on the resilience of the person or on the advocacy that can be mustered to pursue the matter. Parents in particular speak of the intense engagement required to get basic entitlements for their children. Many people thought that streamlining of overly complex and time-consuming approval systems needed to happen.

Cost was another identified factor for many people with disabilities who need multidisciplinary treatments. Most people were of the view that this could be solved by alterations to the medical card system.

Many people identified procedures that are not fit for purpose. For instance, the gradual withdrawal of services to a child at 18 years with a mental disability illustrates the clash between a **systems approach** and a **rights approach**. A **rights approach** to services was described as one where access to services would be decided by an intellectual capacity measure rather than a chronological one. A number of other people also felt that the prevailing **systems approach** poses particular problems for people with rare disorders because they don't have a category to fit into and are therefore not supported on a par with other disabilities.

Many parents also called for a new look at spending priorities as a step towards putting the focus on the needs of children with disabilities. These parents believe that no funding should be given to service providers without an assessment of spending priorities. These parents believed that there should also be an assessment of the impact of public money spent on the services to the child and whether they have made a difference to the child. This would be important learning for the significant funds invested in disability every year.

Most people felt that once access is gained, hospital services tend to be relatively good, although delays in diagnosing infections was regarded as inexcusable and entirely arising from weak hospital administration. People's experience pointed to diagnosis as the first step to a good treatment regime and, while delays are often caused by medical complexities, people felt that they can and should be reduced, especially in cases of chronic pain.

Most people felt that the necessity of proving every year that one's disability still exists when it is a life-long condition was overly bureaucratic.

There was a call for the clarification and definition of the individualised budget concept and a real fear by parents about their lack of expertise in managing a budget allocated to their child. This was accompanied by a concern that the state was shedding its responsibilities. Many people with disabilities will need to qualify for a government subsidy in order to avail of the proposed health insurance model and there is a concern about issues arising based on experiences of existing qualification processes.

Getting respect from staff and being listened to was supportive in terms of maintaining and enhancing dignity - support worker services able to help with information, independent living, counselling and advocacy supports being

particularly important. One person said they enjoyed looking after people with intellectual disabilities but was critical of the absence of training.

Many people felt that that provider staff had too many responsibilities thrust upon them, bringing about too thin a spread of personnel on the ground which affects quality and availability. Deficits in the psychiatric services also presented difficulties for some people, for example, the lack of psychology/behavioural therapy in some areas and the collapse of monitoring and review procedures.

There was a strong view that better services will only come with better accountability, something that is difficult when there is a widespread inability to critically review services. Others felt that separating the funder and the provider would contribute to better accountability

Complaints were made by several people that value-for-money reviews were not inclusive of the members of organisations – reviews need to go deeper and speak to service users. A number of people said that the stress and exhaustion experienced in chasing down services also needs to be factored into any assessment of the impact of service provision.

Many felt that more communication within and between the statutory and non-statutory sectors would also make things better. Some felt that locating responsibility and the power to allocate equipment to one source rather than having to go to separate places would be a step towards better coordination.

An alternative minority view was that it's not the state's place to provide services and that parents might make different choices that would save money if this was the case. Sending a child to football, rather than paying an occupational therapist a substantial fee, could achieve the same outcome at considerable less cost. It would also address the stigma that some people associate with such social services.

Changing cultures within services

Most people were clear that achieving better services will require changes in work practices and organisational cultures as well as greater flexibility by providers. They were adamant that arranging activities around the availability of staff and manager permissions will not bring about a person-focused service. However, they were of the belief that shifting control of the funding towards the individual would enhance the power of the recipient and force improvements and efficiencies.

For whatever reasons, there was a prevailing view among people that medical staff can be brusque in dealing with people with difficulties. Some people felt that

this could be largely remedied through awareness training, while others found it difficult to understand why this was not part of employment induction training.

A number of people were of the view that professional closure, whereby medical personnel are reluctant to take an independent stance to other clinicians when decisions are queried or contested, was bad practice and needed to be rooted out of systems. They felt that this behaviour underpins much of the negative practices that people experience when making complaints. This was summarised by one person as:

‘No redress, no accountability and no proper disciplinary process in place’.

A number of people took a more structural view, concluding that many of the inequalities experienced by people with disabilities are attributable to the two tier health system. People were hopeful that these will be addressed in the proposed universal health insurance model.

Staffing

There was a strong opinion that the additional workload brought upon staff through cutbacks and the failure to appoint the promised 400 specialists or to provide cover for professional clinicians on leave have all resulted in weak, inconsistent services.

A reduction of managerial layers in the HSE, streamlining of the medical card process (which used to be localised and more efficient) and personalised budgets thus eliminating travel and waiting periods, were other suggestions made by people which could be investigated.

In terms of making things better a number of additional suggestions on staffing matters included: reversing cuts to community support workers’ hours (which are less available now than before), more local delivery of services; encouraging national providers (which were viewed as Dublin-centred) to set up regionally; and, aligning income streams to the expertise of specific providers. Being able to select and chose services and to eliminate delays by ensuring that the funding allocated could travel between areas was also suggested by some people.

