

National Disability Strategy Implementation Plan - focus on autism consultation

Introduction

The National Disability Authority is the independent state body providing expert advice on disability policy and practice to the Minister, and promoting Universal Design in Ireland.

The National Disability Authority, as part of its function to support the implementation of the National Disability Strategy, undertook a consultation exercise to find out how the implementation of the **National Disability Strategy Implementation Plan** can most effectively address the needs of people with autism.

Consultation findings

The following summarises the key themes emerging from the views of autism stakeholders who participated in the consultation process in relation to autism and the **National Disability Strategy Implementation Plan**.

Awareness

- The spectrum of need and variety of issues which arise for individuals with autism needs to be better understood among those who develop public policy and those who administer public service delivery, including Local Authority housing officers; librarians and others; and should be addressed in awareness training and practical guidelines
- Autism training, guidance and awareness raising for mainstream community and sporting organisations is required to facilitate people with autism to participate in their community

Training

- Appropriate training and guidance material on autism is required for a range of professionals including teachers and specialist health professionals (such as therapists) who deal with people with autism on daily basis. The level or type of training required would differ for the different groups of professionals
- Front line and “first responder” public servants such as, the Gardaí, mainstream health professionals; Local Authority housing officers; librarians and others; should also undergo training to develop autism competence and improve how they engage with those with autism

Supports

- Access to knowledge and expertise to guide effective services for those with autism is essential
- Access to appropriate intervention throughout life, but particularly in the early years is critical for people with autism reach their potential. Need to address varying levels and gaps in therapy supports to ensure adequate level of support in all areas nationwide
- Need clear guidelines for diagnosis of autism
- Access to support for self, peer, family and independent advocacy would support people with autism to access mainstream services
- Access to support around times of transition is crucial. It will be important, therefore, that the Comprehensive Employment Strategy takes account of the needs of people with autism
- Services for adults with autism who don't have an intellectual disability or a mental health problem are underdeveloped at present
- A clear pathway, in each health region, for adults to access an autism diagnosis needs to be developed and communicated to relevant professionals and autism stakeholders
- Need to ensure better information on autism and autism supports for families
- Need to ensure that new policy directions are more person-centred and take account of the needs of individuals with autism, for example, housing policy

Education

- A range of issues were also raised by consultation participants in relation in the statutory education sector, which in interested of completeness may be best considered in conjunction with the findings of the consultation being conducted by the National Council for Special Education in developing its Policy Advice on Educational Provision for Children with Autism Spectrum Disorders

Employment

- Need for infrastructure to support children with autism leaving school to transition to training and employment, including the introduction of work experiences and access to career guidance counselling during school life
- Ensure the needs of those with autism is a focus of national higher education, training and employment policies

Data

- Better data on people with autism is required, to better understand the numbers people who have autism, but also to better understand the lives they are living and the services that they are using

Context

The **National Disability Strategy Implementation Plan** was published by the Government in 2013. The **National Disability Strategy Implementation Plan** sets out the actions that the Government will take in the period 2013 to 2015 to improve the lives of people with disabilities. The National Disability Strategy Implementation Plan covers all people with disabilities, including:

- physical
- sensory
- intellectual
- cognitive
- mental health
- autism

A copy of the **National Disability Strategy Implementation Plan** can be found on the Department of Justice and Equality website.

The objective of the consultation exercise undertaken by the National Disability Authority was to produce a report capturing the views of a range of stakeholders in the autism sector in order to identify:

- How the implementation of actions contained in the **National Disability Strategy Implementation Plan** can be adequately tailored to the needs of people with autism
- How any other issues raised by consultation participants can be best addressed within the framework of the **National Disability Strategy Implementation Plan**

National Disability Strategy Implementation Plan 2013-2015

As should be clear from the above, this consultation process was not about the creation of a new strategy but about asking consultation participants how, in implementing the **National Disability Strategy Implementation Plan**, the needs of people with autism could best be addressed. Therefore, as part of the consultation process the National Disability Strategy Implementation Plan was summarised for participants.

The National Disability Strategy Implementation Plan represents a joined-up approach by Government Departments and key state bodies to disabilities. The Implementation Plan covers all disabilities - physical, sensory, intellectual, mental health, autism.

The **National Disability Strategy Implementation Plan** covers key policy and service areas which have a major impact on the lives of people with disabilities, such as:

- Employment
- Social welfare
- Education
- Health
- Housing
- Transport
- Communications
- Arts and sports

The **National Disability Strategy Implementation Plan** also covers how public services are delivered across all Government Departments and agencies, in terms of how services can be made more accessible to people with disabilities.

Structure of the National Disability Strategy Implementation Plan

The **National Disability Strategy Implementation Plan** is structured around 4 High Level Goals. These are:

- Equal citizens
- Independence and choice
- Participation
- Maximise potential

These 4 high level goals are broken down into 15 sub-goals¹.

¹ The sub-goals and key actions under each High Level Goal are listed at the start of each of the subsequent chapters of this report.

Consultation process

The **National Disability Strategy Implementation Plan** - focus on autism consultation process consisted of:

- A consultation event for autism stakeholders (which took place on the 31st of January 2014), which was attended by over 30 participants
- A focus group discussion with a small group of adults with autism
- An online questionnaire for all individuals and organisations interested in autism, which was completed by 90 respondents

High level Goal I- Equal citizens

High Level Goal and objectives

The objectives under Equal Citizens high Level goal are –

- People with disabilities enjoy equality before the law
- People with disabilities are treated with equality and respect
- People with disabilities enjoy access to information
- People with disabilities have equal access to public services

Summary of key actions

Some of the key actions in the **National Disability Strategy Implementation Plan** to deliver on these objectives are:

- Publish and enact legislation providing for persons with disabilities to enjoy legal capacity on the same basis as other citizens and to provide the basis for supported decision making
- Ensure the effective operation of Disability Impact Assessment in assessing Government proposals for policy and legislation.
- Develop and support initiatives to promote positive attitudes to disability.
- Disability awareness training for public servants
- Measures to improve accessibility of public services and information about public services

Views of consultation participants

Wording of the High Level Goal I

The only observation made by consultation event participants on the existing wording of High Level Goal I of the Plan or its objectives was that the term “equal benefit before the law” is more appropriate than “equality before the law”². There were two comments from online participants about the wording of this goal. One relates to the need for access to public services to encompass the provision of advocacy for those accessing services. The second comment relates to the concept of “Equal citizens” needing to include an acceptance of people’s differences.

² This distinction is based on Canada Charter of Rights and Freedoms

“Access to public servicesneed[s] to be two directional with direct relation to advocacy for people with autism being developed in real channels so that equality of access is offered”

“Equal Citizens is not appropriate alone but.... Equal Citizens and Inclusion (i.e. equal, inclusive and accepting of their [people with autism] differences)”

Actions under High Level Goal 1

Training

At both the consultation event and in the online responses the issue of training was frequently raised. Consultation participants indicated that they believed that many public servants need more or better training on issues related to autism training.

