

Your Voice Your Choice 2013

Report

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Údarás Náisiúnta Míchumais
National Disability Authority

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Preface

As part of its strategic commitment to raising awareness and promoting positive attitudes to disability, the National Disability Authority (NDA) commissioned a **National Survey of Public Attitudes to Disability in Ireland** in 2011. The survey builds on previous surveys conducted by the NDA in 2001 and 2006, and covers a range of topics including knowledge of disability and attitudes to disability within the workplace, schools and in the neighbourhood.

Arising out of the 2011 survey the NDA has identified a need to develop a National Action Plan on Attitudes towards people with disabilities. As part of this process a **Your Voice Your Choice** forum on Attitudes took place in Cork, in November 2013. I am pleased to present the Report of this event.

This Report captures the views and experiences of people who participated on the day. It reflects how important the effects of negative and positive attitudes are on the ability of people with disabilities to participate as fully as they can in society. The content of this Report offers an excellent insight into what matters to people with disabilities.

This Report is grounded on provisions contained in the **UN Convention on the Rights of Persons with Disabilities**, the **National Disability Strategy Implementation Plan** and the NDA's own **Strategic Plan 2013-2015**.

On behalf of the NDA I want to thank everyone who took the time to share their views and experiences and record the discussions on the day.

Siobhán Barron

Director

Acknowledgements

The success of **Your Voice Your Choice** 2013 was primarily due to the participants who engaged with the process and made extensive and insightful contributions. The rapporteur, facilitators and note-takers were another important component part of the day. 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

Ongoing challenges exist to the development and maintenance of positive attitudes to people with disabilities, in Ireland. This is shown in the National Disability Authority's (NDA) third **National Survey of Public Attitudes to Disability in Ireland**¹ from 2011.

In a presentation made at the launch of this survey² it was noted that there has been a significant growth in negative attitudes and this is a matter of serious concern. It also points out that the research found:

‘such attitudes partly reflect fears that supporting those with disabilities in mainstream schools, workplaces and life activities requires resources which may not be available due to our difficult economic times.’

In its current **Strategic Plan 2013-2015**³ the NDA has an objective to promote positive attitudes to disability. This objective can be met by

- Effective engagement with stakeholders to ensure a strategic approach to promoting positive attitudes;
- Identifying areas that have yet to benefit from experiencing positive attitudes
- Co-ordinated actions fostered among a range of stakeholders
- Evaluation of the efficiency and effectiveness of various promotion measures

To inform this work the NDA organised an event in Cork, called **Your Voice Your Choice**. This gave people with disabilities, their carers and family members the opportunity to share their experiences of attitudes towards them. It also served to identify ways to challenge negative attitudes and promote positive ones. The issues and ideas raised at the event are outlined here.

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<http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/90F8D23334D786A880257987004FCF51?OpenDocument>

² <http://www.researchnet.ie/wp-content/reports/RMN%2015.12.11-HRB%20Lieshout.pdf>

³

<http://www.nda.ie/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/39B3DFB7E7B5DC1280257AFA0033958B?OpenDocument>

Positive developments and ongoing challenges

Those attending the event identified some positive developments in attitudes towards people with disabilities. These were experienced in a number of different contexts including shops and restaurants, accessing public services such as healthcare, using public transport and so on. However, not everyone identified positive experiences in these contexts. Positive developments resulted in people being treated in a respectful way and being welcomed and included. It also involved being treated as a 'whole person' and not only in relation to their disability.

The existence of positive attitudes together with an understanding of disability sometimes also resulted in the removal of physical and other barriers to participation. Participants believed that disability awareness training is central to these positive developments.

Most participants highlighted having experienced negative attitudes in a range of contexts. Paternalism was mentioned as one of the most disempowering attitudes and the prevalence of this was emphasised. Participants believed that many people do not know how to interact with people with disabilities and that this is based on fear and lack of understanding. There is insufficient understanding of different disabilities and of multiple disabilities. Particular mention was made of how this lack of understanding works against certain groups, for example, people with challenging behaviour, schizophrenia, intellectual and hidden disabilities.

Participants felt that negative attitudes and lack of understanding result not only in the ill-treatment of people with disabilities. They also contribute to the maintenance of physical and financial barriers to participation. Participants explained that negative attitudes and a lack of understanding impact on them in many ways. These include psychological, social and cultural, civil and political and economic and financial impacts.

Psychological impacts

At a psychological level, many felt diminished and disempowered by being defined only by their disability. They felt that many people did not understand or see them as full human beings with complex needs and rights.

People also felt undermined and experienced a loss of self esteem when they were treated with a lack of respect or in a 'paternalistic' way. A number of participants emphasised that a lack of awareness results in a 'blame culture' and this can in turn result in people with disabilities being made to feel that they are 'a problem'.

Social and cultural impacts

Participants highlighted impacts on their ability to participate fully in social and cultural life. These include being made feel unwelcome, lack of physical access and lack of supports to assist participation.

Many participants believe that recent cutbacks have reduced the opportunity to participate in different aspects of social and cultural life. It was felt that the nature of the cutbacks seemed to indicate a lack of understanding by some policy makers of the importance of activities such as day-trips and short holidays to people with disabilities. It was also felt that there was insufficient understanding of the central role that personal assistants and individual and group support workers play in enabling people with disabilities to participate in social and cultural life.

Civil and political impacts

Participants emphasised that lack of disability awareness impacts on the ability of people with disabilities to participate fully as active citizens. This includes having a say in matters that affect them. This happens either because they are not asked for their views or if they are consulted, it is in a way that is not accessible to them. It was also highlighted that there are insufficient supports available to enable 'the voice' of people with disabilities. It was pointed out that these are particularly important for individuals and groups that are most marginalised including people with intellectual disabilities.

