# Models of good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community

NDA 2017

# Contents

# Executive Summary

The National Disability Authority was asked to identify models of good practice in effectively supporting the needs of adults with autism, without a concurrent intellectual disability (ID), living in the community. This is one of the additional actions in relation to autism that was added to the National Disability Strategy Implementation Plan in 2015 and which remains in the current National Disability Inclusion Strategy (2017-2021).

This is an exploratory report that looked at evidence of good practice from Ireland and around the world with most of the evidence coming from grey literature. The report looked at service developments for adults with autism without an ID living in the community and focused mainly on health, social care and education services that are in the preventative and supportive realm. Most of the information and examples came from England and Scotland with some from the US.

Adults with an autistic spectrum disorder (ASD) are a heterogeneous group. Approximately 50% have a concurrent ID. This group generally require life-long supports that are provided by ID services. Of the 50% of adults without an ID some achieve professional qualifications, employment, and have generally very little need for services. Many others however struggle with education, finding and keeping employment, and may have health and social care support needs that are frequently not met.

A particular issue for adults with ASD is the invisibility of autism as a condition. Many people with autism do not have obvious physical signs of it and are therefore, sometimes thought to interact in ways that may be considered unusual. We estimate, based on limited data, that between 16,379 and 23,079 adults aged 18-64 with an ASD and without an intellectual disability live in Ireland. However, many of this group are likely to be undiagnosed.

The report looked at various stakeholder consultations on autism in Ireland that were conducted over the last number of years which identified several gaps in availability of, and access to, services for adults with autism without an ID. It also identified the specific needs of adults with autism that are often not met due to the lack of awareness or lack of competence on autism among service providers resulting in many adults with autism without ID not reaching their full potential.

Services are often organised around ID in a way that makes it difficult for adults with autism from being able to access the supports they need if they do not have an ID. They are often neglected in service planning particularly if they don't have

a concurrent ID or mental health disorder as support for adults with autism usually stem from these services. Adults without these concurrent disorders may fall between the gaps created by traditional service boundaries and therefore may not be considered eligible to access support.

This report found that in general there is a lack of research, and a consequent lack of evidence, around the optimal configuration of services and the most effective and efficient supports that are required to ensure that adults with autism without an ID can live as independent and fulfilling a life as possible. The two main services available to adults with autism without an ID, in the UK, are specialist autism teams and One-Stop-Shops. The specialist teams aim to provide local specialist expertise to mainstream services. The configuration of these teams varied from place to place. A comprehensive team in Glasgow provided services from diagnosis, post-diagnostic group courses on accepting and understanding the diagnosis, consultations to reduce stress and anxiety in their lives, and the provision of ongoing services through a self-referral clinic. The One-Stop-Shops, although not always exclusive to adults with autism without an ID, aim to prevent unnecessary referrals of people with autism to more specialist settings by providing support and linking service users to relevant mainstream services. In addition, they act as an information hub for people with ASD and their families.

Although the data are limited, evidence from the report suggests that adults with autism without an ID who have access to these teams have better outcomes, such as they:

- find getting a diagnosis easier
- lead more independent lives
- are more likely to work
- are less likely to have mental health difficulties
- are more likely to have carers who are in work (i.e. parents or other carers have not had to give up their jobs to care for the person with autism)
- are less likely to be in residential care

There is some evidence that a relatively low level of ongoing support for adults with autism without an ID can prevent anxiety and distress, and negate the need for more expensive crisis support later. While One-Stop-Shops and specialist autism services are undoubtedly providing valuable services, the structures and functions vary and they struggle to retain funding for their services. A tension exists between the provision of mainstream and specialist services but from the limited evidence presented it seems as though some level of specialist services

will be required for adults with autism without an ID living in the community to ensure that they have a good quality of life and can meet their life goals. The evidence also suggests that despite the need for an initial investment, investment in such specialist services will be cost saving in the long term.

There are several advances in the third level education sector around inclusion, autism-friendly campuses, and career and employment support. There was some evidence on the effectiveness of these services resulting in better short and longer-term outcomes for these students.

The policy in Ireland is for the majority of services to be provided by mainstream service providers. For this to happen there is a need for extensive training of service providers with specific autism awareness training included as part of routine disability awareness training. In addition, there needs to be more comprehensive training for those who will be providing more in-depth services for adults with autism. While some autism-specific services exist in Ireland for adults with autism without an ID, they are not universally available throughout the country and a formal evaluation including a cost effectiveness analysis of these services may be warranted before any recommendation to expand them is made.

A number of recommendations are provided based on some of the gaps identified in this report. The key ones are outlined below.

**Recommendations relating to research and evidence**

1. Estimate the number of adults with autism without an ID, both receiving and not receiving supports and include the number of undiagnosed adults who may require support in the future. This would include conducting an extensive mapping exercise of who is currently receiving services (the NDA/HSE school leavers survey has started this process)

2. Evaluate the efficiency and effectiveness of existing autism services for adults with autism without an ID that are publically funded. Estimate the costs of replicating the well performing services throughout the country.

3. Develop and pilot test new models of support for the Irish context.

4. Develop a number of case studies of people with autism without an ID documenting met and unmet need to help clarify the existing unmet need.

**Recommendations relating to training and awareness raising**

5. Continue to train public service workers on issues surrounding disability including ASD. ASD specific training for professionals and service providers including gatekeepers and managers involved in ASD services should be further developed.

6.  Consider options that would give access to in-depth training on ASD across disciplines such as through a centre for excellence in autism model.

**Recommendations relating to service improvement**

7.  Identify a clear pathway to diagnosis for adults who are suspected to be on the autistic spectrum. There should be an appropriate referral pathway to address any unmet support needs. Related to this is the need to develop and test new and improved tools for the diagnosis of autism in adults

8.  Explore ways of providing a seamless service in supporting people with autism without an ID through multidisciplinary and inter-sectoral working. This is particularly so for the transition periods, for example, a move from child to adult services

9.  Establish a shared understanding regarding what services should be delivered by mainstream versus specialist services in the context of adults with autism without an ID and in the context of New Directions. There should be a clear outline of what is envisaged for a local community level service and the long-term role of the voluntary sector.

**Recommendations relating to next steps**

10. Bring together the HSE, relevant service providers and other stakeholders to discuss these recommendations in more detail ultimately leading to a policy advice paper for the government (the NDA could facilitate this)

# 1. Background

The National Disability Inclusion Strategy (2017-2021) sets out a programme of actions with the goal of ensuring a whole of government approach to advancing the social inclusion of all persons with disabilities. In 2015 a Programme of Additional Actions in relation to Autism (National Disability Strategy Implementation Plan, 2015) was developed, recognising that an increased understanding of autism across the public sector is required to ensure that the implementation of the plan address the needs of people with autism on an equal basis to other people with disabilities. These additional activities are included in the National Disability Inclusion Strategy. One of the actions in the plan is to identify models of good practice in effectively supporting the needs of adults with autism, without a concurrent intellectual disability (ID), living in the community. This report reviews some of the current issues surrounding autism in Ireland, describes some good practice models and makes recommendations for the enhancement of services for adults with autism, without a concurrent ID in Irish disability services.

Adults on the autistic spectrum are a heterogeneous group. Between 32% and 74% (Morbidity and Mortality Weekly Report, 2012; Bourke et al, 2016; Postorino et al., 2016), frequently cited as 50%, have a concurrent ID and between 8 and 20% of people with an ID have concurrent autistic spectrum disorder (ASD) (Bhaumik et al, 2008, Cooper et al, 2007, Matson and Shoemaker, 2009). This group generally require life-long supports that are provided by ID services. Of the 50% without an ID, some achieve professional qualifications, employment, and have generally very little need for services. Many others however, struggle with education, and finding and keeping employment, and may have health and social care support needs that are frequently not met.

# 2. Scope

This paper focuses on adults with autism without an ID living in the community. There is a lack of evidence with regard to the effectiveness of services for adults with autism. The literature review we started very quickly revealed that few service models for adults have been evaluated. Therefore, the focus shifted to finding models of service largely through a general web search, leading to this exploratory report which looks at Irish and international experiences and service developments for adults with autism without an ID. Some of the documentation does not differentiate between adults with autism with and without an ID and this report will highlight that where relevant. The focus is on health, social care and education services provided for adults with autism without an ID, which are in

the preventative and supportive realm, and will include limited focus on more general autism friendly services such as leisure and social activities. The NDA is conducting other pieces of work on employment, criminal justice and housing supports so these areas are not reviewed here.