Some of the comments captured at the consultation event include:

“Provide training to public bodies and public servants e.g. guards and community officers, and the public in general to increase awareness and understanding of people with autism. Senior Officials in government departments and employees in public bodies need training to increase their awareness and understanding of people with autism”

“This is particularly essential for professions/public servants on how to recognise when dealing with someone with autism and specific advice on how to deal with them. This particularly applies to Gardaí and the probation service. People with autism may not understand the consequences to their actions and therefore may find themselves in trouble with the police”

“Ongoing autism training needs to be made mandatory for all public servants”

“‘First Responders’ in the Public Service and Government Departments require Autism Training”

Some of the online respondents commented:

“Disability awareness training for public servants/civil service: I find in the majority of people there is 'good will' there to learn how to understand how to help and want to know what they can do without being 'patronising' to people with ASD.....”

“... Over the years, the lack of understanding and 'no patience' in public servants to even try and understand how much help and support was needed for the person with ASD. There was 'zero tolerance' shown and lack of respect for the families and the persons themselves which contributed to them becoming more isolated and disabled...”

Training for specific professionals

Many consultation event participants agreed that certain professionals need specific training and awareness-raising around autism. This may require a greater focus on autism in initial training for professionals in health and education in particular and in their continuing professional development.

“Also provide Information to GPs re community programmes and local supports for ASD PEOPLE. The GPs need more understanding and knowledge also, as we found sadly lacking....parent did all the research...online training and information for GP's, make it essential for them. Depression also, is totally debilitating and eliminates the soul of the person, for a while...”

“Irish Early Intervention Centres are currently doing a great job using ABA techniques to prepare children with Autism to integrate into the primary school environments, but I think a gap is forming in Irish school units and home tuition schemes. Teachers and SNAs are not adequately trained to implement the techniques that improve the non academic skill deficits which limit the integration of these individuals with Autism”

Provision of Autism Specific Training

Some consultation participants set out what they believed would be required to deliver an autism specific training programme for the public sector. In their view such a training programme would need the following features:

- Be consistent and comprehensive
- Focus on the key characteristics of people with autism, how to communicate and interact with them
- Contain video case studies of people with autism
- Suggest models of good practice on how to deal with different situations
- Designed by specialists and address different levels of autism in Ireland. The Psychological society of Ireland has an Autism Steering Group
- Provide a useful contacts list so that people know where to go for assistance
- Delivered in a short space of time

Some consultation event participants suggested that part of the content of autism training for public servants should be about equality and the rights of people with autism to access public services.

Training and guidance for professionals in other jurisdictions

A number of consultation event participants highlighted that good quality guides and training material had been developed in a number of English speaking jurisdictions, including Northern Ireland and Wales³, which have been useful for up-skilling professionals in relation to autism.

Initiatives in these peer jurisdictions were described by consultation event participants as including the following features:

- Providing face-to-face training
- Continuing professional development courses (focus on dealing with people with autism within particular situations or environments)
- Publishing dedicated guides for certain key professionals, such as;
 - General Practitioners
 - Teachers
 - Housing support and homelessness professionals
 - Family support professionals
 - People working with older people
 - Primary health professionals, such as dentists and opticians
 - Advocacy service professionals

Some consultation event participants suggested that a framework around the quality, type and level of autism training required by different sectors of the public service or different professionals should be developed.

An existing example of autism training for the public sector

An Autism Safety Project was run in Port Laoise with An Garda Síochána, which some consultation participants indicated had been successful. The Gardaí were given important information about teenagers and children with autism by their parents. The files had details of the children's likes and dislikes, so if one of these children ran away or got into trouble the Gardaí knew how to approach them, what to say to calm them down, etc. Participants noted that this project was a

³ A sample of some of the guides that have been produced in Wales are available on the Welsh Government website: <http://wales.gov.uk/topics/health/nhswales/majorhealth/autism/?lang=en>

good way for the Gardaí to practically manage issues which may arise from the children and young people's behaviour which is linked to their autism. However, they also noted that it was a very good way to get Gardaí to learn more about autism and the diversity of needs associated with autism.

Accessible public services

Autism Friendly sign or quality mark

One consultation event participant suggested that a means of improving public services accessibility for people with autism would be to develop an Autism Friendly sign or quality mark for public services which have met certain criteria.

Public services information and websites

Consultation event participants suggested that public service information and websites could be made more autism friendly by:

- Keeping information simple
- Using Plain English
- Provide information via pictures and use a step by step process. Some people with autism are very visual learners.

It was suggested, by some consultation event participants, that providing access to information in appropriate autism-aware formats should be a statutory obligation on public bodies. It was suggested by these consultation event participants that guidelines for public bodies would need to be developed to assist them to meet this obligation.

Public sector employers

Employment issues for people with autism are discussed in more detail under High Level Goal 3 below. However, in relation to public service accessibility some consultation event participants suggested that by employing more people with autism that public sector organisations would develop a better understanding of autism. It was suggested in this regard that the public sector should have employment targets for people with autism.

Centralised, better information provision on autism and autism supports

There should be a State-funded one-stop-shop type service established to co-ordinate the dissemination of information on services for people with autism. This would also allow public bodies to disseminate important information relevant to people with autism. For example, it would allow the Health Services Executive to disseminate better health and dietary information to people with autism.

Autism identity card

A consultation event participant suggested that people with autism should be provided with an identity card stating that they have autism, or aspersers etc. Such cards exist in other countries and are provided by at least one autism provider in Ireland.

Hearing the voice of people with autism

Some online participants noted that a key to improving service delivery to people with autism is to ensure that people with autism and / or their advocates are included in decision making processes.

“Involve those with Autism where practicable in any consultation processes regarding their needs. Look at ways to gather other diverse groups of people with people with Autism and their advocates to educate each other about the abilities, needs, preferences etc of people with Autism and to de-stigmatise this disability”

“Improving access needs to be two way. In that a real effort be made to contact advocates for autism and involve them in the processes that are being developed”

Queues and “Quiet rooms”

A number of consultation event participants mentioned that queues at public service counters can be a significant accessibility issue for people with autism. Also, busy front desk type service provision can be a challenge for people with autism because of their communication and sensory issues. Public services should be able to accommodate people who require a quiet space to complete a public service transaction.

Autism strategy

A small number of consultation event participants, but none of the online respondents, suggested that a separate national autism strategy is required. It was suggested a necessary first step in this regard would be a discussion within the Autism Sector.

Other consultation event participants suggested that a different approach might also work. It was suggested by some consultation event participants that an overarching strategy covering all disabilities with relevant sub-sections relating to autism and scope to modify actions on a disability specific basis might be more effective than an autism specific strategy.