Economic and financial impacts

Many participants believe that lack of disability awareness impacts on people's access to employment and of securing an independent income. Participants believe that employer assumptions make it less likely that a person with a disability will get a job. It was highlighted by many people that employment is extremely important to most people with disabilities. It is important to self-esteem and confidence, to a sense of well-being as well as a sense of independence.

Participants also mentioned other financial impacts including paying more for services and the additional costs involved in participation in society. It was believed that some policy makers and others do not have sufficient understanding of the additional costs.

Specific contexts

The attitudinal research referred to earlier highlights that there are attitudinal and awareness issues that need attention in a number of specific contexts. These include participation in the community, in services, in work and in education.

Community

Participants stressed the importance of integration in the community to their quality of life. They also emphasised that this can contribute to the development of positive attitudes amongst members of the community. They spoke of the importance of supports to integration and felt that visibility and integration is being undermined by current cutbacks. In addition they believe that negative attitudes act as a barrier to integration and participation.

A number of people living in group homes spoke of negative experiences and said that they were not welcomed.

‘local kids taunted us and threw stones, it was hard but we stuck our ground’

They felt they had to:

‘fight to stay in the community and did not have people to support them’

People also spoke of the specific difficulties met by people with challenging behaviour and their carers. Staff training in how to handle such behaviour is essential. In addition organisations who work with people with challenging behaviour need to engage with the local community in order to increase understanding.

Participants emphasised the importance of involving people with disabilities in sport, to promote well-being and to increase community engagement. This can also increase understanding and awareness. Participants felt that an integrated approach was particularly important. They gave many examples of positive integration in sport in Cork. The cost of being involved in sport was emphasised, e.g. specially adapted equipment such as bicycles; support was needed for this.

Services

As well as the positive developments many participants spoke of negative attitudes and physical and other barriers.

Transport was mentioned by many as still causing difficulties. City buses were acknowledged as being more accessible but difficulties were still experienced in relation to some trains, rural buses, express intercity buses and taxis.

Participants spoke of positive developments in some private services such as shops, cafes and so on. Ongoing difficulties were also identified. These were caused in part by attitudinal barriers but also by physical barriers. These included the height of service machines, product placement and lack of staff skills in signing. It was felt that these showed a lack of understanding of disabilities.

Access to appropriate public medical services was mentioned by many. Some highlighted positive developments such as increased awareness amongst younger medical professionals. Others spoke of difficulties with paternalism and insufficient understanding of multiple disabilities and of the ability to see past the prime disability to consider the whole person.

Work

Many spoke of the importance of work to people with disabilities. Some believe that employers discriminate against people with disabilities.

‘(an) able bodied person is more likely to get the job’

It was felt that discrimination was based on wrong information, for example, assumptions about additional costs and levels of absenteeism from work. It was also felt that some employers make assumptions about the capacity and skills of people with disabilities even if they do employ them. Examples were given of people being allocated to positions way below their qualifications and previous experience.

Education

Most participants believe that the majority of children with disabilities should attend mainstream schools and be given the necessary supports to benefit from being there. These include Special Needs Assistants, counsellors and financial supports to cover additional costs. The importance of early assessment and appropriate interventions was highlighted. It was felt that age seven is too late.

Participants also emphasised that schools need to ensure that all students are made feel welcome and included by all staff and other students. Parents of all students need to be informed that the school is for all children and that supports are in place to support children with specific needs. Some parents of children with disabilities are fearful of ‘speaking up’ if their child is not being treated or supported in a positive way. It was felt that the right of children with disabilities to be in mainstream schools is sometimes perceived as provisional rather than an entitlement.

Promoting positive attitudes and integration

Participants mentioned factors that they feel contribute to negative attitudes and lack of awareness. These include:

- lack of training of professionals and other front line staff
- lack of public awareness campaigns to break down myths and stereotypes
- lack of an organisation wide approach, that is, involving everyone in the organisation and change being driven from the ‘top down’

- cutbacks to services and payments, contributing to a loss of supports required for integration and therefore reducing visibility in the community
- media casting people with disabilities as a burden on public spending
- lack of media attention to positive contributions of people with disabilities
- disability organisations being seen to 'compete' for (reduced) funding
- some parents being overly protective and not being able to 'let go'

Disability awareness training

A strong recurring theme throughout the day was the need for disability awareness education and training for a wide range of sectors and groups. Participants believe this should begin in Early Childhood Care and Education settings and be continued throughout formal and non-formal education. Participants also emphasised that all staff dealing directly with people with disabilities in private and public services need to be involved in disability awareness training.

It was suggested that education and training be made relevant to the needs of those being trained, cover the range of disabilities, challenge myths and stereotypes and include skills such as basic signing. Participants also emphasised the importance of ensuring that people with disabilities are included in the design, implementation and evaluation of training. It was stated that supports are required to allow this to happen.

Creating public awareness

Participants also highlighted the need to develop greater public awareness through public awareness campaigns.

One group summarised this as follows:

'More advertising to educate and increase awareness... has to come from government policy. Pick a disability every week/fortnight/month, show people's strengths and needs. Normalise it. Encourage good news stories'.

A number of people suggested adopting the approach in the campaigns run by the Road Safety Authority. Others suggested including criteria in national and local funding initiatives and programmes, as a way to promote the inclusion of people with disabilities. Another suggestion was to encourage national initiatives such as Tidy Towns to include an emphasis on inclusion of people with disabilities.

Influencing the Media

Many participants referred to the importance of the media in promoting positive attitudes as well as potentially contributing to negative ones. It was felt that the media often focus on problems and that this contributes to negative attitudes and reinforces the notion that people with disabilities are dependent and a burden.