The concept of good practice is hard to define. For the purposes of this paper it will include services that adopt a social approach to disability, that is, where persons with disabilities are supported to achieve independence, social inclusion and participation according to the individual needs of each person.

This document is written bearing in mind the existing Irish policies of taking a mainstream approach to disability services. In an NDA consultation with stakeholders (people with autism, parents and carers, autism service organisations) in 2014, some participants suggested the establishment of a separate service for people with autism without an ID (NDA, 2014). This, however, does not fit with the mainstreaming approach.

The paper begins by describing what is ASD and the prevalence of ASD in Ireland. It then presents the key issues followed by existing policies and services. The paper then presents some good practices in providing services for adults with autism. It ends with a conclusion and recommendations.

Some have suggested that the use of the term 'autism spectrum condition' in preference to autism spectrum disorder to avoid the 'negative overtones of the disorder label' and because the use of condition would still recognise that autism is a medical diagnosis for which individuals need support (Cassidy et al, 2014). However, as the standard terminology used in Ireland in all the research and reports reviewed is Autistic Spectrum Disorder (ASD) this paper uses 'disorder' rather than 'condition' throughout.

# 3. What is Autistic Spectrum Disorder?

ASD is a lifelong pervasive condition. The core difficulties are in social communication, social interaction and social imagination (Wing et al, 1979). In addition, many people with autism have sensory difficulties and unusually restrictive and repetitive behaviours and interests. While the core deficits are present throughout life the expression of these difficulties will vary with age and with the presence of other disabilities or the influence of life events.

The American Psychiatric Association classify autism as a 'Mental Disorder' in their official Diagnostic and Statistical Manual of 'Mental Disorders' (DSM) (2013). Their new classification system in the fifth edition of the DSM eliminates the previously separate subcategories on the autism spectrum, including Asperger

syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, childhood disintegrative disorder and autistic disorder. These are all encompassed under the broad term of ASD. Practitioners in the UK and Ireland tend to reference the International Classification of Diseases; Classification of Mental and Behavioural Disorders (ICD-10), which classes autism as a 'disorder of uncertain nosological validity' and where sub-categories including Asperger syndrome still exist. (WHO 1992). There is a campaign underway to retain the Asperger syndrome diagnosis in the forthcoming ICD-11.[1] The diagnosis of Asperger Syndrome continues to be used and recognised in Ireland.

The term high functioning autism (often called mild autism) is not included as a diagnostic category in either the DSM5 or ICD10. However, it is a term used to refer to people who meet criteria for autism but have an intelligence quotient (IQ) in the normal or above average range and are without a speech difficulty (A Vision for Change, 2006). However, the term is something of a misnomer as it includes a range of people from those who present with very challenging behaviour and who require a lot of support to those with Asperger Syndrome who may have no speech or learning difficulties and are capable of functioning in society with no or minimal support.  Therefore, in this report we refer to the main group of interest – adults with autism without an ID living in the community as 'adults without an ID'. Asperger Syndrome is a sub-group on the Autism Spectrum and usually refers to someone with autism without speech or learning difficulties but this term will only be used in this paper when it is referred to by a particular service.

A particular issue for adults with ASD is the invisibility of autism as a condition. Many people with autism do not have obvious physical signs of it and are sometimes therefore thought to interact in ways that may be considered unusual.

Interestingly some places, for example, Massachusetts in the US are proposing that they no longer use an IQ based eligibility requirement for day services for adults with autism. Instead, they will use a standard definition of a developmental disability that takes into account a range of limitations in adaptive functioning skills (The Massachusetts Autism Commission Report 2013).

## 4.    Prevalence of Autistic Spectrum Disorder

The most recent estimate of the prevalence of ASD in Ireland is 1.55% for school going children (National Council for Special Education (NCSE), 2015). The

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[1] http://asiam.ie/about-autism-2/aspergers-syndrome

prevalence of ASD has been increasing in recent years globally. It is unknown whether there is a true increase in the prevalence, but it is widely believed that the increase is due primarily to increased detection and broadening diagnostic boundaries. In the United States of America, the prevalence of parent-reported ASD was 2% (CDC, 2013).

While there are no studies on the prevalence of ASD in adults in Ireland estimates from the 2006 CSO disability survey suggest a prevalence of 1.1% in the overall population (HSE, 2012). This is likely to be higher now if consideration is given to the NCSE data mentioned above.  Figures from two surveys in England suggest a prevalence rate of 1.1% among adults (Brugha et al, 2009, Brugha et al., 2012). Analysis of data from the first survey suggested that cases are often underdiagnosed in the elderly, people with lower levels of functioning, those in paid employment and men (Brugha 2011). They also found that the rate of ASD is not significantly associated with age. Weakness with this study was its small sample size and that it only surveyed adults living in the community and not those in institutions. No other adult prevalence surveys have been identified.

In order to make a projection of the prevalence of ASD among adults aged 18-64 without an ID in Ireland we used two methods that are outlined in Table 1:

- Method 1- Applying the NCSE prevalence estimate of children with ASD (1.55%) to the adult population – estimate 23,079

- Method 2 – Applying the English prevalence estimate of 1.1% of adults with ID – estimate 16,379

**Table 1: Estimated number of adults aged 18-65 with autism without an ID in Ireland**

| Group | Number method 1 | Number method 2 |
|---|---|---|
| Number of people in Ireland aged 18-64[2] | 2,977,952 | 2,977,952 |
| 1.1% of people aged 18-64[3] | -- | 32,758 |
| 1.55% of people aged 18-64[4] | 46,158 | -- |
| Number with an ASD aged 18 to 65 within the overall national population without an ID (50% of total))[5] | 23,079 | 16,379 |

The second method is likely to be more accurate given the documented increase in the prevalence of autism in children in recent years that would not be reflected in adults. The male to female ratio is generally accepted to be 4:1 (Tsai, 1981). This would mean there are approximately13,103 men and 3,276 women with ASD between 18 and 65 years in Ireland without an ID. For each individual age group there are potentially 341 people with autism without an ID.

There seems to be a consensus that there are many older adults with undiagnosed autism who have not received any services and are largely supported by their families. In her paper on autism characteristics in older adults with depressive disorders, Geurts et al. (2015) found that 31% of older adults with a depressive disorder had increased ASD characteristics compared with 6% in the comparison group. The paper concludes that ASD might be overlooked in geriatric psychiatry and that those treating depression in older adults should consider ASD as a factor.  However, this is potentially a group of adults who will require support as their main supporters die and they may not have the skills to manage alone.

It is estimated that 0.5-1% of people with autism have savant syndrome, a condition in which a person demonstrates profound and prodigious capacities or

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[2] CSO Statbank 2016 population
http://www.cso.ie/px/pxeirestat/Statire/SelectVarVal/Define.asp?maintable=EY007&PLanguage

[3] Brugha et al, 2012, Brugha et al, 2009, HSE, 2012

[4] NCSE, 2015

[5] MMWR, 2012; Bourke et al, 2016; Postorino et al., 2016

abilities far in excess of what would be considered normal (Hermelin, 2001). The most common forms involve mathematical calculations, memory feats, artistic abilities, and musical abilities. There is a misconception that all people with autism have savant abilities. Not all people with autism have savant syndrome and not all people with savant syndrome have autism.

# 5. Challenges for adults with ASD in Ireland

One of the key reasons that support needs for adults with ASD without an ID are not met is that these needs are not assessed and therefore no investment is made to provide services (Higgins, 2009). Without this investment in services, no preventative interventions take place and therefore the government may end up funding expensive mental health services for adults with autism who experience a crisis (National Audit Office, 2009). In addition, if these adults drop out of further education or are unable to access or remain in employment they are at risk of being dependant on benefits, facing social exclusion, and not achieving their full potential.

Where assessment does take place, people with autism are often unable to adequately identify or communicate their needs and therefore those needs are not identified and supported. According to the Social Care Institute of Excellence (2011) in the UK, someone with autism may have a good theoretical knowledge about an issue and appear to have capacity, but in fact are not able to retain or weigh up the information. The National Audit Office, also in the UK, makes an economic argument for increasing diagnosis and support for people with ASD (2009).

Experience from the UK shows that most local authorities only provide services to people whose needs are in the substantial or critical bands which tends to militate against the provision of early intervention services (SCIE, 2011). It is also reported in the UK that only 16% of autistic adults are in full-time paid employment and only 32% are in some kind of paid work (The National Autistic Society, 2016). Although there are no data, the numbers in Ireland are likely to be similar.