Another view expressed by a few consultation event participants was that a National Autism Body which would be able to advise Government on a range of issues (not just health and education) should be established.

Awareness

Many consultation event participants indicated that they experienced an acute lack of awareness of autism across the general public. They felt that there is no awareness of the scope and range of issues associated with autism – the ‘Spectrum’ of autism, with varying needs from one end of the spectrum to the other. The challenge that the spectrum and individuality of autism plays in relation to the awareness of autism and acceptance of people with autism by the general public was also raised by online participants:

Public awareness of ADS can be very negative and misinformed. Each child with ASD is different and [they] have their own individual temperament. However, core issues related to social and emotional intelligence is a common factor. Raising awareness of the challenges of children/teens/adults with ASD would help to provide some better understanding of these challenges and thereby offer people with ASD more support and understanding. Because there is no visible disability present, they are often judged harshly when they behave differently to the norm which can 'make a bad situation worse'.

It was suggested by one online participant that the hidden nature of autism was challenge in terms of public awareness and understating of autism:

“Autism is a hidden disability as there is no visible disability unless the person is hand flapping, leads many people not to understand that the behaviour of the autistic person is because of sensory issues or stress they just think of them being bold, bad mannered and all the hundreds of other things us parents have had to hear at some time or another”

This lack of awareness some participants felt also applied to key professionals in health and education.

A suggestion made by some consultation event participants was that a public awareness campaign, (aimed at the general public), was required to address this lack of awareness of autism. It was suggested that this could take the form of a television advert to build knowledge and awareness of autism and the autism spectrum.

Another suggestion, made by an online participant was to focus autism awareness efforts on school children:

“Educating people is key to them understanding that Autism is a disability. I would love to see a schools programme introduced at both primary and secondary school to teach kids about disabilities in general with Autism included if this happened hopefully the kids would be more understand standing of the difficulty facing the persons with disabilities just to get to school each day without having to deal with the extra stress of being laughed at and considered the weird kid. The kids of today are the adults and leaders of our country in the future and the knowledge and understand they have can make a big change to how people with disabilities are treated in the future”.

Some consultation event participants indicated that the way to tackle the issue of awareness of autism was by including people with autism in mainstream society. These participants suggested that, for example, people with autism should be in mainstream schools, be employed in mainstream workplaces and live in ordinary community based houses. It is through integration, these participants argued, that people with autism will change society and societal views on people with autism.

Disability Impact Assessment

Some consultation event participants cast doubt on the whether the Disability Impact Assessment of Government initiatives could adequately address the needs of people with autism because they felt that there is a lack of knowledge and understanding in the public service of the needs of people with autism.

In addition to Disability Impact Assessment of current Government initiatives, it was suggested that a range of existing schemes aimed at people with disabilities from which people with autism are excluded should be reviewed. An example cited was the Disabled Parking Badge. While this scheme is currently only open to people with physical disabilities, consultation event participants suggested, that some people with autism or their families do need to access this scheme as some children with autism can be “bolters”, meaning that they are liable to run without any regard for road safety. Some families, with more than one child with autism who are “bolters”, risk a fatality every time they took a car journey. Consultation event participants suggested that, given the wide variety of issues associated with autism, existing disability schemes need to be more flexible on eligibility rules.

Supported decision making and capacity

Some online participants raised some issues of concern to them about capacity and decision making. These issues appear to be very much the sort of issues that

will be addressed by the forthcoming legislation [Assisted Decision-Making (Capacity) Bill 2013].

“Care must be taken regarding any proposed legislation that provides for "supported decision making". As autism exists as a continuum of severity, some people with autism will clearly need court-ordered supported decision making, some will clearly not, and many will reside in a grey area. Those in the latter category must never have their right to self-determination infringed upon. Training for public servants should be expanded. While autism awareness initiatives have been and are useful, they must also progress on to improving acceptance of autism - one does not always imply the other”.

“People with Autism need the legal right to own and inherit property”

Criminal Justice system

Some online participants highlighted that there are issues for some people with autism in relation to equality before the law because some people with autism may understand contexts differently to others. Some people with autism may also have reactions in certain situations which unintentionally offend others.

“The specific challenges associated with autism should be factored into meeting these actions, i.e. sensory the same way as a neuro-typical person and therefore may react differently to situations without meaning to upset/harm anyone. This would need to be understood when looking at the action of 'equal under the law' and emotional/behavioural issues. A person with ASD will not think in

When it comes to equality within the law there needs to be certain practices put to work for people with Autism, A. So they have the opportunity to understand the situation they are in properly. B. There needs to be adequate training and understanding to all of those that will be working alongside/opposite the person with Autism. An understanding for all, that the person with Autism may not entirely understand what is going on around them. C. The pace of anything law related needs to be slowed down for those with Autism.

Data on autism

Consultation event participants stressed that data needs to be collected on numbers of people with autism and that this should be done via a question in the

NDA – 9th of June 2014

census and by the development of an appropriate data infrastructure for the health services.

High Level Goal 2 – Independence and choice

High Level Goal and objectives

The objectives under Independence and Choice high Level goal are –

- People with disabilities have an adequate income
- People with disabilities get the quality supports and services they need to be independent
- People with disabilities have a say in decisions that affect them
- People with disabilities exercise a choice in how they live their lives

Summary of key actions

Some of the key actions in the **National Disability Strategy Implementation Plan** to deliver on these objectives are:

- Support the provision of advocacy services for persons with disabilities and mental health difficulties
- Ensure persons with disabilities receive supports and services needed to access housing
- Work to enhance access to voting by adults with disabilities
- Government Departments to develop consultation mechanisms for input from people with disabilities and disability representatives
- Oversee effective implementation by HSE and stakeholders of new strategies/programmes to ensure more person centred supports:
 - move from congregated settings to live in community
 - new models of support to replace traditional adult day services
 - new models of respite support
 - reconfiguration of services for children with disabilities aged 0 - 18 years (including services for children with autism)
 - clinical programmes in mental health

Views of consultation participants

Wording of the High Level Goal 2

One online participant commented on the wording of High Level Goal 2 and its objectives. The comment seems to relate less to the appropriateness of the

wording of the High Level Goal in relation to people with autism and more to the fact that some people with autism may struggle to achieve the objectives.

“I do not think you can generalise on this issue, people with autism find it hard to maintain relationships and unless they find a very structured employment they may find themselves without income”

Actions under High Level Goal 2

Housing supports

In relation to housing support needs of people with autism, many consultation event participants highlighted that most people with autism need their own space. Some consultation event participants argued that people with autism need to live in autism specific housing and that they also need to live with other people with autism. It was argued that such arrangements facilitate people with autism to form friendships and help each other. Living with people with other types of disability does not work, it was argued by some participants. Other consultation event participants indicated that independent living was the most preferable living option.