However people also emphasised that the media has played a positive role including coverage of the Special Olympics and the Paralympics. They also mentioned that the inclusion of a focus on mental health difficulties had made a positive contribution.

Participants pointed out that more work needed to be done with people in the media to improve how people with disabilities are portrayed. It was also felt that local disability organisations could use local media more to promote greater understanding and challenge negative attitudes.

Changing mindsets and systems

Participants recognised the importance of developing awareness and changing attitudes of individuals in all areas and sectors. In addition they emphasised the need to address a lack of awareness at the level of the organisation. This means that senior managers have to be brought on board and encouraged to lead the change process in their organisations. This change would involve changes in policy, procedures and practices.

Participants proposed that there is a need to identify ‘champions’, that is, people who will promote disability awareness, the rights of people with disabilities and the need to remove barriers to people’s participation. Champions can take action in the public arena or within private and public organisations. A number of people mentioned the influence of champions in the area of mental health. Recently a number of public figures have talked openly about their own experiences of mental health difficulties. Participants felt that has promoted a more positive attitude to mental health.

Chapter I: Context

The NDA's third **National Survey of Public Attitudes to Disability in Ireland 2011** builds on previous surveys conducted by the NDA in 2001 and 2006. It was based on a representative sample of 1,039 adults aged 18+, plus a booster sample of 256 people with disabilities.

The survey covered a range of topics on attitudes relating to disability, including knowledge of disability and general attitudes. Specific issues covered in the survey included: education, employment, relationships, state benefits, neighbourhood, and awareness of disability related organisations, legislation and initiatives. The survey also measured social isolation and use of public service websites.

The following outlines some of the key findings in the report.

Summary of key findings

- Physical disability (unprompted awareness) was the most frequently mentioned disability type (81%)
- Unprompted awareness of 'mental health difficulties' as a disability was recorded at 52%, which represents a significant increase on the 2006 figure of 43%, with this increase even more dramatic when compared with the 2001 figure of 34%
- The proportion of respondents aware of someone with a disability (64%) has fallen below the level recorded in 2006 (71%), but still remains significantly higher than the level recorded in 2001 (48%)
- The majority (57%) of respondents believe that 'It is society which disables people by creating barriers'. This represents a fall in agreement compared with 2006 (62%)
- More than four out of ten (44%) respondents believe that 'people with disabilities are treated fairly in Irish Society'. This represents an increase on the 2006 figure of 39%
- Most (68%) respondents believe that there are occasions or circumstances when it is alright to treat people with disabilities more favourably than others. This represents a decline in the level of agreement when compared with 2006 (80%)
- Half (50%) of all respondents believe that in general people with disabilities receive equal opportunities in terms of education (2006, 52%)
- One in five (20%) respondents believe that people with disabilities receive equal opportunities in terms of employment (2006, 15%)

- Respondents are relatively less comfortable having a work colleague with mental health difficulties compared with other disabilities, with the same true for people with disabilities living in respondents' neighbourhoods
- Three out of ten (30%) respondents believe that the state provides adequate or enough benefits for people with a disability (2006, 24%)
- One in ten respondents were classified as being at a high risk of social isolation, with the risk significantly higher for people with a disability (18% vs. 9%)
- Respondents with disabilities were more likely than non-disabled respondents to experience a range of barriers and restrictions to their participation in age appropriate life activities
- Only a minority (33%) of respondents with a disability use Irish public service websites compared with the majority (55%) of others in the survey

A key aspect of the work of the NDA is to challenge negative attitudes. The **Your Voice Your Choice Forum 2013** is part of this work. It gave people with disabilities, their carers and family members the opportunity to share their experiences of attitudes towards them in the contexts outlined above. It also created an opportunity to identify ways to challenge negative attitudes. We outline both these aspects in the following Chapters.

Chapter 2: Overview

About the Report

This report outlines the key messages from the **Your Voice Your Choice** Forum 2013. This event was organised by the NDA, to facilitate people with disabilities, as well as family members, supporters and carers, to share their experience and ideas. It was held in the Clarion Hotel, Lapps Quay, Cork, on Monday 25 November 2013.

The focus of the Forum was on attitudes towards people with disabilities. Participants shared their experiences of these attitudes in different settings. They also identified ways that positive attitudes could be promoted. The insights shared on the day and captured here will help inform the development of a proposed National Action Plan on Attitudes towards people with disabilities.

Participants

30 people attended the event. This included people with disabilities as well as personal assistants, supporters and family members. People with a wide range of disabilities participated. This included people with sensory, physical, learning and intellectual disabilities and people with mental health difficulties. The event was focussed on Cork city and county. Participants also included a good mix of women and men and adults of different ages. The range of people who attended added to the richness of the shared insights and experiences.

The Event

The bulk of the event was given over to facilitating participants to share experiences and ideas. Participants were organised in groups of no more than 6 to maximise participation. Each group also had a facilitator and a note-taker.

The morning session focused on a core question 'what aspect of your life is most affected by the attitudes of people you meet regularly'. The discussion was structured through addressing three sub-questions:

1. What are the positive experiences?
2. What negative experiences bother you or hold you back?
3. If you could suggest three things to improve attitudes what would they be?

The afternoon workshops focused on experiences and ideas for change in specific settings and each group explored one of these. They were:

- Promoting positive attitudes to people with disabilities in the community

- Promoting positive attitudes to customers with disabilities
- Promoting positive attitudes to people with disabilities in schools
- Promoting positive attitudes to people with disabilities in work

These themes emerged as important ones from the NDA's **National Survey of Public Attitudes to Disability in Ireland 2011**. They also represent areas in which people with disabilities and non-disabled people have the greatest opportunity to interact, in a mainstream or everyday setting.