Transparency

Many people were conscious of the need for greater transparency about funding and value for money before failures can be properly ascertained and addressed. Overall, people felt that things could be made better if there was greater clarity about where the money is spent by organisations and whether it gets through to the user – a lot of money appears to be spent on staff and administration. People

were clear that value-for-money concerns relate both to statutory and NGO providers, but there was a particular concern about the percentage of spend getting through to the user in non-governmental organisations.

Concerns were raised by some people about issues of governance and the operational inconsistency of non-statutory providers being difficult to identify and address because no standards or guidelines are imposed by the funder.

Many people found it unacceptable that Chief Executive Officers in disability organisations should continue to receive salaries in excess of €90,000. They felt that mechanisms need to be put in place to monitor performance and to remove management or withdraw funding where practices are flawed or performance is found to be inadequate. A number of people also had questions about fundraising, and whether the additional money raised through this translates into better services or into salaries.

Most people were aware that non-governmental organisations play a significant role in the delivery of disability services. Many of the services provided by non-statutory bodies were well regarded and for that reason people felt they should be multi-annually funded in order to ensure continuity of service for recipients. However, many people were of the view that non-governmental status should not shield organisations from scrutiny and compliance with expected standards. They felt that there is need for a HIQA type inspectorate, equally applicable to both statutory and NGO providers, to investigate complaints and enforce standards.

Family support

For many people with a disability, the most important support is within one's self and having or developing the personal capacity to overcome obstacles, manage difficulties and pursue a fulfilling life. However, human capacity is something that is only developed with the support and assistance of others. There was an acknowledgement that many people with a disability found themselves in a difficult situation, being physically, emotionally and socially isolated, with a minority taking their own lives because of their sense of isolation. The importance of human support cannot therefore be overemphasised. When people feel down, they need somebody they can talk to, someone they can trust and rely upon.

Overall, most people felt that support needs depend on the situation facing the individual; if you are well supported by family, friends or organisations then your basic support needs may be adequately met. There was also an acknowledgement that some people were by circumstance disproportionately reliant upon state funded supports; others relied upon specific NGO supports. The comment by a

number of people indicating that some people might feel even more depressed after contacting some organisations indicated a significant degree of discontent with elements of the supports provided.

By far the single most important support identified by most people in daily living was their family - parents, spouses, siblings and children. The dedication of family members in terms of time, commitment and opportunities provided was regarded as immeasurable and central to sustaining a quality of life. Having someone to listen to was often the primary support provided:

‘Someone to understand where you are coming from but not necessarily to solve problems.’

Parents were especially singled out in providing this type of support. Wider family members were also regarded as a huge support for parents of children with disabilities, especially in cases where early intervention services for the child are patchy.

There was a general appreciation by almost everyone of the centrality of key workers, personal assistants, family support workers, home helps, mentors and ordinary volunteers in providing both tangible and emotional supports. People spoke about their carer in positive terms, describing how they help them materially and emotionally and in assisting them understand social welfare entitlements, giving people the confidence to get their entitlements and being advocates for vulnerable people. Many people also described the valuable assistance they received in controlling feelings, for instance, getting stressed when things go wrong and not knowing how to handle it - an important support that often goes unnoticed and unregarded. The role of carers in assisting communication was also an important support for many people in combating isolation and promoting independence.

Medical care

Almost everybody was in agreement that locally based GP services are the primary connecting point for most people with disabilities, but GPs are often reluctant to take people on because of the perceived workload. This raised questions of principle and regulation which, many people felt should be taken on at Department of Health level.

A criticism that GPs know very little about specific disabilities made by some people may have reflected a frustration about the links between the primary and specialist health systems.

Overall, the majority of people were clear in their desire for a joined-up and consistent medical care system with a greater regionalisation of services to avoid

unnecessary, inconvenient travel for basic procedures. The view of some people was that a primary care trust, which would contract providers, including community organisations, to deliver basic services at local level, may be useful in achieving quality regionalised services.

There was a lot of criticism of medical services in hospitals. People said that the knowledge and awareness of doctors whom one is likely to come into contact with is critical for a person when they first become ill or acquire a disability. Unsurprisingly, many general practitioners have little specific knowledge about particular conditions or issues such as chronic pain. For some taking out private medical insurance was a consideration, partially because of growing waiting period lists, but there is a five-year wait before being able to avail of it.

Many parents spoke of the difficulties of getting treatment, citing HSE waiting lists of several years to get therapy. Some people felt that key workers or advocates would be beneficial in helping to navigate the system.

Better standards of hygiene in hospitals were called for by many people because of the significant cost factor involved in readmissions from hospital generated infections. This was something that many people felt could be remedied quickly.

Stopping waste in the health services by addressing the overlap of services and duplication of roles, perhaps bringing all providers together under one umbrella, was suggested by one person (acknowledging that the HSE does to some extent do this). Promoting teamwork and coordination between professionals was also seen as a key step by many people. Others called for the breakup of the HSE.