Some consultation event participants noted that their experience of housing officers in Local Authorities was they had a poor understanding of the needs of people with autism.

Congregated settings

A small number of consultation event participants felt that there is too much emphasis in **Time to Move on from Congregated Settings**⁴ on closing congregated settings, which doesn't allow for the fact that some people with autism may wish to stay in a congregated setting. These participants suggested that the Congregated Settings implementation group relook at the **Time to Move on from Congregated Settings** report with an autism focus.

Independent and community living

Divergent views on independent living for adults with autism emerged from the consultation event with some participants indicating that autism supports shouldn't be organised with the presumption that independent living was an option for everyone with autism as some people with autism will require intense 7 days a week, 24 hours a day support. Some participants suggested that some

⁴ Report of the Working Group on Congregated Settings (Health Service Executive), 2011, Time to Move on from Congregated Settings

adults with autism would prefer to live in an autism specific cluster environment away from the community and that providers should be funded to provide such services.

Other consultation event participants suggested that, while there was currently a lack of services to support people to live in the community and to develop independent living skills, this should nonetheless be the objective upon which future supports are based.

An interesting point raised by one consultation event participant was that the idea of community living for some people with autism may be quite different to what others perceive as community living. The question posed by the participant was, “what if your preference for community living is to live in a house by yourself in an isolated rural setting?”

Person centred & autism skilled supports

Many consultation event participants agreed that services for people with autism need to be much more person-centred. Participants also concurred that service providers need training in how to produce appropriate services for people with autism. Many people with autism have to access supports via disability services which some participants noted can have limited resources in terms of psychologists and behavioural intervention and autism skills more generally.

“Future supports provided by the HSE should be highly flexible. The ways in which autism is expressed are as varied as those who have it, therefore person-centred supports should, by definition, accommodate these differences”

“... any of the staff who have given resource to my daughter have had no training in ASD and the various challenges which can present. Girls present differently from boys and are usually not diagnosed until later, possibly 9 yrs and upwards. Yet, when we went to a HSE child mental health unit, they displayed very little knowledge of this and the severe behavioural issues which can result in some cases”

Some participants suggested the establishment of whole new autism-only service system because people with autism “don’t have an intellectual disability and don’t have mental health problems”. However, some participants indicated that a mechanism needs to be implemented to hold service providers to account and to monitor quality and effectiveness of the supports that are provided to people with autism in a variety of different service settings.

Another suggestion from consultation event participants was that each Health Service Executive area should have one autism specific team who are responsible for best practice, training and dealing with particularly complex cases.

Such a hub of expertise around autism could a resource to a range of statutory bodies, consultation event participants suggested.

Training for key professional

Some consultation event participants argued that while a level of autism guidance and training would be valuable right across the public services, this would need to be complemented by a more in-depth training programme for key health and educational professionals who work most closely with children and adults with autism. It was suggested by these participants that a dedicated pot of funding would be required to ensure that appropriate autism specific could be delivered to the required numbers of professionals.

Services – evidence base

A point, closely related to the point above, about appropriately autism skilled services, raised by one online participant, was that there should be a greater focus on the evidence base around the efficacy of interventions for people with autism

“...gather all international expertise and experience of successful interventions for people with autism and ... implement them in consultation with those affected”

Similarly, some consultation event participants suggested, that in order to ensure we are providing the best services possible for people with autism with the resources available, there should be an examination of whether the supports funded in Ireland are cost-effective compared to similar supports provided in other jurisdictions.

Some consultation event participants also suggested that a body, (a type of national centre for excellence), with responsibility for collating and disseminating knowledge and expertise on autism needed to be established.

Access to appropriate services

Some consultation event participants highlighted that some disability service providers say that they don't provide services for children with autism if they have challenging behaviour. Participants asked whose responsibility was it to ensure that services' access criteria don't exclude some children and adults from accessing available disability services.

Consultation event participants noted that access to appropriate services is dependent on geographical location with some areas having reasonably well developed services available to children with autism and some with very limited availability. This was described as a “location lottery” which needed to be addressed by way of a planned approach to service delivery based on evidence of need.

Services – therapy and early intervention

Many consultation event participants highlighted the difficulties that they had experienced in accessing therapy services. This issue of access to an appropriate level of therapy services was mentioned by consultation event participants in relation to young children, older children and adults.

An issue raised, by both consultation event and online participants, was the need to ensure that children with autism get appropriate supports as early in their lives as possible. Some consultation event participants emphasised the importance of an early diagnosis. A number of participants made the point that investment in early supports is best way, not only to maximise the capacities of the individual with autism, but also to reduce the future costs to the State of supporting adults with autism who have failed to reach their potential due to lack of supports. The following quote from an online participant describes this issue very well:

When the necessary supports are available (psychologists, psychiatrists, O.T. [Occupational Therapists] and Speech and Language Therapists) from a young age, (necessary interventions) these people have a better chance at some level of interacting with the world around them

Access to services - community connectors

Some consultation event participants indicated that some people with autism will need support from a community connector type support person for them to be able to participate in mainstream community activities. Families may be able to provide this type of support for their children but adults with autism in particular can require some support to engage in mainstream community activities, according to consultation event participants.

Diagnosis of autism in children

Some consultation event participants suggested that clear guidelines for professionals on the diagnosis of autism needed to be developed. It was also suggested that there should be supports available to families around the time of diagnosis as families can find this event very stressful and not all families have strong family and social networks around them to help them cope.

Assessment of need under the Disability Act 2005

Some consultation event participants highlighted the problems that exist in the operation of assessment of need under the **Disability Act 2005**. Some consultation event participants suggested that the assessment of need under Part 2 of the **Disability Act 2005** is not working as intended and that in some areas the timelines are consistently missed. Given the importance of early intervention consultation participants felt that it is a very significant concern that therapists are “bogged down in doing assessments and then there is no time left for doing early intervention”.

It was suggested by participants that the assessment of need under the **Disability Act 2005** needed to be reviewed with a view to getting children into early intervention or school aged services as quickly as possible.

It was also noted, by consultation event participants, that the assessment of need under the **Disability Act 2005** was supposed to produce data on unmet need and the need for therapists in the system etc. This is not being done in a satisfactory manner as there is still no clear information in the public domain about gaps in disability services.

Women with autism

Women with autism present differently than men with autism and this is often not well understood by professionals, suggested consultation event participants. Autism is missed in women and it, therefore, goes undiagnosed. Women with autism tend to suffer a lot of anxiety, stress and may have self-confidence issues. Consultation event participants suggested that primary care professionals needed guidance and training in the area of woman with autism to assist them to identify those who may have autism.

Autism and mental health

Child and Adolescent Mental Health teams state that they do not provide services for children with autism, according to some consultation event participants.