Chapter 3-Disability Awareness

Positive developments

Throughout the day participants emphasised the importance of disability awareness amongst all groups in Irish society and in all types of settings. Many highlighted that when such awareness exists it impacts hugely on them in terms of how they experience their everyday lives.

It can change how they are treated, for example, in shops, cafés and other local businesses. It can result in the service provider making an extra effort to support them to overcome physical barriers which prevent them getting an item or service.

Others highlighted that awareness is shown when they are treated as ‘a whole person’ and not only in terms of their disability. A number of people mentioned that being welcomed and made feel part of a particular setting makes a big difference to their everyday lives. The downside of this was also highlighted. In other words, participants pointed out that when this awareness and approach is absent, they sometimes made to feel as if they are ‘a problem’.

Participants highlighted that it was clear when staff had done disability awareness training. A number mentioned specific businesses such as Bus Éireann and Marks and Spenser. In relation to shops, some mentioned that staff in larger shops seemed to be more aware and more likely to have had training.

A number mentioned that younger medical professionals seemed to be more aware and have greater understanding of the complexity and range of disabilities that exist. This enhanced their interactions with people with disabilities as well as their family members and carers. It also potentially contributed to better diagnosis and treatment.

Specific mention was also made of organisations that are committed to being inclusive. These included many local community organisations as well the local authority. It was highlighted that Cork City and County Councils demonstrate this through consulting and taking account of the views of the Cork Access Group. This group advocates for a more physically accessible city.

University College Cork (UCC) was also mentioned as demonstrating such a commitment. Participants highlighted that the organisation demonstrates this in a number of ways. These include accepting people with disabilities with lower

points under the Disability Access Route to Education (DARE)⁴, having physically accessible rooms and through specific efforts within the College of Psychiatry. The latter includes providing a course on disability for medical staff.

Participants identified a number of factors that they believe have contributed to positive developments in disability awareness. These included:

- Special Olympics, which included a very high level of positive media coverage
- recent media focus on mental health
- people with disabilities being more visible in the community
- NDA support for the 'voice' of people with disabilities
- groups advocating for services and equality for people with disabilities
- disability awareness training
- actions to create awareness of disabilities by young people (without a disability), for example, Transition Year students

A number also stated that people with disabilities are more prepared to 'stand their ground' and speak up for themselves. It was felt that the direct voice of people with disabilities is one of the most powerful ways of increasing awareness. People also mentioned specific things that had supported them to be more visible and vocal. These included:

- life skills training
- support to take up roles on committees
- personal assistants, support workers, carers and family members
- community organisations

Many raised concerns that current cutbacks could undermine this progress and result in the loss of the above supports.

Overall, participants emphasised that the positive developments involved changing attitudes which then resulted in changing how people are treated. It was stated that disability awareness should also result in the removal of physical and other barriers. A number mentioned that the achievement of more accessible city buses and a more accessible Cork city centre was an example of this approach.

⁴ <http://accesscollege.ie/dare/index.php>

Ongoing challenges

Most participants outlined positive developments however they also highlighted things that cause them ongoing difficulties and challenges. Many felt they were still treated in a 'paternalistic way'. The examples they mentioned included:

- being 'patted on the head' if they are wheelchair users
- being talked down to
- not being talked to directly and questions being addressed to carers or family members
- being ignored or passed over

A number of people believe that the treatment they encounter is based on 'fear', myths and stereotypes. They also think that many people do not know how to interact with people with disabilities. One participant shared a powerful example of a lack of understanding, in which a child, who approached a person in a wheelchair and held the handle, was loudly corrected by the child's parent or guardian, who said:

'don't touch that, you might get what they have'.

Participants said they believe that many organisations which provide services show a lack of awareness. In their opinion people with disabilities are treated in ways that are paternalistic and disrespectful. Providers of goods and services also show a lack of awareness by allowing physical barriers to exist which make it difficult for people to access day to day services. Participants highlighted examples, including:

- the height at which products are placed
- the size of print, particularly prices
- poor lighting in shops and streets
- the height of counters and ATM machines

It was emphasised that physical barriers still exist in some areas of public transport. While participants mentioned improvements in the accessibility of city buses, many also mentioned difficulties they still encounter in rural buses, inter-city express buses, some trains and taxis. People also highlighted the difficulties caused by the fact they cannot reserve seats in advance when travelling by train, if they have a travel pass. Wheelchair users highlighted that they have to advise their travel plans in advance so that a ramp is made available to enable them board the train. It was also mentioned that the 'Cycle to Work' scheme is not inclusive of people with disabilities. It does not take account of the very high costs of adapted bicycles.

Participants believed that some medical professionals also lack awareness. They gave examples of professionals who spoke to their carers or family members about them rather than directly to them. Others believed that some professionals do not understand the complexity of their needs especially if they have a number of disabilities. Some family members pointed out that they were not listened to sufficiently either. In addition they felt that their understanding of the needs of the family member for whom they care are not sufficiently respected or taken into account.

Participants gave other examples which in their view show a lack of sufficient awareness by medical and other professionals, these included:

- making children with 'challenging behaviour' queue for services
- associating all illnesses with the prime disability or overlooking other disabilities

Another common theme mentioned by many participants, is the existence of different attitudes and different levels of awareness of different disabilities. A number highlighted that, more recently, there appears to be more understanding and positive attitudes to people with mental health difficulties. Yet it was felt that some mental health conditions are seen as more 'acceptable' than others. A number referred to more positive attitudes towards people with depression or who are bipolar. They did not think that the same applies to people with schizophrenia. It was felt that negative media coverage contributed to this, as coverage often links violence to people with schizophrenia.