## 5.1 Issues highlighted by stakeholders

In 2014, the NDA undertook a consultation exercise to find out how the National Disability Strategy Implementation Plan could most effectively address the needs of people with autism. The consultation included adults with autism, autism stakeholders, and completion of an online questionnaire for individuals and organisations interested in autism. With regard to adults with autism, there

were a number of key areas of concern for consultation participants, which included:

- Different rules in different parts of the system often mean that a person with autism loses supports when they move from one part of the system to the other. For example, having the support of a SNA in school but may have no, or much more limited, support when they go to third level.

- Lack of access to disability support services for people with autism if they do not have an ID.

- A legacy of under-investment in intervention from early in the person's life and particularly during teenage years resulting in people not achieving their potential

- An inconsistent range of services available.

- Loneliness and not having someone to talk to about his or her problems.

A review of autism services was undertaken by the HSE in 2017 which including a public consultation. However, the findings of that review are not available at the time of writing. However, submissions to a similar review in 2012 and a consultation with stakeholders highlighted a number of gaps in services and those of particular relevance to this piece of work are listed below:

- Lack of defined pathways for services and difficulties with access to adult services particularly for young adults transitioning from children's services or mainstream schooling

- Lack of multi-disciplinary intervention and supports within adult services, in particular psychological supports and behavioural therapy

- Lack of employment options

- Lack of family support services and in particular support for parents who are involved in caring for their adult children

- Lack of comprehensive information on the number of adults with ASD to support service planning

- The absence of information on services and entitlements and the difficulties encountered when engaging with many aspects of life such as seeking employment, housing and benefits

- Absence of choice in terms of service provision

The experience of stakeholders is exacerbated by the lack of awareness about autism among some social care staff, other professions and society generally. There is also a lack of skills and competencies among many staff who support

people with autism. Where relationships with professionals are established, a lack of consistency in staffing is frequent and can be difficult for people with autism. In addition, there is uncertainty around what a support package for adults with autism without an ID should be.

These findings are backed up by the literature. An SCIE research briefing (2013) found that adults with autism experience difficulties with access to social care, difficulties with transition periods, limited training for health and social care staff, and poor outcomes for adults on the autistic spectrum including isolation. An Irish survey of young adults with autism without an ID found that outcomes in adulthood is variable with some living very restrictive lives (Farrelley, 2001). It also found the following when parents were asked to outline the service needs of their adult children with autism:

- A structured lifestyle
- Reduced dependency on parents/family
- Employment where disability is recognised and understood
- Life-skills training
- Good-quality education
- Help in forming relationships and building self-esteem
- Access to appropriate training and courses to enable them to find appropriate work

## 5.2   Autism and Mental Health

Mental health difficulties are a common feature among people with ASD. Roughly 40% of people with autism are estimated to have symptoms of at least one anxiety disorder at any time (Skokauskas and Gallagher, 2012). Other studies have estimated that around 30% of adults with autism have obsessive compulsive disorder (Russell et al, 2013) and between 5% and 34% have depression. It is common to have both anxiety and depression together. Iemmi (2017) states that at some point in their lives, 80% of people with autism suffer from a mental health difficulty. Others have found that people with autism have a higher risk of suicide and suicidal ideation (Hirvikoski et al, 2016, Cassidy, 2014).

No evidence could be found as to the whether the rate of a psychiatric co-morbidity among people with ASD was higher in people with an ID or without an ID.  Mental health difficulties are difficult to diagnose in those with ASD. They can be over diagnosed due to overlap between autism symptoms and those associated with the mental health difficulty. Aspire, an Irish organisation that offers support and information to people who have Asperger Syndrome and their families, reports that some people have been misdiagnosed as having mental

health difficulties and were later diagnosed with autism.[6]  People with ASD and a mental health difficulty can see a worsening of their autism symptoms, which can interfere with their education and behaviour. Many of these mental health difficulties can be treated successfully with effective behavioural therapy and medication.

Autism stakeholder consultations identified lack of access to mental health services and needing to reach crisis point in order to access services as key concerns (HSE, 2012a, NDA, 2014). They called for mental health services to be specific to individuals with autism without an ID (Farrelley, 2001). A Health Services Executive (HSE, 2012a) review of Autism Services stated that

> 'The difficulties in accessing mental health services can be attributed to the lack of clear policy and pathways to mental health services for adults on the autistic spectrum. [...] Some adults with autism receiving services through autism specific services providers have also in many cases had their mental health needs met by arrangements specifically put in place by these service providers. Others have had to navigate their way through generic mental health services with difficulty.'

Ireland's mental health policy 'A Vision for Change' (2006) does not explicitly identify the needs of those with autism without an ID despite the known high prevalence of mental health difficulties in this group. The mental health needs of children with ASD and adults with ID are specified but not adults with ASD without an ID.

In their guide for parents on mental health in children and young people with autism, the National Autistic Society in the UK suggests that people with ASD may be more susceptible to experiencing mental health difficulties due to their feeling of not fitting in in their day-to-day lives. Often they are not understood and therefore remain unsupported. They may also have difficulty communicating how they are feeling and therefore their problems increase and are not dealt with early (National Autistic Society). In another study.

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[6] http://www.aspireireland.ie/cmsWP/reasons-why-you-might-need-a-diagnosis/

# 6. Existing services and policies

## 6.1 Getting a diagnosis of Autism

A diagnosis of autism is difficult to confirm in young children. Due to long waiting lists, many parents seek an assessment and diagnosis privately. Children are entitled to an assessment of their health and education needs arising from their disability under the Disability Act (2005). This process must be conducted in a timely fashion and is coordinated by the HSE. It results in an assessment report and a service statement. The assessment of need may include a diagnosis if that has not already been obtained. Children's disability services are being reformed as part of the transformation of the sector under the Progressing Disability Services for Children and Young People.[7]

For adults there is no clear pathway for getting a diagnosis of ASD. The Assessment of Need outlined in the 2005 Disability Act does not yet extend to adults. One route to diagnosis is to get a referral from a GP for a psychiatrist or clinical psychologist.[8] There can be long waiting lists in the public system and again some people will choose to get a diagnosis privately if they can afford it. It is recommended that adults seeking a diagnosis look for someone who is experienced in diagnosing autism and GPs or autism organisations may be able to make recommendations. Many adults would not have been diagnosed as children, as ASD was not well recognized and diagnostic tools were limited. However, some adults with autism may not have the insight or skills to seek a diagnosis, may feel that they have some problems but are coping ok, or may feel that a diagnosis will not make any difference to their lives and therefore do not see the point. The literature does not give any indication of what proportion of diagnoses are initiated by a health professional who suspects that a person has ASD. Aspire, the Asperger Syndrome Association of Ireland, gives reasons why someone might need a diagnosis of ASD as an adult. These are to:[9]

> 'Understand themselves. Learn about the condition and understand what areas they have difficulties in and why.

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[7] http://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/

[8] http://www.aspireireland.ie/cmsWP/peoplewithas/adult-diagnosis/

[9] ibid

Gain the understanding of others. Other people can be more empathetic when they understand that there is a reason for a person's difficulties.

Receive services appropriate to their needs. A diagnosis can allow a person with autism to seek autism-specific services or services from people who specialise in autism.

Joining the autism/AS community. Some people get support from meeting others with autism/AS either through autism/AS support groups or through the internet.'

The HSE envisages that in future, with improved assessment and diagnosis for children and clear pathways for accessing services, the majority of adults will have received their diagnosis of autism as children, and will have undergone assessment of future needs. The new systems under Progressing Disability Services for Children and Young People should help with this process. They will then undergo appropriate transitioning into adult services (HSE, 2012a). However, the HSE recognizes the need to develop a clear, consistent pathway for diagnosis for autism in adults and describes how a key worker/case manager would be assigned to the adult to arrange assessments, liaise with relevant agencies, coordinate services and provide information and guidance.

## 6.2   Residential Services

A number of the submissions to the HSE Review of autism services (2012a) indicated a lack of capacity and appropriateness of adult residential options for people with autism, particularly in their local area. This causes particular problems around the time of transition from child residential to adult residential services. It is also particularly difficult for families where the behaviours of the adult with ASD are challenging and are impacting negatively on other members of the family. The HSE reported that the number of new residential placements developed for adults with autism in recent years has been small in comparison to the number of places developed for adults with learning disabilities and has not kept pace with the emerging needs for this client group. Some residential service providers also provide respite services giving families and the person with autism a break.