A number of people felt that access to social and personal services, such as weight management, a live issue for many people, also need to be given some priority. Many people thought that research that identified effective treatments for mental health would be beneficial in improving treatments.

3. Participating in the community

Being able to participate in local communities, to pursue collective interests and objectives and to utilise the supports that communities create and provide is central to social fulfilment. Participating in community life is reliant on both physical factors, such as, an accessible environment, transport, the availability of facilities and on social factors, such as inclusiveness, tolerance and positive communication.

Employment

Right to employment

There was a strong view expressed by many people that the right to an education, a job and an income are basic economic, social and cultural rights. Many people also strongly expressed the view that creating employment opportunities for people with disabilities needs to be seen as contributing to the common good, even in difficult economic circumstances. Many people were in agreement that high unemployment levels are currently a problem for the general population, but employment downturns bring even more difficulties for people with a disability, who have a pre-existing experience of being unable to access employment or to even get on a pathway to employment.

The relative absence of people with disabilities as employees within disability service provider organisations highlights the failure of employment strategies to date. Most people felt that even though there has been a lack of success in public service employment quotas, the concept of quotas should be maintained. A 5% quota was generally considered as reasonable.

Importance of employment

Having a full time job was regarded by many people as a positive factor in their lives and help from job coaches and colleagues was regarded as an important employment support. The importance of supported employment in helping people to fulfil their ambitions and make life better was also stated by many.

‘Living independently with a house close to a job’

was the perfect situation that many imagined, underpinning the widespread desire for security of income, convenience and being part of a community. These simple requirements were listed by people as the ingredients which together add up to substantial change in the quality of life experienced.

Working was regarded as positive and important by many people, both for its social aspect and for:

‘Being able to pay the bills’

People need to work for a whole set of reasons, not least to generate an income, have some social interaction and to make a productive contribution to the economy. Doing a job well brings satisfaction and a sense of being valued. The fear of poverty and trying to make ends meet on Disability Allowance was another reason why people wanted to work, believing that without a job their life would be extremely difficult.

People spoke of:

‘the independence my job gives me’

and the social and personal benefits this brings, citing social enterprise development as an example. Most participants expressed a desire to work. One person spoke about how they volunteer as a radio DJ and their dreams of being paid to do this job. Other people wanted more accessible workplaces or options to work for two or three hours a week.

Many people thought that employers could be made more aware of the abilities of people with disabilities rather than focusing on the disabilities. The inability to read and fill-in forms requiring personal information meant that people with visual difficulties faced disadvantages in applying for management positions, something that becomes apparent to employers in making appointments.

Many people felt that accessing employment continues to be extremely problematic, and has been made worse because of the failure of employment inclusion strategies in the public service. The introduction of an employment embargo in the public sector has exacerbated this situation.

Maintaining employment was also a challenge for some people. A small number of employers provided supports but this was rare in the general labour market. Some people made significant efforts to maintain their employment like rising at 4.30am to get from Navan to Ballyfermot by bus. An additional challenge articulated by one person related to fears about personal safety on the streets at night when coming home from work.

Pathways to employment

The difficulties of finding work and getting appropriate work training was highlighted by many people with many people unable to get onto the established pathways that seamlessly connect education to training and employment.

Work experience, was felt by many to be a mechanism that has been underutilised for people with disabilities, yet it is clearly a vital linking mechanism between education/training and employment.

Many people felt that there is a need for employment assistance and empowerment training, not just for people who have been left behind in terms of jobs but also for people who have lost jobs, so they gain/regain skills. Rehabilitation courses were not regarded by many people as being enough, there is a need to go beyond this.

Attitudes and awareness in employment

Many people felt that the dismal employment picture for people with disabilities extends to those who are lucky enough to have a job, with a widespread experience of barriers being put in the way of career development and promotion. These attitudes and practices were illustrated in the difficulties encountered by those trying to reinstate previous work relationships following the onset of a disability. Many people were taken aback by the abrupt change of attitude they faced.

There was a call by many for a better understanding by employers of the benefits of flexible work options, as many people with disabilities find it difficult to fit into expected work schedules, for medical or transit reasons.

Barriers to employment

A shared view was that accessing employment is still extremely difficult as employers are simply not willing to take the chance of employing someone with a disability.

Many people were conscious that the need for sick days because of their disability posed problems for employers. Employers see this as unreliability and are reluctant to take this risk in recruitment, as one person put it:

‘The unpredictability of my condition is a barrier for employers’

Lack of training for different jobs was also identified by many people as a factor that affects job entry and job mobility. One person spoke of the difficulty in getting to a workplace and only resolved this with help from fellow travellers; trains were specifically mentioned in this respect.

Because of the nature of the condition, people with autism said they faced particular social barriers in accessing employment. Despite being denied or understated, the anecdotal evidence is that employers tend to recruit people that they can ‘get along with’. Many people felt that this explicable prejudice could be somewhat overcome through a focused awareness campaign with employer

organisations, and could be further enhanced by the introduction of incentivised voluntary quotas.