It was mentioned that some people have negative attitudes towards people who display 'challenging behaviour'. Members of this group are not always welcomed in public spaces, such as restaurants. Participants believe that there is limited understanding of autism including the fact that people with autism experience communication difficulties. These difficulties can result in great levels of frustration for the individual concerned.

It was highlighted that there is also a lack of understanding of 'invisible disabilities' including sight and hearing loss, dementia and mental health difficulties.

A number of participants mentioned there seemed to be a 'hierarchy' in terms of how people with disabilities are viewed. Overall it was felt that more positive attitudes exist towards people with physical and/or sensory disabilities compared to people with intellectual disabilities. This was qualified by others who stated that the specific context is very important and that how people are treated can vary from place to place.

Participants mentioned factors that they feel contribute to negative attitudes and lack of awareness. These include:

- lack of training of professionals and other front line staff
- lack of public awareness campaigns to break down myths and stereotypes
- lack of an organisation wide approach, that is, involving everyone in the organisation and being driven from the 'top down'
- cutbacks to services and payments, contributing to a loss of supports required for integration and therefore reducing visibility in the community
- media casting people with disabilities as a burden on public spending
- lack of media attention to positive contributions of people with disabilities
- disability organisations being seen to 'compete' for (reduced) funding
- some parents being overly protective and not being able to 'let go'

Impacts of lack of disability awareness

Participants identified impacts at a number of levels. These include:

- psychological,
- social and cultural
- civil and political
- economic and financial

Psychological impacts

At a psychological level, many felt diminished and disempowered by being defined only by their disability. They felt that many people did not understand or see them as full human beings with complex needs and rights. During the course of the Forum, the rights mentioned included the right to:

- education, training and work,
- an adequate income,
- quality healthcare
- appropriate accommodation
- holidays, leisure and sports activities,
- be connected to the community,
- have relationships and a family life
- live as independently as possible.

People also felt undermined and experienced a loss of self esteem when they were treated with a lack of respect or in a 'paternalistic' way. Most people were very positive about the support they get from family members. Some mentioned that on occasion some parents or family members can contribute to a feeling of lack of confidence. This occurs if they are overly protective or talk on behalf of the person. A number of participants emphasised that a lack of awareness results in a 'blame culture' and this can in turn result in people with disabilities being made to feel that they are 'a problem'.

Social and cultural impacts

Participants highlighted impacts on their ability to participate fully in social and cultural life. Some of these have already been mentioned under the section which outlines 'ongoing challenges'. These include not being made to feel welcome, lack of physical access, lack of interpreters for people who are deaf and lack of personal supports to assist participation.

Many participants believe that recent 'cutbacks' have reduced the opportunity to participate in different aspects of social and cultural life. It was highlighted by one participant that day outings or a short holiday to Kerry were no longer possible. A number of people commented that the nature of the cutbacks seemed to indicate a lack of understanding by some policy makers of the importance of day-trips and short holidays to people with disabilities. It was also felt that policy makers have insufficient understanding of the central role that personal assistants and individual and group support workers play in enabling people with disabilities to participate in social and cultural life. It was emphasised that the impact of cutbacks to these supports was significant.

Civil society and political impacts

Participants emphasised that lack of disability awareness impacts on the ability of people with disabilities to participate fully as active citizens. This includes having a say in matters that affect them. This happens either because they are not asked for their views or if they are consulted, it is in a way that is not accessible to them. It was also highlighted that there are insufficient supports available to enable 'the voice' of people with disabilities. It was pointed out that these are particularly important for individuals and groups that are most marginalised including people with intellectual disabilities. Participants also mentioned that there needs to be a greater emphasis on encouraging people with disabilities to register and use their vote.

Many referred to the right to be treated with respect and play a part as full citizens.

Economic and financial impacts

Many participants believe that lack of disability awareness impacts on people's access to employment and therefore to securing an independent income. It was highlighted that some employers assume there are additional costs or overestimate these. Also that people with disabilities will be absent from work more often than co-workers without a disability. Participants believed that these assumptions make it less likely that a person with a disability will get a job. It was also highlighted that some employers make assumptions about the capacity and skills of people with disabilities even if they do employ them. Examples were given of people being allocated to positions way below their qualifications and previous experience. It was highlighted by many people that employment is extremely important to most people with disabilities. It was stressed that it was important to self-esteem and confidence, to a sense of well being as well as a sense of independence.

Participants also mentioned other financial impacts associated with lack of disability awareness. These included paying more for services, for example, some taxi drivers run the meter from the time of arrival rather than from when the journey begins. Many additional costs associated with having a disability were mentioned throughout the day. It was emphasised that some policy makers do not appear to understand these sufficiently, for example, the costs of equipment to allow people take part in sports.

Chapter 4: Participation, integration and awareness

The research outlined in Chapter 1 highlights that there are attitudinal and awareness issues that need attention in a number of specific contexts. The second part of the Forum focused on these contexts. These included participation in the community, in services, in work and in education. This chapter outlines the main issues mentioned by participants in relation to these contexts. Some of the issues had already been identified in the morning session and have been outlined in Chapter 3, as far as possible these are not repeated here unless they were expanded upon.

Community

Some people felt members of their communities are aware and welcoming. A number felt that it is not possible to generalise as people have different experiences from place to place. It was pointed out that this seems to link to the nature of the disability as well as to the living arrangements, for example, whether the person or people with disabilities live with their families, on their own or in a group home. One participant living in such a context mentioned they were accepted but explained this as follows:

‘houses in..... are not worth anything so people accept us in the community’

Others, living in a group home, said that they were not welcomed.

‘local kids taunted us and threw stones, it was hard but we stuck our ground’

They felt they had to:

‘fight to stay in the community and did not have people to support them’

The issue of different attitudes to different disabilities was mentioned again with a particular emphasis on more negative attitudes encountered by people with challenging behaviour and their carers. Participants suggested that staff training in how to handle such behaviour is essential. It was also stressed that organisations who work with people with challenging behaviour need to engage with the local community. This can help increase understanding amongst members of the community. It was pointed out this could also have the affect of connecting people in the service with members of the local community.