## 6.3   Day Services

A census of day services for people with disabilities conducted by the HSE as part of the New Directions review of day services (2012b) identified 25,000 people in receipt of HSE-funded adult day services, with 357 adults identified as having a primary diagnosis of autism (1% of the overall day service population). It is likely

that there are also many adults using services with a secondary diagnosis of autism although this figure is not recorded. One hundred and eight locations were identified as providing day service supports to adults with autism but only 24 of these locations were providing autism-specific services with the remaining locations catering for a primary diagnosis of learning disability, mental health or physical & sensory disability. In addition to these day services, the HSE funded rehabilitative training for 2,798 people, of which 2.8% had a primary diagnosis of autism (roughly 78 people).

There is also information available from the 2017 School Leavers survey conducted by the HSE and NDA (unpublished). This study profiles school leavers who apply for a day service or rehabilitation training place in their final year of school or on exiting rehabilitation training. In 2017, of the 1,456 applicants 502 (34%) had an autism diagnosis. Of these, just over half 278 (55%) had autism and ID. Of the remaining 224 without an ID several had a co-existing mental health difficulty (n=64, 29%). It was reported anecdotally that some community health areas only accept applications from people who have an intellectual disability, which would prevent someone with autism without an intellectual disability from applying.

## 6.4   Employment and training supports

There is a range of employment and training supports for people with disabilities including autism to help with getting a job and staying in employment. The Department of Social Protection provides these supports through local employment services offices and Intreo centres.[10] SOLAS provides vocational training. The HSE is responsible for rehabilitative training that focuses on the development of an individual's life skills, social skills and basic work skills with the objective of enhancing the trainee's quality of life and general work capacity.

Other organizations assist specifically in helping people on the autism spectrum to find employment. Specialisterne is a consultancy that recruits and supports people with autism in a number of diverse workplaces.[11] Focus group participants from the 2014 NDA consultation felt that with access to a low level of support, such as a mentoring or counselling services, many people they knew could have remained in jobs or education and training courses.

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[10] Intreo is a service from the Department of Employment Affairs and Social Protection that provides a single point of contact for all employment and income supports.
[11] http://www.specialisterne.ie/#after_full_slider_0

## 6.5    Other support services

There are some examples of services provided for adults with autism without an ID. These include ASPIRE - the Asperger Syndrome association of Ireland which provides a helpline, support groups and career training and other supports nationwide.[12] The HSE funded ASPECT, part of the Cork Association for Autism, provides key workers who provide support and guidance on education, employment and social and communication skills.[13] Autism Initiative provides outreach services for people with Asperger Syndrome.[14] AsIAm provides general awareness raising around autism and promotes autism friendly spaces.[15] Although it would seem that the services provided are very valuable and appreciated there is no evidence that these services have been formally evaluated in terms of their effectiveness.

## 6.6    Policies

An Autism Spectrum Bill is currently (at the end of 2017) before the fifth stage of the Seanad. This Private Members Bill requests the Minister of Health to develop and implement an ASD strategy. A similar bill was introduced to the Dáil in 2012, and while it did not pass, it was instrumental in a programme of actions on autism being developed. These were incorporated into the National Disability Strategy Implementation Plan (2013-2016) and subsequently into the National Disability Inclusion Strategy (2017-2021). While these disability strategies set out actions for implementation by government departments and public bodies with the goal of ensuring a whole of government approach to advancing the social inclusion of all persons with disabilities, the additional programme of actions on autism were to ensure that these strategies address the needs of people with autism on an equal basis to other people with disabilities. The autism actions are in keeping with the cross disability, whole of government social model of disability approach set out in the disability strategies.

Reconfiguration of existing health and social care services for people with disability are currently underway through three main approaches:

• Progressing Disability Services for Children and Young People (0-18s)[16]

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[12] http://www.aspireireland.ie/cmsWP/

[13] http://corkautism.ie/aspect/

[14] http://www.asdi.ie/?tabindex=7&tabid=3297

[15] http://asiam.ie/

[16] http://www.hse.ie/progressingdisabilityservices/

- Time to Move on from Congregated Settings (HSE, 2011)

- New Directions Personal Support Service for Adults with Disabilities (HSE, 2012b)

In Ireland, health and social care related support services to adults with autism without an ID are primarily provided either directly by the HSE or by voluntary autism specific services providers (who are often funded by the HSE). However, many people with autism without an ID will not be accessing any service, some because they do not need it and some because they cannot obtain access. Only where specialist knowledge, skill or expertise is required are people referred to specialist services. Mental health supports can be accessed through the local primary care team structure. However, for adults with autism without an ID there are limited existing specialist services and those that do exist are often provided by the voluntary sector, frequently with long waiting lists.

The HSE autism review (2012a) looked at the UK Department of Health Autism Strategy which, similar to Ireland, promoted a mainstream approach with specific services and supports dedicated to adults with autism when necessary and which may be required to enable people with autism to use mainstream services effectively. It found that despite all the commitments in Fulfilling and Rewarding Lives, the UK autism strategy (2010), those planning and or operating front line public services generally still didn't have a good idea of how to ensure the service they deliver can include people with ASD. Many public servants, or those who deliver services on their behalf, assume that costly specialist responses are required to support people with ASD and have very little knowledge of how they would practically operationalise a support or accommodation for someone with autism.

The HSE review recommended several elements of service provision as being key for development and improvement of services for adults with ASD (2012a). Ongoing education/training and support for families, service providers and professionals working with adults with ASD is crucial so that those delivering services have the necessary knowledge, understanding, experience and skills to deliver the service and supports to the individual. It is also important so that they can make reasonable adjustments for adults with autism. Appropriate transition arrangements were also highlighted recognising that there should be minimal barriers to move between services and supports. However, the review has not really translated to policy, and many of the recommendations of the HSE review seem to be outstanding.

## 6.7    Gaps in services and policies

There is currently an underdeveloped service response for adults with autism as highlighted in the HSE review of services and the concurrent stakeholder

consultations (2012a, NDA, 2014). This is partly due to the lack of knowledge of the number of adults with autism, their location and their needs. Funding of services tend to be relatively short term without thinking of the longer term benefits that may accrue, for example, investing in a child with autism will pay dividends as an adult. The concept of spending now to save later or to achieve savings in another sector is not always encouraged and can be challenging for policy makers (Iemmi, 2017). Iemmi outlines how it is necessary to take a life course view, which extends to the funding of services but also acknowledges that performance targets may mitigate against this approach (2017).

There is a growing cohort of people with autism coming through the school system, which needs comprehensive planning around supporting transitions and provision of services for the range of varied needs, many of which will not suit the traditional day service model. This planning model has been developed and is in the early stages of implementation. There is a lack of expertise throughout the mainstream health and social care system in dealing with people with autism as indicated in the feedback from autism focus group participants. There is a lack of supports for those who drop out of school or work. For example, there is no clear system of support for people with autism who left school and pursued third level education but did not cope and dropped out. There is currently no comprehensive mapping of autism services in Ireland and little evaluation of existing services.

There is also a lack of data in Ireland on the costs of care for people with autism and the lack of this data makes cost effectiveness studies of certain interventions more difficult. Having more specific cost data would allow the development of a stronger evidence base to be used by policy makers in deciding how to allocate resources. The cost of supporting an individual with an ASD without intellectual disability over their lifetime was $1.4 million in the United States and the United Kingdom (£0.92 million) (Buescher, 2014). Costs were driven by special education services and parental productivity loss for children and residential care or supportive living accommodation and individual productivity loss in adults. The study found that 90% of the overall cost of autism arose in adulthood (2014).

## 7. Models of good practice in autism services

Although there is a lot of evidence that early intervention for children with autism improves outcomes, this is often hampered by inflexible and reactive services. For a diagnosis of autism to be useful, there is a need for it to lead to appropriate, personalised services being assigned, which is not always the case. For example, for an adult receiving a diagnosed of autism, a diagnosis may make

no difference to his life unless he receives supports or services that improve his life. People with autism often have complex and highly individual needs that are hard to accommodate in services delivered to groups of people (Beadle-Brown et al, 2009). While there is a shortage of strong evidence about which services work best for people with autism, indications are that specialised and individualised services achieve better outcomes (Mills and Francis, 2010).