Mainstream activities

Many people described how being an integral part of community life, and therefore able to draw on the support that is willingly available, enhances independent living while countering the boredom arising from isolation. The importance of a supportive community where needs are responded to without having to ask was also acknowledged and valued.

Taking part in activities was regarded as important and beneficial by many people. Activities, such as, creative writing and sport many people said provided a new focus in life and a good means to meet and make friends. Having local groups on the ground where people are available for a cup of tea or chat was singled out for mention by some people because it provided a channel to get the required help and support needed. Many people described how community support often takes the form of encouragement and belief that the person can succeed. Prominent local individuals in the community, such as TD's and Gardaí were regarded by some people as supportive and attentive listeners in this regard.

There was strong support for Family Resource Centres and community projects which provide a range of activities such as gardening, participating in designing the neighbourhood and hill walking ('even though I'm in a wheelchair!') which contribute to people's social development. Many people outlined how being involved in community activity is beneficial in both direct and indirect ways, for instance, providing activities for children lessened the likelihood of vandalism and provided an avenue to a wider set of helpful relationships.

NGOs were widely regarded as important for people with disabilities. Building and maintaining representation through NGOs was crucial because people need to have a say in how policy is developed and money spent and representative bodies are an effective means of doing this.

The need for a successor organisation to People with Disabilities in Ireland was called for by some people, who felt that in the interim funding should be restored for People with Disabilities in Ireland networks to facilitate local networking and mutual support. Making multi-annual funding available to organisations providing vital services was also recommended by some people, such as, the Jack and Jill Foundation. This would allow them to plan and deliver their services in a more efficient and strategic way.

Finally, it was recommended by many people that proper consultation like the **Your Choice Your Voice** event on the 19th of June should be held regularly, perhaps quarterly.

Relationships

Some people felt that having a disability makes it much harder to have meaningful relationships. The reality of being totally dependent on others for assistance can be disempowering and inhibiting in developing a relationship.

Most people agreed that not being able to access a Personal Assistant or home help at weekends and public holidays limits the social interaction choices for people with disabilities, although assistive technologies, including motorised wheelchairs and hearing aids, have allowed people to extend their options and choices.

Celebrating the good things in life and making them better was regarded by many people as important. Having a strong sense of self and being accepted within a parent or peer group was also regarded as important. The company of others was considered by most people to be of central importance in maintaining or pursuing this goal. Adopting a generally positive disposition towards people - friends, girlfriend/boyfriend, family and particular interest group - was specifically mentioned.

Getting out of the house and finding something to do was important for many people. Drama; photography; swimming and power soccer were some of the activities mentioned. Involvement in these various activities improved the quality of people's lives. Their availability, however, depended on different factors, such as, access; funding; and transport.

There was a widespread belief that technology can help people to access activities, but it does not compensate for the companionship of people or address the isolation for people in rural areas. Many people were of the opinion that lots of these problems can be resolved and social life can be maximised by developing life skills. This would allow people to become more aware of choices and enhance their capacity to make demands for particular amenities. Social skills development was therefore considered to be an important factor in training and development strategies.

Social life

Having choice and control, being able to socialise, to:

‘Go out when I feel like it’

was regarded as a huge issue for people with disabilities. Perhaps, it was even more so for those with less visible difficulties, because of the low awareness and understanding of some conditions such as mental health problems. Most people thought that living within a neighbourhood or community made it easier to exercise choices, especially if living near one's family.

Social interaction is important to people but for many it also brings its challenges because it is dependent upon communication, awareness, attitudes, access and mobility. In the opinion of many people it requires effort and energy to leave the comfort zone of the home.

Barriers to social life

Most young people, have strong feelings about being excluded from places like discos and pubs that are pivotal to their social development. Having been integrated in school, they then find themselves disintegrated because they cannot socialise with their friends. Others felt that controlling the side effects of medication and accessible toilet facilities are other inhibiting factors.

Conducting an ordinary social life was considered difficult by a lot of people, for instance, trying to find places that are comfortable to have a meal/drink, with sufficient space around the table. Some people thought that the inconsistency and inflexibility of the Personal Assistant's system reduced the potential of the service to contribute to social interaction.

Most people were agreed that forward planning was required to do anything. The lack of social outlets especially in rural settings was another problem mentioned.

Those with access to a car found it easier to socialise. The support of families, especially the support of a spouse, and the commitment of friends and other people, enabled many people to expand their options and their sense of comfort and safety.

Access to transport

There was a general view that the ability to get about, to access work and leisure and to undertake social activities is all dependent to some degree on transport. Not having access to transport results in reliance on family and friends and loss of independence.

People acknowledged that accessible public transport provision has improved significantly over recent years. Everyone was of the view that joined up public transport and the advent of trams in Dublin was a great improvement. Public transport, however, has disimproved for many rural users, which limits opportunities for social interaction for people with disabilities in those areas and presents additional difficulties in accessing services and healthcare.