A key theme throughout the day was the importance of people with disabilities being involved in and visible in the local community. It was stressed that this is

vital to breaking down barriers and challenging negative attitudes. It was emphasised that this engagement and visibility needs to be supported. It was also pointed out that engagement is not often possible without these supports.

A number mentioned that involving people with disabilities in sport is very important for their own well-being, as a way to increase community engagement and as a way to increase understanding and awareness. Participants felt that an integrated approach was particularly important. They gave positive examples of integration in sport in Cork. These included Beech Hill Table Tennis Club, Leisure World Functional Zone, Rebel Wheelers, Foróige and Stroke Victims Support Group. In each case the sporting activity included people with disabilities and non-disabled people.

The cost of being involved in sport was emphasised, e.g. specially adapted equipment such as bicycles. It was proposed that there should be support available to assist with these costs. It was also suggested that community based or parish based sports organisations such as the GAA, have an important role to play in promoting involvement in sports amongst people with disabilities.

Participants also emphasised the importance of participation in other leisure facilities in the community such as fun and theme parks. Some examples were given of positive developments in this regard, with some rides being accessible to wheelchair users. Funderland used to have a day for people with disabilities but this has now been cancelled. Participants reported that management said this was because of overcrowding and they questioned whether some 'people had taken advantage'? One participant wondered if this view was based on an assumption that all people with disabilities are in wheelchairs. It was suggested that providing people with disabilities with an identity card saying they have a disability, is one way of dealing with situations like this.

Some participants raised the issue of abuse of people with disabilities in the community. A number mentioned that it was common for people to take 'disability only' parking spaces. Some became abusive when challenged by a person with a disability. These and other comments made by participants reinforced the opinion, repeated throughout the day, that people with disabilities have to fight for what they are entitled to, not just at an official or government level but also at community level.

One participant stated that people with disabilities have to rise above abuse; they stated:

'you can come down to their level or you can ignore it'

It was suggested that assertiveness training should be offered to people with disabilities to enable them to challenge abusive or negative behaviour. It was also suggested that in a service context, the manager of the service should be advised of inappropriate staff behaviour.

Participants raised concerns about the possibility of abuse in community homes and care homes. They emphasised the need for better staff training and a client-centred approach as well as the need for regulation of these settings.

Participants highlighted the need to address the issue of use of appropriate language. It was stressed that this is very important to shaping attitudes to people with disabilities. It was acknowledged that sometimes people with disabilities themselves and/or their carers can use inappropriate language and that this reflects what is out there in the wider society.

One of the strongest themes throughout the day and which was also stressed in the context of the community was the need for strenuous efforts to promote disability awareness amongst all ages. It was emphasised that this should begin as early as possible including with pre-school children. Many participants proposed that the creation of disability awareness should be built into formal education at all levels.

It was also felt that youth organisations such as Foróige, which has locally based youth clubs, can also make an important contribution in this regard.

Services

Chapter 3 outlines a number of issues, highlighted by participants, about their experience of accessing services. This includes positive examples, such as more accessible transport for some and a more accessible city centre. It also includes more awareness on the part of some service providers in the private and public sectors. On the other hand participants also highlighted significant challenges which still exist. These include lack of awareness amongst some organisations in both private and public sectors. It is believed that this results in people being treated in a non-inclusive and disrespectful way. It also contributes to the persistence of a range of barriers which makes accessing goods and services difficult.

Additional opinions given in the afternoon and linked to a lack of awareness include:

- automation of services can contribute to isolation
- service machines not sufficiently accessible and lack of staff to assist
- being made feel a nuisance when asking for assistance

- lack of required equipment in hospital, for example, hoists
- waste in health system, for example, some equipment can't be returned for re-use
- doctors surgeries and hospitals not sufficiently accessible to people with sensory difficulties
- lack of panic buttons for people with hearing difficulties which link directly to emergency services
- lack of application of universal design guidelines, examples include, lack of automatic doors, toilet doors too narrow or opening in the wrong direction, fire doors swinging back
- environment not geared for motorised wheelchairs
- public service application forms not sufficiently accessible
- lack of information on entitlements
- lack of use of disability equipment at Cork Airport due to airline companies refusal to pay

A number of participants also mentioned that they did not think all public services operated in an equitable way. In their view some people with disabilities got more than others. They attributed this inequality of access to the fact that service providers responded to 'those who shout the loudest'.

Work

Many participants, including those with intellectual disabilities, emphasised the importance of work to them. The opportunity to work increases people's sense of self-worth and gives some degree of financial independence. Participants also emphasised that the inclusion of more people with disabilities in the workplace potentially contributes to greater awareness and understanding of disability.

Participants also highlighted difficulties in accessing work. A number believe that discrimination still exists against people with disabilities.

'(an) able bodied person is more likely to get the job'

Some wondered would a person with a disability even get an interview if they disclosed the disability in advance. Others mentioned that the school they attended could indicate that they had a disability.

Many did not feel it was an option to conceal their disability at the application stage as:

- wheelchair users would have to check if the premises were accessible

- a deaf person would have to ensure that there was an interpreter present
- some people would have to get permission to involve their PA in the interview

Therefore it was pointed out that employers had to become more disability aware so that people with disabilities would think it was worth their time making an application.

Some mentioned that the Civil Service was positive in this regard and that people with disabilities were offered:

‘a disability accessible interview process’

However it was also mentioned that the target of 3% in the Civil Service, for the employment of people with disabilities, was too low and should be increased.