Choice

Some parents at the consultation event indicated that they often feel that they are “at the mercy of the local disability service provider” because they have no options for services and supports beyond whatever they are offered by their local provider.

Some parents at the consultation event highlighted that location or organisation of supports limited their choices in very significant ways. For example, in some areas the only available supports for school-aged children, some parent

participants argued, are accessed through special schools, which limited the choice of schools for their children.

Service provision across the lifecycle

Consultation event participants highlighted that different rules in different parts of the service system often mean that a person with autism loses supports when they move from one part of the system to another. The examples of children losing supports when moving from pre-school into school and later when moving out of school were highlighted.

It was suggested that much better transition planning involving all the relevant organisations needs to be a feature of how services are provided to people with autism. It was suggested by consultation event participants, for example, that planning for post-school transitions should commence when young people with autism are 13 years of age.

Access to adult autism supports

Adults with autism, but without an intellectual disability, often don't have access to any service according to consultation event participants. Many participants agreed that there needs to be autism specific adult services which, in many places, simply do not exist at present.

This issue of access to services for adults with autism was addressed by the group of adults with autism who participated in a focus group for this consultation. These focus group participants highlighted the difficulty accessing any supports. They indicated that mental health services could only be accessed by an adult with autism if they had reached a crisis (if a person was suicidal for example). Similarly, focus group participants argued that they couldn't access disability support services as they didn't have an intellectual disability.

Focus group participants felt that with access to a low level of support such as a mentoring or counselling service that many people they knew could have remained in jobs or education and training courses. However, the absence of access to any supports has meant that when adults with autism are in stressful situations, they can find themselves engaging in behaviour that is not appropriate for the context (such as repeating actions or utterances). Focus group participants indicated that if there was a mentor or counsellor available to them at times of stress it would make it easier to control their behaviour and consequently to hold onto jobs, participate in mainstream activities and maintain relationships.

Some consultation event participants felt that mainstream schools, colleges employers needed to play a greater role in supporting and mentoring adults and young adults with autism.

Focus group participants indicated that being provided with an appropriate space to hold peer support groups would encourage more people to participate in such groups.

Adult diagnosis

The issue of appropriate channels for adults in the community to access a diagnosis of autism was raised by consultation event participants. The current process, they said, is that when someone is in crisis they may be referred to the mental health services. Some consultation event participants argued that Irish mental health services are not skilled in the area of autism. Consultation event participants argued that there should be a very clear system by which any adult who is query autism can get an assessment in a timely fashion without being in crisis.

Some consultation event participants indicted that they knew several adults who received a diagnosis of Schizophrenia but were later re-diagnosed with autism. Therefore, these people had taken psychiatric drugs that they did not need to take, due to their misdiagnosis within the mental health system.

Individualised funding

In the context of personalised supports, the issue of individualised funding was raised by some consultation event participants. Some consultation event participants suggested that giving their adult children money directly would be unfeasible, that parents would have to have a role in managing the money on behalf of their adult child. Other consultation event participants argued that adults with autism could manage their individualised funding if they had been trained to manage their money. As part of this discussion, it was suggested that an external body would need to monitor and manage how the individualised funding monies are spent. On the other hand, some consultation event participants indicated that they would welcome the introduction of individualised funding.

Services - family supports

One online participant suggested that supports for the families of people with autism should not be limited to when families reach a crisis point. Similar to the points made in relation to early intervention the participant notes that by not supporting families adequately or in a timely fashion the State may ultimately incur greater costs.

“Parents’ needs some level of family support (as do siblings as it is very challenging to grow up in a house with an ASD Child) and the family also need some form of respite. The HSE [Health Service Executive] appear to let people 'burn out' before anything is put in place at which time it can be too late for family relationships

(marriage breakdown, child/parent relationship and depression all around due to lack of support). The result of family breakdown will cost the HSE [Health Service Executive] far more in terms of children in care, hospitalisation of other family members due to depression etc., than it would if some level of support and care was given at the outset”

Services – respite

Some consultation event participants suggested that how respite is provided to people with autism needs to be reviewed. Specifically, it was suggested that the ‘host family’ model of respite may not be appropriate for a lot of people with autism as the environment is unfamiliar, which can be a source of stress. It was also suggested that in some areas staff recruited to provide respite to people with autism had no autism experience or expertise.

Costs of services and potential future savings

Spending on services for people with autism is always described as a cost when in fact it is an investment, consultation event participants suggested. If those who fund services took a longer view they would see that investment in earlier interventions will result in a saving to the system in the future. Consultation event participants suggested that embedding such thinking in those who fund and plan health and education services is critical.

Advocacy

Consultation event participants suggested that there was an absence in Ireland of mechanisms to assist people with autism to become self-advocates. It was also noted by consultation event participants that under the **National Quality Standards: Residential Services for People with Disabilities in Ireland**⁵ people are entitled to access advocacy services. Consultation event participants suggested that there is therefore significant scope to improve self, peer and independent advocacy services for people with autism.

Advocacy and rights of family advocates

Both consultation event and online respondents highlighted the need for more access to advocacy services for people with autism and families of people with autism. A number of participants indicated that access to advocacy should cover not just representative advocacy but also access to self-advocacy and peer-advocacy supports.

⁵ Health Information and Quality Authority, 2013, National Standards for Residential Services for Children and Adults with Disabilities

One online respondent suggested that people with autism themselves should be better represented on the management and governance structures of organisations who claim to be advocating on behalf of people with autism.

“People with autism must be allowed to have significant, tangible and real input into advocacy services. Sadly, in some cases people with autism have no voice in the very groups that claim to speak for them Perhaps the State could reconsider its relationship with any disability advocacy groups who do not enjoy the support of the people who they claim to represent”

One consultation event participant also noted that, as a parent advocate for an adult with autism, it can sometimes be difficult to access information from public bodies or publicly funded bodies.

Parent consultation event participants also noted that parents are ‘way down on priority list’ in terms of access to the National Advocacy Service.

Adequate income

The finances required for independent living were discussed with reference to the reduction of the disability allowance and the length of processing time for new applicants and it was noted that there was an issue with autism not entitling people to certain grant aided schemes

High Level Goal 3 – Participation

High Level Goal and objectives

The objectives under Participation high Level goal are –

- People with disabilities have access to jobs
- People with disabilities can access the places they want to go
- People with disabilities live and are part of the mainstream community
- People with disabilities can enjoy friendships, relationships and a good social life
- People with disabilities are safe and free from abuse

Summary of key actions

Some of the **key actions** in the **National Disability Strategy Implementation Plan** to deliver on these objectives are:

- Publication of a comprehensive employment strategy for people with disabilities
- Works to ensure achievement of minimum of 3% of employees in the public sector are those with disabilities
- Ensure public areas and public buildings are accessible in line with relevant building standards as far as practicable.
- Community development projects funded by Local Authorities shall require focus on accessibility and inclusion issues
- Ensure that no sports organisation in receipt of sports capital funding discriminates against people with disabilities
- Ensure library and arts services support people to participate in mainstream activities in the community

Views of consultation participants

Wording of the High Level Goal 3

An online participant made one observation on the wording of High Level Goal 3, which appears to acknowledge both the need for integration and participation and the need for appropriate safeguards for those who require them.