Free public transport was highly regarded by everybody but there was a call for more information about coverage, destinations and the listing of private transport companies that accept the travel pass. A number of people felt that more toilets on regional buses would make this freedom even better. One person said that having to provide two days' notice for an accessible bus in rural areas was problematic.

There was widespread agreement that signage information that is comprehensible to people with disabilities also enables independent movement, provided that physical access is also enabled. Many felt that information displays on tram and bus systems has opened up wider access possibilities. Audible readouts on buses and on DART service and stations would make things better, and bus timetables could be visually improved. Changing buses was a problem for people with intellectual difficulties and could be made easier with better information systems.

While accessible public transport was regarded as important, for many others the maintenance of funding for a proper day service was more immediate to their lives.

Many people, especially those from rural areas, were particularly critical of rail travel, which continues to lag behind other forms of transport – unaided physical access, the absence of a ramp, predominance of unmanned stations, inability to cater for groups of wheelchair users and having to rely on the assistance of members of the public being primary examples.

Poor frequency of buses, and high costs were also listed as inhibiting factors. Buses which only allow one wheelchair or one pram were also considered problematic. Bus ramps were also mentioned as they frequently do not work when it rains. Safety on buses was mentioned by another person as being less than satisfactory.

Many people said that sometimes taxis are the only means of transport but there is no discounted taxi service for people with a disability and therefore they are financially inaccessible for many. A subsidised taxi grant would be useful.

Some people said that wheelchair accessible taxis have not made things better since taxi drivers are not trained to help people with disabilities and as a result avoid picking them up— listing it as 'too much hassle' As a result 'sometimes you can end up stuck somewhere and can't get home'. People were adamant that so-called accessible taxis (with two ramps that fit at the side of the car) are simply not accessible for all types of chair. Overall, people said there was an urgent need to promote the grant system for accessible taxis to achieve better take-up.

For others, having more accessible taxis and better regulation in the licensing of accessible taxis would complete the circle. Taxis are often the only viable means of travel for many people with a disability. Having a car and being both mobile and independent was hugely appreciated by some people who previously had to rely on public transport.

One person said that airline companies still do not take sufficient care with wheelchairs, which given the reliance on this piece of equipment, was unacceptable.

Technical aids

A number of people pointed to the central role of assistive technology in meeting daily requirements and fulfilling their broader aspirations in terms of personal/medical support, learning and communication. Computers in particular were regarded by many people as liberating, with internet access and email prompting better social interaction and supporting independent living.

Assistive technology was a focus for many people in living their lives. The cost of technical fixes for people with visual and hearing issues is a problem often leaving people unable to read their own letters – something that can be addressed with modern screen readers. The problems presented in listening to individuals talking when there is a crowd could also be overcome through technology. Most people agreed that technical fixes were available at a cost.

‘Out of the box’ technologies such as Smart phones and Kindle have been particularly important, but they are also expensive and therefore out of the reach of many people with a disability. Some people felt that there is some scope to insist that products are made more accessible by linking government grants and tax breaks etc., to compliance. Having e-versions of newspapers and magazines, similar to the UK Monocle service, were suggested developments that would also be useful in promoting development and choice. An app (application) showing accessible toilets, mapping services and facilities and a directory of services were some of the more immediate suggestions made.

Many people spoke of the need for training in the use of appropriate technologies, something that could be addressed by a ‘centre of excellence’. Such a centre would advise people with a range of impairments on the best design for living - which light bulbs to get, which assistive technology suits best and what communications technology works better and in which format.

There was almost total agreement that technical solutions have made a huge contribution to improving the life of people with disabilities and should continue to be imaginatively applied to the disability context. Many people felt that greater

use of this technology should be encouraged and incentivised - the development of apps for smart phones being an obvious example.

4. Maximising potential

People with disabilities experience difficulties in their life because of their condition, but these are often outweighed by the difficulties that are socially imposed or by those that could be overcome if facilitated or supported. A truly supportive healthcare system would focus on maximising independence and physical and psychological comfort. A coherent set of welfare and public services should mould an inclusive education system, ensure income adequacy and guarantee employment opportunities on a par with those available to the general population. Progress on all of the things that allow people to realise their potential no matter what their inherent condition can only be judged on outcomes.

Education

Schooling

In general, most people had a positive view of schooling, both primary and second level, although they also felt that having a uniform, high quality education service for all children, with better services and available speech and language therapy would make things better.

Cutting back on Special Needs Assistants was viewed by most people as a false economy when the savings made are set against the cost of special school provision. A point made by some people was that many improvements in schools are in part due to developments undertaken by schools with a positive attitude towards inclusion of children with disabilities rather than arising from policy decisions.

Many people were of the view that if Individual Education Plans (which are not mandatory) were drawn up with a psychologist and/or occupational therapist, they would contribute to better outcomes from schooling.