The National Audit office in the UK found that some of the difficulties faced by people with autism could be addressed or reduced if low-level, often relatively inexpensive services were provided promptly (2009). They also found that effective support could substantially reduce cost. However, the cost of autism in the UK was estimated at £32 billion in 2014 (Beuscher et al, 2014), an increase from £28 billion in 2007 (Knapp et al, 2009). This led Iemmi to conclude that despite years of programmes, strategies and initiatives in the UK, the needs of autistic people are still unmet and the expected economic dividend never materialised (2017).

This report found that the evidence base for the effectiveness of many support practices and interventions in current use was limited or of poor quality. The sections below explore some models of good practice across mainstream public services, dedicated autism services and normal daily life.

## 7.1 Good practice in making public services more autism aware and autism friendly

### 7.1.1 Multi-agency planning

Services are often organised in a way that prevents people with autism from being able to access the supports they need. They are often neglected in service planning particularly if they don't have a concurrent ID or mental health difficulty as support for adults with autism usually stem from these services. Adults without these concurrent disorders may fall between the gaps created by traditional service boundaries and are not eligible to access support. To address these issues Higgins outlines how local authorities in England are increasingly developing autism planning groups to facilitate integrated planning (2009). This move has been driven by the 2010 English autism strategy. The strategy recommends that a joint commissioner across health and social care chairs the groups and includes family/carers, learning disability and mental health commissioners, relevant local authority and health managers, voluntary sector representatives, and children and young people's services representatives. Housing and employment services representatives may also be invited.

In Gloucestershire, an ASD partnership Board was set up in 2006 following a needs identification conference. Its focus was on unlocking mainstream agencies

in order to develop better support for adults with autism. They implemented a training programme at local level and developed a clear pathway to assessment and diagnosis. Leicestershire and Rutland formed a similar ASD Planning Group. It focuses on strategic planning to enable fair access to services for adults with autism. Their main achievements were developing a clear pathway for people to access community care assessments and developing a training framework for community professionals (Higgins, 2009).

### 7.1.2  Mentoring, buddies and counselling

Mentoring, life coaching, buddy systems and counselling were mentioned in consultations with autism stakeholders as possible supports that would help people with ASD to navigate daily life and social situations. In the review of autism strategies and policies in various countries, the Netherlands was proposing that the post of life-coach be made a permanent feature of the care provided to people with autism.[17] The support needs for people with autism vary considerably and for some, support with tasks such as paying bills and filling out forms, can make the difference between living independently and getting into debt (SCIE, 2011). The National Audit Office's research found that specialist advocacy befriending services and support within the criminal justice system all have the potential to improve outcomes for people with autism (National Audit Office, 2009). However, evidence as to the effectiveness of these schemes is limited, but anecdotal evidence would seem to be that they do work.

It is important that the people with autism can choose who supports them (SCIE, 2011). The most effective way to deliver occasional counseling and support to adults on the autism spectrum without another diagnosis remains uncertain although the specialist teams and One-Stop-Shops described later in this document may provide an appropriate mechanism. However, where these do not exist there is a limited amount of self-referral and affordable options.

The Asperger Autism Network's Life Management Assistance Program in the US [18] provides life coaches to help clients with Asperger Syndrome identify their strengths and overcome barriers. It aims to improve quality of life, increase independence and help people with autism reach their full potential. It is currently being evaluated.

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[17] NDA internal draft. Autism strategy/arrangements. NDA 6 country review. 2014

[18] LifeMAP http://www.aane.org/about-us/programs-and-services/adult-programs-and-services/lifemap-coaching/

### 7.1.3 Co-ordinator/Key worker

A co-ordinator or key worker is mentioned in several strategies such as in England (Department of Health, 2010) and Norway[19]. Their role is to ensure that one person has the main responsibility for follow-up and coordination at all times with regard to accessing services. The quality measures for autism by NICE (2012) relate to evidence of local arrangements for people with autism to be offered a named key worker to coordinate the care and support detailed in their personalised plan. Several organizations report using this approach but there is no evidence of its effectiveness for example in terms of outcomes for the service users.

There are some arguments against a key worker model. It implies on-going service even if not needed and is likely to be costlier, and less replicable, than a drop-in or self-referral model as provided by some of the One-Stop-Shops and specialist teams described later in this document. An obvious advantage of the key-worker system is the ability to provide more targeted individualised support and the building of a relationship, which is important for people with ASD. However, there is no research on the effectiveness of different types of models.

Some consultation event participants indicated that some people with autism would need support from a community connector for them to be able to participate in mainstream community activities. This role is becoming more important as services become more community based.

### 7.1.4 Good transition support

Good services and supports for people with autism should carry through to supports at times of transition such as leaving school or college and starting a job or changing accommodation. Although important for all people with a disability, aspects of autism can make transition particularly difficult for many reasons. These include the lack of a structure, difficulty with change, inability to conceive a possible range of options, limited adult services or education options available, and dealing with personal relationships (Mills and Francis, 2010; SCIE, 2011; Taylor and Marrable, 2011). If transition for people with autism goes badly they can be stuck in poor quality services and have limited independence (Department of Health, 2009). According to Higgins (2009), good practice during transition needs to include:

- Full involvement of young people with autism and their families in multi-agency transition planning

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[19] NDA internal draft. Autism strategy/arrangements. NDA 6 country review. 2014

- Respect given to the preferences of young people with autism
- Better information given to families as young people approach transition
- Better communication between adults and children's services.[20]
- Training in autism for transition staff
- Attention to the needs of young people with autism who display challenging behaviour
- Differentiation in assessments between support needs and education needs so that people are not put on academically limited courses due to their communication difficulties

### 7.1.5 Student supports

Transition to third level education is a key area where support is often required for people with autism. Colleges are becoming more aware of this and are increasingly offering tailored supports. Trinity College Dublin has seen a huge increase in students with ASD. They are using supports from the Disability Service and occupational therapy service who have developed a model of support for students with ASD, which aims to support the students at all stages in their student journey from College entrance to graduation and employment.[21] Dublin City University is aiming to become Europe's first autism-friendly campus and is including many of the good practices listed below.[22]

A College Inclusion Charter, developed in the UK by Ambitious About Autism (2012) as part of the Finished at School Campaign, aims to get colleges to commit to delivering quality education opportunities to learners with autism and other disabilities. The charter includes eight actions that colleges can take to improve their services to young people with disabilities, which include supporting transition, flexibility, inclusive teaching methods, reasonable adjustments, social supports, and a whole college culture and ethos of inclusion.

The Finished at School group developed a document highlighting good practice in colleges. Many of the examples pertain to planning for the transition from post-primary to third level education. Key approaches recommended by the colleges were to be as flexible as possible in designing learning programmes and to be led by the aspirations and needs of each individual learner rather than by structures within the college. They also recommended building relationships with local

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[20] Some local areas in the UK are placing children with disabilities staff within adult teams to promote joint working. Others are adopting a 'single trusted contact' model. Research is needed into whether approaches like this can be effective in improving outcomes.

[21] https://www.tcd.ie/disability/services/ASD-Support.php

[22] https://www.dcu.ie/news/2016/jan/s0116j.shtml

employers, supported employment providers, and adult services, to support a successful transition out of college and into work or independent living. They also highlighted the importance of including leadership teams in training on inclusion and disability to ensure the culture of inclusion starts at the top and filters through the college.

Several of the colleges included in the good practice document highlighted how they supported people with autism in every aspect of college life including learning, socialising, gaining independence, career development, and how they worked with students to ensure their efforts were inclusive. Some specific examples of good practice and reasonable accommodation included in this guide and elsewhere (Emerson and Robertson, 2008; SCIE, 2011) are:

- break clubs before and during college
- a buddy and mentor system
- a dedicated 'meeting and greeting' area at the college reception
- personalised curriculum, including late starts or early finishes as required
- availability of a personal tutor
- support around organizing time e.g. accessible timetables
- feedback diaries and plenary recaps
- staff autism awareness training
- disability awareness events
- supported social interaction through the use of a social room
- parent and carer support group
- taster sessions so that learners can try different courses
- Asperger social group
- quiet periods in the Fresher' Fair
- web-based courses
- pastoral support from trained staff
- information provided in clear and literal language, including in exams
- providing extra time for coursework
- support around organising time
- extra support around exam time and other periods when routines change
- making specific teaching and learning accommodation arrangements, taking into account sensory sensitivities for example, 'low arousal' classrooms

The colleges reported several positive outcomes including increased retention, achievement and enrolments of people with disabilities. They also reported happy students who were more confident, willing to share ideas, supportive of each other and ready to take on new and exciting challenges. The students made a positive contribution within the local community and interacted with a mix of people, which was crucial to their personal and social development. The colleges

also reported that parents and carers have developed a trust in the organisation to teach and care for their young people. The college formed sustainable partnerships with schools, colleges, local authorities, housing associations, employers and local communities. This has led to tangible benefits: improving outcomes for learners, promoting social and economic inclusion and well-being, enriching lives and demonstrating value for money.