Participants felt that some employers operate out of unfounded myths about people with disabilities. This includes the belief that it would cost them money to employ someone with a disability and that they would experience higher levels of illness related absenteeism. Some employers make assumptions about the capacity and skills of people with disabilities. An example was given of a person with a hearing impairment and qualified in accounting being sent to work in a hospital library, ‘stacking shelves’, rather than being assigned to the accounts department.

Participants stressed the need for disability awareness training for employers and that this should include awareness on ‘hidden conditions’ such as autism.

The introduction of new employment schemes, such as Tús⁵, which are not open to people with disabilities, were felt to be a sign of lack of awareness on the part of policy makers, about the importance of work to people with disabilities. Participants mentioned that in some cases this new scheme has resulted in people with disabilities being displaced from Community Employment Schemes.

Other barriers to employment mentioned include:

- some people with disabilities fear they will lose their medical card and other entitlements if they take a job
- education and training schemes are overly complex and involve ‘difficult paperwork’ and can result in places not being taken

⁵ <http://www.welfare.ie/en/Pages/Ts--Community-Work-Placement-Initiative.aspx>

- lack of interpreters in the workplace is a block to deaf people

Participants in this workshop also suggested a number of ways to improve access and retention in employment for people with disabilities. These include:

- provide disability awareness training to all staff involved in education and training programmes and base the design of the training on a training needs survey
- incorporate disability awareness training with other mandatory training, i.e. manual handling
- involve people with disabilities in the design and delivery of training
- inform employers about the facts of employing people with disabilities including the costs involved
- set up an Awareness Day for Jobs and Disability (or a week)-'bombard people with awareness'
- simplify the paperwork to support employers taking up funding schemes which promote the employment of people with disabilities
- involve an occupational health nurse in grading the return to work process
- provide job coaches to assist, in the initial stages of employment

Education

Most participants believe that people with disabilities should attend mainstream schools. However, some also believe that mainstream school may not be the best option for a small number of children. It was emphasised that the needs of children and how best to support them to achieve their maximum potential and 'be happy' should be the determining factor. Children who attend 'special needs schools' should have a development plan with goals, including for social development. The plan should be continuously monitored and adapted.

Participants emphasised the need to support children with disabilities in mainstream schools so they benefit from being there. This included the support of Special Needs Assistants and counsellors, for those with mental health difficulties. Financial supports were also needed to cover the costs of transport, special equipment and so forth.

Participants stressed that disability awareness was essential for all those involved in education and in school communities. The latter includes all staff and non-disabled students as well as parents or guardians of these students. It was also felt that the parents of children with disabilities would also benefit from support and awareness training. This should emphasise the importance of being able to 'let go'

and to support their children's involvement in all aspects of school life including sports.

Participants highlighted that principals play a very important role in ensuring schools are inclusive. It was suggested that principals need to make it clear that the 'school caters for all students'. They need to make sure that all parents are aware of this. They also need to inform parents that there are students in the school with disabilities and that some students may have challenging behaviour. They should reassure parents that supports are in place which will support all students to progress in a positive way.

Participants also suggested that it is important that parents of children with disabilities explain the nature of the disabilities, to the principal and relevant staff. They should also highlight what supports their children need. It was also emphasised that schools need to be open to listening to parents of children with disabilities. One participant stated 'some families are afraid to speak up' as the rights of children to be in the school is sometimes seen as provisional rather than an entitlement.

The importance of early assessment of children was highlighted. It was felt that age seven is too late. In addition, it was stressed that relevant interventions need to be put in place as soon as possible after assessment. Participants also emphasised the need to monitor how children are doing and adjust supports if necessary.

The main focus in the discussion was on initial schooling but it was also highlighted that there needs to be more supports for progression to third level. Participants were positive about the introduction of the approach at third level which allowed students with disabilities access to third level with lower points.

Chapter 5: Promoting Positive Attitudes

Throughout the day participants shared ideas for increasing disability awareness and removing barriers to their participation in a number of contexts. They felt that these actions would result in more positive attitudes to and treatment of people with disabilities. They also felt that increased awareness would result in improved organisational policies and practices. In addition they hoped they would lead to more informed government policies.

Disability awareness training

One of the strongest themes throughout the day was the need for disability awareness training. Many participants highlighted positive developments in attitudes (see Chapter 3) which they linked to the provision of such training.

Participants identified the following key groups for inclusion in disability awareness training:

- medical and educational professionals
- architects, engineers and planners
- staff in all front line services including in voluntary, community, public and private organisations
- senior management in organisations providing services to people with disabilities
- employers in all types of organisations
- national and local policy makers
- members of the media
- members of national and local voluntary organisations
- members of community organisations including sporting and other leisure organisations
- carers and family members
- the general public, including children and young people

Participants emphasised that people with disabilities need to be involved in the design and delivery of training. The lived experience of people with disabilities needs to be central to creating awareness. It was also suggested that people with disabilities should be offered training and support to be involved.

Many participants emphasised that including disability awareness programmes within schools was central to progress in this area. Participants stressed that this

should begin at the earliest possible age and include preschool children. It was also emphasised that these should be provided in an age appropriate way. The engagement of young people as active citizens was stressed. In this way they could become part of the solution, through increasing awareness amongst others, both within their schools but also within their communities. Participants gave a number of positive examples, in which Transition Year students have developed specific projects to do this. One such project involved the young people pushing local politicians in wheelchairs around parts of the city to highlight the physical barriers which exist.

Participants also emphasised that local youth and sports organisations have an important role to play in increasing awareness of disabilities amongst their young members.

Participants emphasised the importance of providing disability awareness training to all front line staff. Many provided examples of where this has proved to be very effective in both private, voluntary and public service settings. These positive examples included staff working in shops, in public transport and in the medical profession. Participants also highlighted the importance of involving senior management as they should lead initiatives within their organisations.