Among parents of children with disabilities there is a strong sense of the divide between principles/commitments and implementation. People were clear that guaranteeing access to an appropriate education for every child is a fundamental right that should be guaranteed by the State. People felt that the **Education for Persons with Special Educational Needs Act (EPSEN) 2004**, which provides for the provision of Individual Education Plans for students with special needs, if implemented in full, would enable the vindication of that fundamental right.

In terms of schooling, many parents believed there should be a central system allocating teachers to schools rather than resource teachers being employed by

mainstream schools. This generated a discussion on whether public funds should be attached to a service provider, a school or an area.

Some people thought there should be a better understanding of sign language as an inclusive means of communication and that it should be part of the school curriculum.

The practice whereby schools don't want to accept a child with a disability generated a lot of discussion amongst parents. There was some consensus that an advocate would be useful to interface with the school (and with other service providers) on behalf of the parents, saving parents a lot of time and unwarranted stress.

Breaking out of the 'nine to five, Monday to Friday world' and providing more night time classes was seen by many as a means of opening up access to education. They felt that this would enhance pathways to fuller participation in education and improve access to higher level courses.

People were agreed that funding for education shouldn't distinguish between part-time and full-time courses or between the various FETAC levels.

Integrated education

There was an overall feeling that education for people with disabilities is improving because of the acceptance of concepts such as inclusive education and mainstreaming. Most people thought that integrated education had particularly benefitted children with autism and other learning difficulties. Many people expressed concern about a growing antipathy by parents of non-disabled children towards integrated education, believing that it hindered their child's educational progression. Competitiveness and the lack of unemployment opportunities were considered to be the main reasons for this change.

However, most people were clear that integrated schooling is a positive measure only if it is delivered with appropriate supports. Special Needs Assistants are a key support for children with disabilities within integrated schools but funding cuts to this service will negatively affect the outcomes from education and reinforce inequalities that arise from educational disparities. There was a view expressed that if supports, such as, Special Needs Assistants, are not economically viable then alternative means of supporting integrated education need to be identified.

The lack of education opportunities for people over 16 years of age with intellectual disabilities was identified by many people. Mature students with intellectual disabilities complained about the lack of integration they experienced in education.

While some satisfaction with third level entry and integration was expressed by some people not having Special Needs Assistants for second and third level was regarded as a problem.

Awareness training within education

Many people felt that there was much better awareness of disability within education systems. They were also of the view that mentoring in third level education and inclusive practices in other levels is slowly breaking down barriers and changing attitudes. Deaf awareness training was also considered to be generally good in schools however people were also aware that others in the disability community do experience labelling and language barriers.

Training

Participating in skills training, work placements and other employment pathways was a great support for many people, fulfilling a social requirement, contributing to personal and career development and to an adequate income. Training initiatives, Community Employment schemes and part-time employment were all regarded as important mechanisms in this respect.

Many people were extremely happy with their life but were concerned about the sustainability of their situation in training centres where people are subject to time limitations with little corresponding thought about progression pathways.

In the opinion of many people some providers were very tuned into needs and generally 'getting it right'. There was also more satisfaction with courses with a high degree of personal development and/or functional skills such as training in leadership, childcare, computer skills, art and creative writing. Courses provided by specialist NGO organisations were generally regarded as better focused than mainstream providers.

There was a lot of criticism by some people of courses provided by FÁS, which did not put the person at the centre of the learning process. The **Springboard Initiative** in Higher education appeared to be a better option, and access to people on **Disability Allowance** has now been opened up.

Some people felt that accessing training courses continues to be difficult and the poor quality of some courses needs to be highlighted, especially those that are tokenistic to people with disabilities. The continuous failure to adjust courses to encompass very different learning preferences and pace of learning, and the difficulty in getting good information/advice about courses was also noted by some people.

Some people highlighted how costs for certain courses impacted on whether or not a person with a disability could do the course. Some full time courses, for

example, are free, but the same course on a part-time basis carried a fee. If a person with a disability could only do a part time course they would end up having to pay fees. Similarly, many people were of the view that the charging of tuition fees on non-CAO (Central Applications Office) courses puts people with disabilities at a disadvantage. Most people with intellectual disabilities would like some of the barriers to their participation in education removed – having to be in a disability centre or service to get the required additional college support, and opening up basic education to adults were examples.

Employment

Career development and progression was important for those with jobs. Employer expectations of people who have disabilities are low and there is subtle discrimination within the workplace. Many felt that employer incentives would improve matters, although the **Wage Subsidy Scheme** was viewed as having a negative connotation because it separates the person with a disability from other employees.

Physical and mental well being

There were calls from many people to place more focus on quality of life issues for people with disabilities. Even small changes, many of which are cost neutral, such as changing bus timetables and traffic light sequences, can have a big effect.

Social contact was an important mental health issue but when places in training are cut this reduces the social contact that people have, unless there are other means opened up. Many people spoke of the impact on personal dignity associated with the lack of accessible and appropriate toilet facilities - something that people without disabilities seldom encounter. All of these small things can impact on the situation and status of people with disabilities.