### 7.1.6  Staff training

Autism education and training must be available at a range of levels to suit a range of staff development needs from basic awareness through to advanced specialist knowledge. Generic awareness raising can be done as part of general disability training for staff or as a stand-alone training. For example, during 2016 the NDA facilitated train the trainer sessions conducted by an autism support and education organisation, AsIAm,[23] to enhance autism awareness and customer service within the public sector.  Autism education should be a core part of the curriculum for several health and social care professionals. Continuing professional development courses should be available for people who will be working more directly to support people with autism that focus on dealing with people with autism within particular situations or environments. Professional forums for sharing experience can also be valuable.

However, there are limited courses available to acquire in depth knowledge for those who need it. Centres of excellence such as in Middletown Centre for Autism[24] could provide a model for providing training and sharing experience for relevant professionals working with adults with autism. While Middletown is focused on education, there could be scope either to expand or to develop other centres of excellence in other areas such as challenging behaviour or employment support, which would be assessable to a wide range of professionals.

The literature reports that training is often done inefficiently with an ad hoc approach without an overarching planning and coordination of training (Ravet, 2012). SCIE in the UK recommends that commissioners should insist that good autism training is built into the services they purchase (2011). Some of the key principles that training should include are as follows (SCIE, 2011; Taylor and Marrable, 2011; Ravet, 2015):

- Follow up after training to ensure that the practitioners are supported in changing practice

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[23] https://asiam.ie/

[24] https://www.middletownautism.com/

- • Practitioners should be able to form an 'autism lens' through which they can recognise and make sense of the behaviour and responses of clients
- • Practitioners should be able to develop appropriate interventions and reasonable adjustments to meet the needs of people with autism
- • Include input from people with autism and their families
- • Raise awareness about autism without an ID
- • Include management staff in training so that they can anticipate the impact of the organisational structures, processes, environment and resources upon clients with autism, and make executive decisions about appropriate adaptations across the workplace to ensure consistency and coherence

During the NDA consultation with autism stakeholders in 2014, some 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.

## 7.2 Good practice in dedicated autism services

### 7.2.1 A menu of interventions

The Scottish Government Autism Strategy (2011) recommended that agencies and services developed a menu of interventions for advice, therapeutic intervention and counselling supports for people with an ASD. The group tasked with developing the menu took an innovative approach and, rather than listing the myriad of interventions available, they took a needs based approach. Firstly, they looked at the challenges people on the autism spectrum face, secondly they looked at the needs arising from these challenges, thirdly they looked at the types of service provision required to address these needs, and finally they looked at the gaps in existing services. They gave examples of how this method could be used for an individual and how the gaps in services could be filled over time (Meil-MacLachlan, 2013; The Scottish Strategy for Autism, 2013). The menu of interventions can be found in Appendix 1 and includes a variety of interventions ranging from post diagnostic discussions and individualised counselling, to targeted social communication programmes, access to social groups and friendship circles, work on assessing behaviour and recognising triggers and developing behaviour support plans, and career guidance.  The authors were unable to make evidence based recommendations on these interventions due to a lack of research but included interventions that are being widely used in practice and which appear to have success. The interventions are relevant to all with ASD regardless of whether they have an ID.

### 7.2.2 Specialist Autism Teams

The English autism strategy proposed the introduction of a range of specialist services for people with autism, built around specialist autism teams (2010). These teams aim to provide local specialist expertise to mainstream services. Teams often consist of a social worker, training coordinator, autism employment adviser, clinical psychologist, therapist and community psychiatric nurse. The strategy also recommended sub-regional centres of excellence, which can provide a collaborative approach by pulling together services and expertise across local statutory agencies and the voluntary sector.

In Nottinghamshire, both the NHS trust and the adult social care departments have established autism specialist teams. The health team is made up of a clinical psychologist, occupational therapist, and speech and language therapist, and focuses on multi-disciplinary diagnostic assessment and post-diagnostic support. The social care team, made up of five social care staff, provides specialist assessment, care management and short-term interventions. The team also provides social and emotional support and assistance with employment and accommodation. The team is able to offer community care assessments by assessors who have a good understanding of autism (Higgins, 2009). It is not clear whether the specialist team is specific for adults with autism without an ID or for all those with autism. Higgins also describes a specialist team in Oldham, which was specifically set up to target vulnerable adults with autism who do not have an ID or a mental health illness.

Scotland also developed specialist autism teams. In the Greater Glasgow and Clyde health authority in Scotland, in response to an increase in referrals, the Adult Autism Team developed a new partnership-working model. Adults with autism were enabled to make informed choices about how they led their lives, and how and when to draw on different types of support (Gallagher et al, 2013). The programme, targeted at people with autism without an ID, aims to improve their understanding of their condition such as:

- Identify strategies to enable them to keep themselves healthy and safe,
- Recognise when they may benefit from supported self-health
- Access a service appropriate to their needs at the right time.

The team facilitates access to mainstream services and a large part of their work is supporting adults with autism who are not currently receiving support from any other service. The team comprised a clinical lead who was also a speech and language therapist with expert knowledge of autism, four clinical autism specialists and limited time from two consultant psychiatrists.

Those who receive a diagnosis of autism or those previously diagnosed are offered a place on a post-diagnostic group course that discusses issues such as social interaction, stress and anxiety. Follow-up consultations are then held to help participants to develop a 'Living for Today Success Plan', which supports participants in understanding where sources of stress and anxiety exist in their lives so that stress-reducing coping strategies may be identified and developed. The service also provides 'easy-in, easy-out' advice surgeries. These are self-referral clinics with a presenting difficulty, which usually manifests itself as stress and anxiety. The team helps to work through the problem and develop possible solutions. Common challenges presented include the breakdown of relationships, the death of a close family member, a change in employment status, disputes at work, with neighbours or family members, and physical illness. The person with autism is usually seen within a week or two and usually requires two or three one-hour sessions. Sometimes onward referral will be required and the autism team offers joint working with the other professionals. These surgeries are considered essential in keeping people with autism healthy and safe.

Feedback from the target group of adults with autism, who are not receiving another service and who have been involved in the programme, have been very positive. However, there has been no formal evaluation conducted.

Research conducted by the National Audit Office in England found that supporting more people with autism without an ID (through specialist autism teams) quickly becomes cost neutral and can potentially lead to long-term savings (2009). These savings come from higher tax incomes and reduced benefits payments as people are supported into employment. They also come from reduced carer, mental health, and criminal justice costs through supporting people before they reach crisis points in their lives. The key determinants of whether such benefits are realised were:

- the proportion of the local population with autism without an ID which the service could identify

- the proportion of its clients in supported housing or residential care who could more cost-effectively be cared for in private households

- the proportion of its clients finding employment

Although the data are limited, evidence from the report suggests that people with autism without an ID who have access to these teams have better outcomes, such as they:

- find getting a diagnosis easier

- lead more independent lives

- are more likely to work

- are less likely to have mental health difficulties

- are more likely to have carers who are in work (i.e. parents or other carers have not had to give up their jobs to care for the person with autism)

- are less likely to be in residential care

As outlined in table 2 the report estimated that if established autism specific services identified and supported around 4% more adults with autism without an ID in their local area, they could over time become cost-neutral for overall public expenditure. Increasing the identification rate to 6% could lead to potential savings of £38 million per year, and an increase to 8% to savings of £67 million. There are no similar economic estimates in Ireland.

**Table 2: Estimated savings from increasing autism specific services**

| Increase autism specific services to adults with autism without an ID | Result |
|---|---|
| 4% more adults | Become cost neutral |
| 6% more adults | Save £38 million |
| 8% more adults | Save £67 million |

Source: National Audit Office, 2009

Despite these positive examples of the specialist teams and the findings of the National Audit Office, the National Institute for Clinical Excellence (NICE) in the UK found little evidence to guide the establishment and development of these teams (NICE, 2012: 41). It found

> '...uncertainty about the precise nature of the population to be served (all people with autism or only those who have an IQ of 70 or above), the composition of the team, the extent of the team's role (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), the interventions provided by the team, and the team's role and relationship with regard to non-statutory care providers. Therefore, it is likely that in the near future a number of different models will be developed, which are likely to have varying degrees of success in meeting the needs of people with autism.'