As already highlighted participants stressed the importance of offering teachers awareness training to ensure that schools are fully inclusive for children with disabilities. It is also necessary so that teachers and schools can deliver disability awareness programmes. Participants also stressed the need for training for youth workers and leaders and for those involved in sports.

Participants placed particular importance on the need for disability awareness training for all staff in the health services. They emphasised that this should include staff in community homes and community care settings. It was also suggested that the model used in UCC's School of Psychiatry should inform the inclusion of disability awareness in initial training of all medical (and other) professionals.

Participants highlighted that employers in private companies should also be involved in disability awareness training and that they should drive this within their companies. It was proposed that the training should include facts about people with disabilities in employment, including costs, retention levels, levels of attendance and so forth. This will help challenge some of the myths which exist. Others emphasised the need to train those who provide employment and training services in both the private and public sectors.

Some participants stressed the importance of training engineers, architects and planners to ensure that universal design principles are more widely applied.

A number of other proposals were made in relation to disability awareness training. These were:

- include information and a focus on the range of disabilities which exist, including hidden disabilities, autism and communication difficulties, brain injury, in those who have had strokes and how to handle challenging behaviour
- include a focus on multiple disabilities
- include training in basic signing
- make the training relevant to the interests and needs of those being trained

Creating public awareness

Participants also highlighted the need to develop greater public awareness as well as providing targeted disability awareness training. This is important to support the greater integration of people with disabilities in all areas of life and in the community. One group summarised this as follows:

‘More advertising to educate and increase awareness... has to come from government policy. Pick a disability every week/fortnight/month, show people’s strengths and needs. Normalise it. Encourage good news stories’.

A number of others ways to do this were proposed including:

- organise public awareness days, weeks or months
- use TV ads to promote greater understanding along the lines of those used by the Road Safety Authority
- include criteria in funding initiatives and programmes to promote the inclusion of people with disabilities and monitor implementation
- encourage national initiatives such as Tidy Towns to include an emphasis on inclusion of people with disabilities
- put in place awards schemes to recognise best practice in promoting inclusion
- encourage organisations which work with people with disabilities to have open days for members of the local community

Participants emphasised that campaigns and initiatives should highlight the strengths and achievements of people with disabilities. It was also stressed that it is vital to ensure that people with disabilities ‘speak for themselves’.

Influencing the media

Many participants referred to the importance of the media in promoting positive attitudes as well as potentially contributing to negative ones. It was felt that the

media often focus on problems and that this contributes to negative attitudes. The lack of coverage of positive contributions and achievements reinforces the notion that people with disabilities are dependent and a burden.

However it was also emphasised that the media has played a positive role. Participants highlighted specific examples of this including, coverage of the Special Olympics and the Paralympics. They also mentioned that the inclusion of a focus on mental health difficulties had made a positive contribution.

Participants pointed out that more work needed to be done with people in the media to improve how people with disabilities are portrayed. It was also felt that local disability organisations could use local media more to promote greater understanding and challenge negative attitudes. It was emphasised that local radio is particularly useful in this regard.

Changing mindsets and systems

Participants recognised the importance of developing awareness and changing attitudes of individuals in all areas and sectors. In addition they emphasised the need to address a lack of awareness at the level of the organisation. This means that senior managers have to be brought on board and encouraged to lead the change process in their organisations.

Participants emphasised this in a number of ways including the need to:

- report negative staff behaviour to managers
- train frontline staff and managers in disability awareness
- recognise the importance of the principal in school contexts
- recognise the importance of senior managers in all organisations

In addition to involving senior management in change processes, participants mentioned a number of other ways to achieve organisation-wide and system-wide changes.

Participants proposed that there is a need to identify ‘champions’, that is, people who will promote disability awareness, the rights of people with disabilities and the need to remove barriers to people’s participation. The actions of champions can be in the public arena or within organisations. In the former case they can influence public attitudes and in the latter they can impact on the organisation and its work. A number of people mentioned the influence of champions in the area of mental health. Recently a number of public figures have talked about their own experiences of mental health difficulties. Participants felt that has promoted a more positive attitude to mental health.

Other ideas for system changes included:

- link funding to the inclusion of people with disabilities, specific areas mentioned include sport and the arts
- promote greater use of universal design principles to ensure that the built environment is accessible to all citizens.
- partner with local authorities as they have a significant role to play regarding housing, the built environment, parks and leisure facilities as well as many other areas including arts, libraries, etc.
- make sure local and national strategies include a focus on people with disabilities, for example, housing strategy
- promote and support the leadership of people with disabilities, in a real way; support this with training, mentoring and resources
- encourage voluntary organisations concerned with disability to work together to remove the perceived element of competition and to strengthen their collective voice

All the discussion groups highlighted the need to review recent cutbacks. Participants felt they are having a negative effect on the lives of people with disabilities. They also felt that they are having a negative effect on progress in developing more positive attitudes to people with disabilities. Participants believe they are doing this in two ways:

- by reducing the visibility of people with disabilities because they are more constrained in where and how they can participate
- by seeming to create competition between people with disabilities and non-disabled people for public resources.

Throughout the day participants emphasised the importance of building on progress in promoting positive attitudes and in ensuring that the integration of people with disabilities in the community is not curtailed. Two examples of how important this is, on a day-to-day basis, are captured in the comments below.

‘In XXX I get my eyebrows waxed; staff know my name and are lovely- they see me as an individual not the wheelchair’

Another participant spoke of the importance to her husband (who has speech difficulties) that he can go to the café and feel welcome. She summed up this as follows:

‘positive things in a person’s life changes his life; attitudes of others make him feel positive’.