Appendix I: Your Voice Your Choice Information Leaflet

Your Voice Your Choice

Information Leaflet



Údarás Náisiúnta Míchumais
National Disability Authority

What is Your Voice Your Choice?

- This is an event organised by the National Disability Authority
- This event is the forum announced by Kathleen Lynch, TD, Minister for Disability, Equality, Mental Health and Older People
- This event is about listening to your views on the issues that matter most to you in living with your disability

Who should come?

If you are:

- A person with a disability
- A parent/guardian/carer of a child or young person with a disability
- An advocate for a person with a disability
-

Your Voice Your Choice is for You. People will attend in an individual capacity and not as a representative of any group.

Places are limited. Please book early. We will do our best to let as many as possible attend but **you** must **book** your **place**.

When is it on?

Tuesday 19 June 2012 from 11:30 to 15:30

Where is it on?

Royal Hospital Kilmainham, Dublin, an accessible venue about 5 minutes from Heuston Station

What will happen on the day?

Your Voice Your Choice is about you having your say on what is important for you as a person with a disability.

We will work in small groups of about 8 people in each group. In the first half of the day, we want to listen to what you have to say about **everyday life and what matters most to you**

- What's the most important support you have for daily living?
- What's the biggest challenge that you face every day?
- What's good in your daily life but could be made better for you?
- If you are the Minister and could fix just one thing – what would that be?

Workshops

After lunch, we will have 4 workshops. Each workshop has a different topic. Choose the one that matters most to you. Places are limited but we will do our best to give you the workshop you want to go to.

We will end the day at 15:30.

Workshop 1- Becoming who I want to be

This workshop looks at what is important to you in making the most of your potential. This would include things like education and learning; health and well being; the world of work...and much more

Workshop 2- Being treated equally

This workshop looks at what is important to you in being treated equally. This would include such things like attitudes; having accessible public services, access to information and public buildings; protection from abuse; mental health legislation and other laws; the UN Convention on the Rights of Persons with Disabilities...and much more

Workshop 3- Living the life I choose

This workshop looks at what is important to you in having choice and independence to live your life. This would include such things like advocacy;

independent living; personalised budgets; having quality in services that support you; moving from institutional settings to a place that suits you...and much more

Workshop 4- Participating in the community

This workshop looks at what is important to you in being able to participate in the life of the community. This would include such things like accessible environments; transport; communications; inclusive communities; participating in sport and cultural life...and much more

What happens after this event?

We will take all your ideas and suggestions and write up a report. We will give the report to the Minister for Disability, Equality, Mental Health and Older People. This report will be important. It will help inform what needs to be done in the new Disability action plan called the National Disability Strategy Implementation Plan. We will also make copies of the report available on our website www.nda.ie.

Remember

This report will be about **You, Your Voice Your Choice** and what is important to you. The report will present peoples views and will not say who said what. Be free to say what you really think, because what you say will not affect the service you currently have.

Want to find out more?

If you would like to attend **Your Voice Your Choice** let us know by

Web: www.nda.ie

Email: yourvoice@nda.ie

Phone: Lo Call 1890 632 631

Places are limited. Make sure you let us know you would like to attend. We will do our best to facilitate as many as possible. We will also be organising other ways in which **You** can have **Your Voice heard**. Details will be on our website www.nda.ie or LoCall 1890 632 631.

Appendix 2: Breakdown of Participants

120* attendees in total participated in the day

- 83 people with disabilities
- 22 parents of young people and children with disabilities
- 15 Advocates for people with disabilities

*There were an additional 13 people attended as non-participatory Personal Assistants

Breakdown of participants per County

| County | No. of Participants | Percentage |
|---------------|---------------------|------------|
| Co. Clare | 11 | 9.2 |
| Co. Cork | 3 | 2.5 |
| Co. Donegal | 1 | 0.8 |
| Co. Dublin | 39 | 32.5 |
| Co. Galway | 11 | 9.2 |
| Co. Kerry | 4 | 3.3 |
| Co. Kildare | 5 | 4.2 |
| Co. Kilkenny | 2 | 1.7 |
| Co. Laois | 3 | 2.5 |
| Co. Limerick | 2 | 1.7 |
| Co. Louth | 2 | 1.7 |
| Co. Mayo | 3 | 2.5 |
| Co. Offaly | 2 | 1.7 |
| Co. Roscommon | 1 | 0.8 |
| Co. Sligo | 1 | 0.8 |
| Co. Tipperary | 1 | 0.8 |
| Co. Waterford | 4 | 3.3 |
| Co. Westmeath | 6 | 5.0 |
| Co. Wexford | 2 | 1.7 |
| Co. Wicklow | 15 | 12.5 |
| n/a | 2 | 1.7 |

Breakdown of participants according to their self-declared primary disability

| Type of Disability | Percentage (approx.) |
|----------------------------------|-----------------------------|
| Intellectual, Learning or Autism | 33 |
| Mental Health | 9 |
| Physical | 42 |
| Sensory | 12 |
| Unknown | 4 |

Appendix 3: Your Voice Your Choice Online Questionnaire

You can have your say and contribute to the discussion which took place at the **Your Voice Your Choice** event on 19 June 2012 in the Royal Hospital Kilmainham, Dublin. Please complete this questionnaire. This phase of the consultation will end on 30 June 2012.