NICE recommended a large-scale observational study, which should provide important information on the characteristics of teams associated with positive

outcomes for people with autism in terms of access to services and effective coordination of care. There is no information as to whether this recommendation is being advanced.

### 7.2.3 One-Stop-Shops

Following a pilot of two One-Stop-Shops in Scotland, a further six were developed under the Scottish Autism Strategy (2011). These One-Stop-Shops aimed to prevent unnecessary referrals of people with autism to more specialist settings by providing support and linking service users to relevant mainstream services. As well as acting as an information hub for people with ASD and their families, they work closely with other groups and agencies collaborating to understand and respond to the needs of the autism community. The term 'one-stop-shop' can be a bit misleading, as it does not mean that all autism services are delivered from a central location. Rather, it works to enhance the capacity of other services as well as the capacities of the people who access them. Tait et al (2013) have suggested a 'first-stop-shop' or 'autism hub' as better terms.

The approach is based on two assumptions; firstly, that the provision of reliable and accessible locally relevant information is used by services users, their families and service providers as a valuable means to improve outcomes. Secondly, by providing timely preventative services to those who are not usually in receipt of direct service provision can significantly reduce the costs of support later. Tait et al (2013) have reported how in the eight years of operation, the two original One-Stop-Shops (Edinburgh and Glasgow) have demonstrated a consistent and steadily growing demand on the services they provide. One of the success factors was the embedding of a high level of involvement from service users and their families from the start. While a final report is not yet published on the six new One-Stop-Shops, feedback from service users have been positive and it seems as though the pilots were a success. The issue now seems to be around sustainability and continued funding.

The one-stop-shops provide a range of services with four examples provided below and in table 3. An example from Ireland and England are included in addition to two from Scotland. Although the Irish and English services do not identify themselves as One-Stop-Shops the services they provided are similar.

- Aspect –Asperger Syndrome Support Services run by the Cork Association for Autism. This was set up as a small pilot project in 2007 and now caters for 250 clients with Asperger Syndrome or ASD without ID. Each client has a key worker who he or she meet with regularly for support.[25]

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[25] http://corkautism.ie/aspect/

- Matthew's Hub –Hull, England. Families for Individual Needs and Dignity (FiND). This charity was set up in 2000 to meet the needs of people with high functioning Autism and Asperger Syndrome.[26]

- The Lanarkshire one-stop-shop was one of the six new pilots set up by the Scottish Government. A self-evaluation using the Learning, Evaluation and Planning Framework found that the service had high demand and that it was an invaluable resource to families and professionals. Unfortunately, this project ended after three years funding as local funding did not materialise. (Scottish Autism, 2016) [27]

- The Autism Resource Centre in Glasgow was one of the original One-Stop-Shops set up by the Scottish Government and has now been operating for 10 years. It is a partnership between Glasgow City Council, NHS Greater Glasgow, the Scottish Society for Autism, the National Autistic Society and Strathclyde Autistic Society. An evaluation after the first two years (2004-2006) found that 87% of people with autism who used the service felt that their overall experience at the Centre was 'very positive' or 'positive' (Marwick and Tait, 2006). Most found that the service met their needs and that it is the one safe place they can go to relax and be understood and they outlined a range of benefits from their contact with the centre. Most parents and carers (69%) felt that their overall experience of the Centre was 'very positive' or 'positive'. The results indicated that the Centre is meeting its aims in relation to service users.[28]

The One-Stop-Shops vary in whether they provide services for people with autism with an ID. While some clearly do not and concentrate on those with autism without an ID, for example, Aspect and Matthew's hub, others such as ARC include people with autism and ID in their services and the Lanarkshire one-stop-shop provides separate sessions for adults with autism without an ID.

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[26] http://matthewshub.org/

[27] http://www.scottishautism.org/services-support/support-families/one-stop-shops/lanarkshire-one-stop-shop

[28] http://www.autismnetworkscotland.org.uk/autism-resource-centre-arc-the-glasgow-one-stop-shop/

## Table 3: Profile of services provided by selected One-Stop-Shops

| Services provided | Aspect (Cork, Ireland) | Matthew's Hub (Hull, England) | Lanarkshire OSS (Lanarkshire, Scotland) | Autism Resource Centre (ARC) (Glasgow, Scotland) |
|---|---|---|---|---|
| Adults only | X | X | | X |
| Self-referral | X | X | X | X |
| Promoting independence | X | X | X | X |
| Link with statutory services | X | X | X | X |
| Information/advice | X | X | X | X |
| Counselling | X | | | |
| Social / communication skills training | X | X | X | X |
| Courses/workshops/seminars | X | X | X | X |
| Volunteering and work | | X | X | |
| Drop in service | | X | X | |
| Support to relatives | X | | X | X |
| Sensory integration interventions | X | | | |
| Social groups | X | | | X |
| Online social networking | | X | | |
| Regular social outings | X | | | |
| Advocacy | | X | | |
| Diagnosis and assessment | | | | X |

## 7.2.4 Services for children with autism

There are many innovation and developments of services for children with autism particularly in education. The Middletown Centre for Autism in County Armagh is one such example. The decision to establish the Centre came about through the North-South Ministerial Council, which endorsed the agreement, which had been reached between the respective Departments of Education north and south. The centre, which focuses on the area of education in children, recognises the need to address the increasing prevalence of Autism Spectrum Disorders on the Island of Ireland, recognise good practice, and support and complement current services. It does this through research, training of parent and professionals, and advice and guidance to individual children. This approach could

have the potential to be replicated for adults. For example, a centre with a focus on employment and autism could deliver the same type of training and sharing of best practice in addition to offering job-coaching services.

### 7.2.5 Accreditation and standards

A number of autism accreditation organizations exist across the developed world (European Platform for Rehabilitation, 2009). Accreditation is a means to gain objective recognition of quality, to distinguish the organisation and benchmark at national or international level. It also offers a framework for quality improvement within the organisation. Most accreditation is based on a level of self-examination followed by either a formal peer review or specialist accreditation body review. Standards are set using expert opinion in consultation with stakeholder groups with particular emphasis on the participation of clients with autism. They can help identify both good practice and service gaps, which should lead to service improvements. The British National Autistic Society is the most advanced and most recognised organisation running an autism-specific accreditation programme of service provision and is associated with high standards of excellence.[29] Some service providers in Ireland have achieved accreditation from this body.[30]

Some autism consultation participants from the HSE review of autism services suggested that a mechanism needs to be in place to hold service providers to account and to monitor quality and effectiveness of the supports they are provided to people with autism in a variety of different service settings (HSE, 2012a). The Health Information and Quality Authority in Ireland has responsibility for the regulation of residential services for people with disabilities but does not have a role in regulating standards for other services provided by disability service providers such as autism-specific non-residential services. The National Institute of Clinical Excellence (NICE) in the UK have developed guidelines on best practice advice on the care of adults with autism and an associated pathway (NICE, 2012).[31] It outlines how to develop and manage local care pathways and how these care pathways can promote access for adults, promote a range of evidence-based interventions, and be integrated across all care settings.

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[29] http://www.autism.org.uk/professionals/accreditation.aspx

[30] http://www.nuahealthcare.ie/accreditation

[31] http://pathways.nice.org.uk/pathways/autism

## 7.3    Good practice in making normal daily life more autism friendly

### 7.3.1  Autism friendly environments

In the service context an autism friendly environment has been defined by Ravet (2015: 105) as

> '...a service context in which the physical, sensory, social, communication, learning and organisational environments have been purposefully modified, using the autism lens, in order to maximise the inclusion and well-being of individuals with autism.'

The Irish Disability Act (2005) aims to promote equality and social inclusion and therefore the provision of autism friendly services should be a priority for all professionals. Specialist knowledge of autism is a key requirement for the development of an autism friendly service. Over the past year, the NDA has been advancing work under the Programme of Autism Actions to improve services available to people with ASD through fostering a better understanding of autism. It has revised the Code of Practice on Accessibility of Public Services and Information provided by Public Bodies,[32] with the specific aim of including a focus on autism. The NDA has also developed guidance for justice professionals and housing officers on communicating with people with autism, and is in the process of developing guidance for line managers in employment settings.