“People with disability need to be protected from abuse and segregation”

Actions under High Level Goal 3

Participate in sports, social and cultural activities

Many consultation event participants highlighted the need for appropriate opportunities for adults and children with autism to participate in sports, social and cultural activities. Consultation event participants had different experiences of how autism inclusive their local clubs or associations were. Many consultation event participants concurred that mainstream community groups and clubs can support the inclusion of people with autism if those clubs get some support in the form of advice and training.

Some consultation event participants suggested that large national sporting and community organisations, (such as the GAA, Football Association of Ireland or the scouts, etc.) should have an autism mentor, to assist their local branches to become more autism inclusive.

Consultation event participants suggested that mainstream organisations needed to be consistently better at including children and adults with autism. At present, it was argued, there is a lot of luck as to whether your local sports club or association is autism inclusive. To improve autism inclusion in mainstream community organisations would require appropriate guidance and training. Some consultation event participants suggested that it be made mandatory, for sporting and cultural bodies receiving state funding, to ensure that their staff are trained in autism awareness.

Some consultation event participants noted that some people with autism may like team sports but that more individualistic sports, such as, swimming or martial arts were very good for people with autism.

Some consultation event participants highlighted the role good, locally-based but privately-run activities which can be very positive for children and young adults with autism, such as, Coder-Dojo, JudoAssist and drama groups. It was suggested by these consultation participants that, perhaps with some creative thinking, participation in such programmes could be subsidised in some way for children and young adults with autism, as participation in these activities is very positive for building social skills capacity, making friends, improved physical coordination, etc. Given the current difficulties in meeting the demand for occupational therapy and physiotherapy, it was argued by consultation event participants, that such a scheme could be a cost-effective way to address unmet demand for services.

Some consultation event participants mentioned that issues at sporting events which are often the most difficult for an adult or child with autism to deal with are queuing and waiting around rather than the sporting activity itself. It was suggested that with some consideration about how to include people with autism these types of issues could be addressed.

Consultation event participants suggested that the onus should be organisations and clubs to communicate that they are autism inclusive, as even those clubs that are autism inclusive tend not to communicate that people with autism are welcome in the services or events that they run. Again, it was suggested that for those organisations receiving State funding that the State should demand this.

Autism specific events, such as, autism cinema screenings, were praised by a number consultation event participants. Other consultation event participants noted that, with very basic training in autism for staff in theatres and cinemas and some simple accommodations around lighting, it would be possible to ensure such venues / services are accessible to all people with autism.

A general conclusion from the consultation event participants was that, while it often is possible to find an autism inclusive sports club, association or event it is usually more to do with luck and generally not because the information on autism friendly mainstream activities in an area has been made available to a family.

Participation in mainstream activities

A common feature of autism is a reduced ability to generalise from one context to another, some consultation event participants observed. Therefore, many people with autism will need to complete a “trial run” of an activity or service before they could access it independently. Providing “trial runs” needs to be part of what is considered to be a normal, reasonable accommodation in providing a mainstream community service.

Attitudes & awareness

A common theme running through the comments of the online participants and consultation event participants is public awareness of autism and attitudes towards people with autism will need to be addressed for people with autism to successfully participate in mainstream community activities:

“Initiatives that improve public awareness and acceptance of those on the autistic spectrum are incredibly important. Education and the dispelling of myths and unfounded fears is paramount. Although there are known exceptions, very few people with autism are child prodigies or savants. Also, just because someone behaves oddly does not mean that they are dangerous, or that they cannot contribute to society”

“Educate the public about barriers people with autism face in accessing venues, building relationship and being equal members of the community they live in. Help their communities to help them feel safe and secure where they live”

Support parents

Consultation event participants suggested that parents of children with autism need to be supported to ensure that they have the capacity to support their child to participate in mainstream community activities. This can be done, participants suggested, by way of:

- Training parents of people autism about how they can be the best support for their children
- Providing parents with access to low cost events, workshops, training etc. that highlight how people can maximise **their own** physical and mental wellbeing
- Supporting parents of children with autism to themselves volunteer to participate in the running of clubs or organisations in which their child participates
- Provide families with respite when they it is required

Parents and advocacy

Some parents at the consultation event stated that they had experienced resistance when they had tried to act as advocates on behalf of their children, including adult children, when trying to access community based organisations and services. Again, it was suggested that this issue stemmed from poor understanding of autism in many community based organisations which could be addressed through information, guidance and training.

Autism identity card

Some consultation event participants had mentioned the use of Autism identity cards in relation to accessing public services but some others suggested that they could equally be used in a range of other everyday situations where someone with autism is accessing a mainstream community service or event.

Library services

A few consultation event participants indicated that libraries were inaccessible to them as their child/children with autism were unable to be quiet during library visits, which created stress. It was suggested, by one participant, that libraries could perhaps provide a space or room where the issue of maintaining silence could be relaxed.

Accessing transport

Being able to access transport is often a requirement of participating in community events. A number of consultation event participants highlighted that transport can be an issue for people with autism. It was suggested by participants that with appropriate transport training many people with autism could access mainstream public transport. However, these consultation event participants argued that there are some people with autism for whom accessing public

transport, even with training, would be very challenging. It was therefore argued that such people should perhaps have access to some mobility / transport subsidies to meet the cost of paying for taxis etc, which currently are available to people with other disabilities.

‘Pre-mainstream’ support

A few consultation event participants argued that public policy emphasising mainstream participation could disadvantage some people with autism. That some people with autism will always need specialist services. These consultation event participants suggested that some people with autism will need “pre-mainstream” supports to develop their capacities to access mainstream supports.

Independent living skills

A number of consultation participants highlighted the fact that young adults with autism need help in areas such as social skills and independent living skills. It was suggested by some that young adults with autism should be able to access such training through their schools. Below is an example of a comment from an online participant:

“Schools which have pupils with autism need to be equipped to not only focus on improvements of academic performance. They need to provide teaching of social, communication and daily living skills which in turn will help individuals with autism reach these goals. BCBA’s [Behaviour analysts] employed in or by the Department of Education will provide such a service which is beyond the qualifications of the traditional teacher for all individuals not only those with autism”

Some consultation participants suggested that there should be a much greater emphasis in schools on developing the social skills of young people (13 - 18) with autism and a variety of mechanisms, such as, buddy systems should be used to progress this.