We look forward to receiving your feedback.

1. I am

| | |
|--|--------------------------|
| A person with a disability A | <input type="checkbox"/> |
| A parent/guardian/carer of a child or young person with a disability | <input type="checkbox"/> |
| An advocate for a person with a disability | <input type="checkbox"/> |

2. I am

| | |
|--------|--------------------------|
| Male | <input type="checkbox"/> |
| Female | <input type="checkbox"/> |

3. I am

| | |
|---|--------------------------|
| A Parent/Guardian/Carer of a young person with a disability | <input type="checkbox"/> |
| 18 – 34 | <input type="checkbox"/> |
| 35- 54 | <input type="checkbox"/> |
| 55 + | <input type="checkbox"/> |

4. Which most closely describes the type of disability which you, your child or the person you care for has. Please choose only one.

| | |
|----------------------------------|--------------------------|
| Sensory | <input type="checkbox"/> |
| Physical | <input type="checkbox"/> |
| Intellectual, Learning or Autism | <input type="checkbox"/> |
| Mental Health | <input type="checkbox"/> |

5. If you answered “Sensory” question to question 4 above please indicate which type of disability you, your child or the person you care for has:

| | |
|--------------------------------|--------------------------|
| Deafness | <input type="checkbox"/> |
| Hearing impairment | <input type="checkbox"/> |
| Blindness or vision impairment | <input type="checkbox"/> |
| Other (please specify) | |

6. If you answered “Physical” to question 4 above please indicate which type of disability you, your child or the person you care for has:

| | |
|---|--------------------------|
| A difficulty communicating with people in your daily life | <input type="checkbox"/> |
| A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying | <input type="checkbox"/> |
| A difficulty with pain | <input type="checkbox"/> |
| A difficulty with breathing | <input type="checkbox"/> |
| Any other chronic illness or condition (please specify) | |

7. If you answered “Intellectual, Learning or Autism” to question 4 above please indicate which type of disability you, your child or the person you care for has

| | |
|--|--------------------------|
| A difficulty with learning | <input type="checkbox"/> |
| A difficulty with remembering or concentrating | <input type="checkbox"/> |
| Autism | <input type="checkbox"/> |
| Other (please specify) | |

8. If you answered “mental health” to question 4 above please indicate which type of disability you have or your child or the person you care for has

| | |
|--------------------------------------|--------------------------|
| A psychological, emotional condition | <input type="checkbox"/> |
| Mental health issue | <input type="checkbox"/> |
| Other (please specify) | |

In the remainder of this questionnaire you will asked some questions about what is important to you under four headings:

- Becoming who I want to be
- Being treated equally
- Living the life I choose
- Participating in the community

You can answer some or all of these questions.

Becoming who I want to be

What is important to you in making the most of your potential? In your answers you might consider such things as education and learning; health and well being; work and employment.

9. What's working well in terms of people with disabilities reaching their potential?

10. What are the main barriers to people with disabilities reaching their potential?

11. What improvements should be made in terms of people with disabilities reaching their potential?

12. What one thing would you fix in terms of people with disabilities reaching their potential?

Being treated equally

What is important to you in being treated equally? In your answers you might consider such things as attitudes; having accessible public services, access to information and public buildings; protection from abuse; mental health legislation

13. In terms of equality for people with disabilities what's working well?

14. In terms of equality for people with disabilities what's difficult?

15. In terms of equality for people with disabilities what could be made better?

16. In terms of equality for people with disabilities what one thing would you fix?

Living the life I choose

What is important to you in having choice and independence to live your life? In your answers you might consider things like advocacy; independent living; personalised budgets; having quality in services that support you; moving from institutional settings to a place that suits you.

17. What's working well in terms of people with disabilities exercising choice and independence?

18. What are the main difficulties in terms of people with disabilities exercising choice and independence?

19. What could be improved in terms of people with disabilities exercising choice and independence?

20. What one thing would you fix to enable people with to exercise more choice and independence?

Participating in the community

What is important to you in being able to participate in the life of the community? In your answers you might consider things like accessible environments; transport; communications; inclusive communities; participating in sport and cultural life.

21. What's working well in terms of people with disabilities participating in the life of the community?

22. What are the main difficulties in terms of people with disabilities participating in the life of the community?

23. What needs to be improved in terms of people with disabilities participating in the life of the community?

24. What one thing would you fix to enable people with disabilities to participate more fully in life in the community?

25. Please fill in the details below so we will be able to send you a report from this online questionnaire

| |
|--------------------------|
| First Name |
| Surname |
| Address |
| County |
| Contact telephone number |
| Email |