Employment

Some consultation event participants welcomed the development of a Comprehensive Employment Strategy which would address the needs of people with autism. It was suggested by these participants that people with autism often need ongoing mentoring around dealing with social interaction challenges that arise for them in a mainstream workplace. Therefore, this access to mentoring could be an autism specific feature of the Comprehensive Employment Strategy.

A few consultation event participants suggested that the Comprehensive Employment Strategy by being targeted at the general population with disabilities may not be autism specific enough. For people with autism, the barriers to work

are often related to anxiety and social interaction. It was argued, by these consultation event participants, that a focus on pre-employment training around social skills and dealing with anxiety would be required to ensure that the Comprehensive Employment Strategies could meet the needs of people with autism.

Post-school Transition Programme

Some consultation event participants suggested that an infrastructure to support young adults with autism leaving school needs to be developed.

A suggested model of post-school transitions was made by these consultation event participants:

1. Volunteer information transition person, such as, a peer support person in college.
2. Personal control facilitation coaches, which could be paid and voluntary. These coaches would assist the person with autism around issues like accessing public transport or appropriate ways to act in certain social contexts relevant to the young person with autism.
3. Paid or voluntary mentor (perhaps a family friend) should sign a “contract” agreeing to be a volunteer mentor to provide the young adult with autism with guidance and support. If people are invited to be a mentor for a year it is less daunting but many people in fact go on to be a mentor for many years.
4. Work experience for young adults with autism should start while they are in school.
5. Young adults with autism need early and frequent opportunities to Job Sample. While all young adults may need work experience young adults with autism particularly need it as some of them may not intuit many of the norms associated with the workplace around social behaviour, personal care, dress code etc., as easily as their peers. Consultation event participants noted that it was often these types of issues around work place norms rather than capacity to do a task which would be a barrier to a young adult with autism getting and maintaining a job.

Employers

Consultation event participants suggested that many workplaces are “autism blind” but that, with a little training and guidance they can and do become workplaces where, people with autism can contribute positively. Many consultation event participants indicated that they believed that Irish employers underestimate what people with autism could contribute to companies and organisations. An online participant comment as follows:

“Some companies have actively come out and openly sought people with Autism - they have identified all their positive traits - regular routine... commitment ... loyal ... hard working but this is only the tip of the problem ALL companies should be doing this and saying that applicants are welcome from this field thus ensuring that the individual knows they can apply, they wont be ridiculed for doing something wrong and that there is a framework to support them within the entity”

A number of consultation event participants stressed that employment supports for people with autism should only be focused people with autism gaining and maintaining employment in **mainstream** workplaces. However, some participants felt that micro and social enterprises models operating in Australia and New Zealand which provide enjoyable work, tailored to the interest of individuals with autism, should be investigated in an Irish context.

Supporting young adults

A number of consultation participants highlighted the fact that the level of services, (therapy services in particular), available for school-age children and teenagers is very low. The participants argued that those services seeking to support adults and young adults with autism today are dealing with the consequences of a legacy of under-investment in intervention from early in the person’s life and particularly during teenage years. Some of the online participants’ comments on this issue are as follows:

“Because of the lack of support for people with ASD in Ireland from childhood, a lot of these people do not get to complete school (as they cannot cope with the system and there is no meaningful support) or go to college so therefore find it very difficult to get employment. Even if they get through the school system and make it to college and into employment, they do not have any support when they reach 18 and can therefore struggle in society. There is a total lack of any form of structure for people with ASD in Ireland from childhood to teen/adult which only gets worse when they are over 18 when any little support which was there up to that point disappearing as if the person is magically going to be cured !!”

,,, it all comes back to proper and accessible professional supports and interventions when young and ongoing but in the late teens and early 20's for higher functioning people it will be less intervention, maybe 4 times a year, but only if they get the help and understanding and awareness when they are young ... from EIT

[Early Intervention Teams] and services 0 – 18 [Children’s Network Teams] ... Anxiety from confusion in world and trying to understand it can be debilitating but with the supports and relevant professionals and public service people from Doctors, nurses, teachers, SNA'S and everyone being trained with ongoing updates and patience and understanding and tolerance can it happen....”

Confidence in work settings

In addition to the social skills training mentioned above a number of participants mention the fact that people with autism can often lack confidence in their skills and their capacity to contribute in a work environment. A number of participants suggested that training and ongoing mentoring was required to address this issue of lack of confidence. An example of a comment, from an online participant, highlighting this issue is as follows:

“Have specific training / up-skilling for people with autism so that feel competent and confident, and so that they may have better access to jobs”

High Level Goal 4 – Maximise potential

High Level Goal and objectives

The objectives under High Level Goal 4 – Maximise potential are –

- People with disabilities are enabled to maximise their physical and mental wellbeing and capacity for independence
- People with disabilities get the education and training that enables them to reach their potential

Summary of key actions

Some of the key actions in the **National Disability Strategy Implementation Plan** to deliver on these objectives are:

- Improve accessibility of mainstream health services via roll-out of guidelines for accessibility.
- Strengthen community mental health teams for both adult and children
- Local Sports Partnerships will continue to assist in and support developments for the inclusion of people with disabilities in sport and physical activity.
- Ensure effective supports for children with special education needs [this will include the development by the National Council of Special Education of a new model of resource allocation for children with special educational needs in schools and review of autism supports in schools]
- Effective Rehabilitative Training programme for those who need such support.
- A focus on disability by SOLAS, the National Training and Further Education Authority
- Ensure provision of vocational education for people with disabilities by the Education and Training Boards (replacing VECs).
- Support students with disabilities to participate in higher education through the Fund for Students with Disabilities and implement the **National Plan for Equity of Access to Higher Education**.
- Improve supports for children with disabilities in the preschool year

Views of consultation participants

Actions under High Level Goal 4

Early education and care

A number of consultation event participants highlighted that, parents of children with autism who may wish their child to attend a local pre-school, find there are very few relevant supports that a pre-school can offer their child, because they have no specific resources to support children with disabilities.

Some consultation event participants indicated that a preference for many parents for their child's pre-school education was the home tuition scheme. However, some consultation event participants argued that in practice this scheme had a major flaw as the teachers approved by the Department of Education and Skills to deliver the home tuition have no training in how to teach children with autism.

Some consultation event participants expressed the view that qualified psychologists and Applied Behavioural Analysts would be willing to take up home tuition posts but cannot do so because of the rules of the scheme. Some participants suggested that this scheme be reviewed from the point of view of maximising the outcomes of the child with autism and their family.

This view was echoed by some online consultation participants:

“Formally including people with Applied Behavioural Analysts qualifications into the home tuition grant scheme would be beneficial to improving both the educational and non academic barriers which are limiting the social and employment opportunities later in life, as research shows the earlier intervention is introduced the greater the improvements. I think the current scheme is limiting the learning of the children with autism because it allows teachers who may never have taught a child with disabilities to enter a home with no direction to 'teach'”

Statutory education system

The role and function of Special Needs Assistants should be reviewed according to some consultation event participants. These participants argued that the Special Needs Assistants scheme is too narrowly focused on care needs but should be focused on the “support needs” of children with autism who may for example need support to stay focused on their school work, which is not a care need. It was suggested also by participants that at least a proportion of Special Needs Assistants should have a reasonable level of training in autism.

It was noted by consultation event participants that the National Council for Special Education is developing policy advice on the education of children with autism. It was suggested that the National Council for Special Education policy review should focus on modifications in relation to school curricula and schools inclusion policies to ensure the inclusion of students with autism.

It was suggested that the Physical Education curriculum in schools could be easily tailored to be autism friendly, with more of a focus on fitness and individual sports. Some consultation event participants mentioned that, exercises and routines useful for sensory processing and self-calming, etc., could quite easily be incorporated into mainstream Physical Education sessions if guidance and training was provided to Physical Education teachers.

July provision

It was suggested by some consultation event participants that the home-based July Provision scheme should be reviewed. It was suggested that the review should consider whether outcomes for children and families might be better if the scheme's remit was broader than education support and included social skills training, behaviour management, and independent living skills training. If the scheme was revised along those lines, it would need input from professionals other than teachers, consultation event participants suggested.

Attitudes and awareness in education settings

Consultation event participants suggested that some teachers and principals do not understand that a child with autism does not choose their behaviour; they do not make a cognitive decision to be disruptive. It is a mistake therefore to think of their behaviour as being their fault. Accepting this has been a challenge for many teacher and principals, participants suggested.

A number of online participants also highlighted the issue of attitudes of teacher and other students towards people with autism in school settings.

“Awareness in the community was considered an important element to successful participation of people with autism with particular reference to school staff”

“De-stigmatise autism by education programmes in schools, community setting and workplaces”

“Efforts should be directed at keeping as many people with autism in mainstream education as possible, as this will lead to greater awareness, tolerance and acceptance of people with autism amongst their typically-developing peers. A "buddy system" where

emotionally mature typically-developing children help teach children with autism social skills could be immensely beneficial in this area”

Bullying of children with autism in schools

Children with autism, who may have difficulties in the areas of communication and social interaction, can be labelled as “loners” in schools and be susceptible to bullying, according to consultation event participants. It was suggested that buddy systems; improved teacher training; as well as, school activities around inclusion; can reduce the risk that children with autism are bullied.

Counselling and career guidance in schools

Some consultation event participants indicated that Guidance Counsellors in schools can potentially play a pivotal role in supporting children and teenagers in schools and assisting them in successfully transitioning to their post-school option. It was therefore suggested by consultation event participants that autism training for all Guidance Cancellers would have a positive impact on education / career outcomes for young adults with autism.

Autism Units

Some participants argued that there are some children with autism for whom full integration with their peers in the mainstream classroom is not achievable. Therefore, it was argued that autism units and rooms in special and mainstream schools need to be part of the continuum of provision. However, consultation participants did express a significant concern that very little is known about the outcomes for children in special autism units. The following comment from an online participant also raises questions about the effectiveness of autism units.

“I am continuously hearing [and] have also seen first hand how children entering units are regressing. I do not blame the teachers for this [as] I recognise they are trying their best with limited qualifications for catering for individuals with autism”

These participants recommended that a monitoring system be set up to ensure these units are assessed for the quality of education they provide and the outcomes for the children and young people who attend them.

Resource allocation in education

Some consultation event participants suggested that the National Council for Special Education needs to stop allocating resources based on a diagnosis and instead allocate on the basis of need. A child’s educational support needs should be identified through their Individual Education Plan Person, it was argued.

A comment from an online participant highlights the need for schools to focus on the individual child with autism and how to meet their needs, rather than rigidly applying school rules.

“Assist students with their Individual NEEDS. Some schools allow laptops, some don't, some grant exemptions some don't - there should be one board that can be applied to for standardising these issues and keep it accessible and don't just give kids laptops without teaching them to type !!!! Provide support infrastructure to get these kids as far as they can go... as they are in general VERY bright!”

Teacher training and autism

Some children with autism become disengaged from the mainstream curriculum, consultation event participants observed, and they argued that this was mainly the result of lack of autism awareness and training among teachers. These participants argued that if class teachers had more autism training at primary degree level and were able to keep their pupils with autism engaged in the curriculum then:

- Teachers would be better able to manage their classroom and have more confidence in how to cope
- Special Needs Assistants would be able to cope with their tasks
- Resource teaching hours would be better used

Gifted children

Both online and consultation event participants highlighted the need for schools to be better equipped and more willing to meet the educational needs of gifted children.

Teacher qualifications and Applied Behaviour Analysis

A few consultation event participants suggested that adding access to Applied Behaviour Analysis to the support continuum available to children with autism in schools would be a positive step.

Cross departmental work

Co-operation between the Department of Education and Skills and the Department of Health and agencies under their auspices, was criticised by some consultation event participants. It was noted by these participants that this lack of cooperation becomes a major issue at points of transition for the child, such as, when the child is transitioning from:

- Pre-school to primary school
- Primary to secondary

- Secondary to their post-school option

The ideal arrangement, some consultation event participants felt, was that health funded therapies (Occupational Therapy, Psychology, Speech and Language) could be provided through schools and that this should perhaps be a longer term goal.

Similarly, some consultation event participants suggested that the Department of Children and Youth Affairs needed to be more engaged with autism issues and working with other relevant Government Departments to ensure children with autism and their families can access required mainstream and specialist supports.

Mainstream health

Consultation event and online participants highlighted the need for a range of health professionals to be better trained in autism. Primary care staff; GPs and dentists; were specifically mentioned, as requiring more knowledge and training. One online participant noted, however, it is not just that health professionals need to be more knowledgeable about autism they also need to be more accepting of the views of parents and people with autism:

“..anyone in close contact with ASD people are fully trained and understanding the DISABILITY they are dealing with **and** listen to the parents..”

Training agencies and autism

The remit of the various training agencies - such as, EmployAbility (Supported Employment), INTREO and SOLAS and the Education and Training Boards - in relation to people with autism should be clarified, according to consultation event participants.

The current Solas model for vocational training through specialist training providers is not appropriate for those with autism in the view of some consultation event participants. The participants suggested that the Education and Training Boards need to develop an appropriate model for those on the autistic spectrum. It was suggested that the Autism Programme in Northern Ireland and Peterhouse College in Liverpool be looked at in this regard.

Advocacy

According to a number of consultation event participants access to advocacy is key to ensuring that children and adults reach their potential,