### 7.3.2  Autism card

A number of Autism Support Groups have developed an autism card. For example, Irish Autism Action has a card that allows a person to be identified with ASD.[33] It is recognised by many state bodies and organisations that will provide specific services to people with an ASD, for example, Dublin Airport. The card can be presented to staff in all kinds of situations where communication is difficult for the person who has an ASD, or there is the risk that their behaviour might become inappropriate or open to misinterpretation. Cards may be specific to a jurisdiction so may be of limited application for some. In addition, some people do not want to disclose that they have an ASD due to stigma and they want to appear neurotypical so these cards do not benefit everyone.

In Scotland one of the autism specialist teams supported people with ASD to develop an 'Individual Guide to Successful Interactions' (Gallagher, 2013). This

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[32] http://nda.ie/Good-practice/Codes-of-Practice/Code-of-Practice-on-Accessibility-of-Public-Services-and-Information-Provided-by-Public-Bodies-/

[33] http://autismireland.ie/autism-id-card/

laminated card can be shared with service providers and others to optimise communication exchanges and make communication less challenging. For example, the guide may say 'Please don't touch me without warning' or 'More than one person speaking at a time is very stressful'.

### 7.3.3 Assistive technology and the internet

Face to face communications can be particularly challenging for people with ASD. The internet can therefore provide a medium in which people can exert more control over the timing pace and flow of both giving and receiving information. Interacting online may have real benefits for many people with autism and service providers should therefore look to this as a method of communication (SCIE, 2011). Mental health services in particular have adopted this approach. Silver Cloud offers on-line supportive programmes for a range of mental and behavioural health issues with content that is designed to be motivational, easy to use, relevant and interactive.[34] Other examples include Aware[35] that provides on-line discussion forums, Help-Link[36] that provides on-line or phone counselling and HeadStrong[37] that provides a text service. The UK autism research charity Autistica[38] are working on the development of an app for people with ASD to self-manage their anxiety.

With the increase in technology in recent years, the use of assistive technology for people with autism is increasing. Portable organisers, personal digital assistance, smart phones or tablets can be useful as cognitive aids and to aid in communication. Applications (apps) specifically to address the communication difficulties experienced by people with autism have been developed such as Avail[39] and there is an app called Autism Apps, which contains a list of apps suitable for autism, which provides descriptions and reviews. No evidence of the usefulness of these approaches specifically for people with ASD have been reviewed but they seem to be broadly welcomed by autism stakeholders.

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[34] http://www.silvercloudhealth.com/

[35] http://www.aware.ie/

[36] http://www.helplink.ie/

[37] http://www.headstrong.ie/

[38] https://www.autistica.org.uk/research/mental-health/

[39] http://www.availsupport.ie/

# 8. Research

Lack of evidence about effectiveness and cost-effectiveness of interventions to support people with ASD can lead to a waste of effort and resources when scarce resources are invested in interventions that do not work. In general, there is a clear need for large scale systematic and rigorous peer reviewed research on the best social care approaches for adults with autism without an ID. Iemmi and colleagues (2017) highlight the lack of funding for research and acknowledge that some researchers appear to over-claim the relevance of their findings. Piven (2011) reports on the research gaps for older adults with autism and suggests that this group may have more need for services and supports as their primary carers die. Some of the research gaps identified by Iemmi and Piven are as follows:

- There is a need to develop better and more specific diagnostic tools that are adult specific and are based on adult symptom profiles and not on historic childhood data which may not be available for older adults

- More descriptive and other studies using epidemiological population-based samples should be conducted

- More investigations into co-occurring morbidities such as epilepsy

- More long-term studies of interventions looking at effectiveness at different ages

- Develop, test and evaluate new models of care (including long-term care) based on the specific needs of older adults with ASD

- Develop and promote mechanisms to support training in research on aging in people with an ASD

# 9. Conclusion and recommendations

In general, there is a lack of research, and a consequent lack of evidence, around the optimal configuration of services and the most effective and efficient supports that are required to ensure that adults with autism without an ID can live as independent and fulfilling a live as possible. There is some evidence that a relatively low level of ongoing support for adults with an ASD can prevent anxiety and distress, and negate the need for more expensive crisis support later. While One-Stop-Shops and specialist autism services have had some success in doing this, their structures and functions vary and they struggle to retain funding. In the Irish context, few services were identified for people with autism who may

require low-level or preventative services. The evidence from the UK, although weak, mostly focuses on specialist services to support mainstream services and suggests that, despite the need for an initial investment, the investment will be cost saving in the long term. More evidence is needed about how specially trained multi-disciplinary or multi-agency approaches work but they currently suggest a promising way forward.

The lack of a clear pathway to diagnosis and assessment for adults with autism needs to be addressed. While this should resolve over time as autism is increasingly diagnosed in childhood, there is a need for some action now. Examples from the UK of diagnosis, assessment, and subsequent supports provided by specialist teams may be required in Ireland.

The policy in Ireland is for mainstreaming services for people with disabilities including ASD with services and supports that are more specific provided as necessary. However, in reality the majority of people with autism without an ID use mainstream services but are either experiencing gaps in services or are unable to access these services. The HSE also currently funds some specialist services for people with autism without and ID but based on feedback from stakeholder consultations there remain many gaps and these services are not provided evenly throughout the country. It would be beneficial to know both the number of people with autism without an ID with an unmet need for services and to define which services for people with autism without an ID should be provided by mainstream services and which by specialist services. It would also be useful to conduct a formal evaluation including a cost effectiveness analysis of existing specialist services for people with autism without an ID. All this information would allow a discussion with commissioners and providers of services to determine the opportunities for a more systematic provision of services for this group of adults.

For autism services to be successfully embedded in existing services there is a need for extensive training of service providers. This includes both autism awareness training as part of routine disability awareness training and more comprehensive training for those who will be providing more in-depth services for adults with autism.

A number of recommendations are provided below based on some of the gaps identified in this report.

## Recommendations

### Recommendations relating to research and evidence

1. Estimate the number of adults with autism without an ID, both receiving and not receiving supports and include the number of undiagnosed adults who may require support in the future. This would include conducting an extensive mapping exercise of who is currently receiving services (the NDA/HSE school leavers survey has started this process).

2. Evaluate the efficiency and effectiveness of existing autism services for adults with autism without an ID that are publically funded. Estimate the costs of replicating the well performing services throughout the country.

3. Develop and pilot test new models of support for the Irish context.

4. Explore the development of autism research priorities for Ireland and ways this research might be funded. For example, conducting a comparative study on a drop-in type support centre for people with autism without an ID and a key-worker service model would provide valuable information for future service planning.

5. Develop a number of case studies of people with autism without an ID documenting met and unmet need to help clarify the existing unmet need.

### Recommendations relating to training and awareness

6. Continue to train public service workers on issues surrounding disability including ASD. ASD specific training for professionals and service providers including gatekeepers and managers involved in ASD services should be further developed.

7. Consider options that would give access to in-depth training on ASD across disciplines such as through a centre for excellence in autism model.

8. Identify the support needs and challenges of carers of people with autism without an ID and support them in their role.

### Recommendations relating to service improvement

9. Identify a clear pathway to diagnosis for adults who are suspected to be on the autistic spectrum. For those diagnosed with autism without an ID there should be an appropriate referral pathway to address any unmet support needs. Related to this is the need to develop and test new and improved tools for the diagnosis of autism in adults

10. Explore ways of providing a seamless service in supporting people with autism without an ID through multidisciplinary and inter-sectoral working. This is

particularly so for the transition periods, for example, a move from child to adult services

11. Establish a shared understanding regarding what services should be delivered by mainstream versus specialist services in the context of adults with autism without an ID and in the context of New Directions. There should be a clear outline of what is envisaged for a local community level service and the long-term role of the voluntary sector.

12. Examine, and where relevant improve, the policies, procedures and supports available to people with autism without an ID who drop out of school, college or work due to their autism.

13. Ensure choice, control and person-centred planning are central in working with people with autism without an ID.

**Recommendations relating to next steps**

14. Bring together the HSE, relevant service providers and other stakeholders to discuss these recommendations in more detail ultimately leading to a policy advice paper for the government (the NDA could facilitate this)

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# Appendix

**Appendix 1**

## Menu of Interventions for advice, therapeutic interventions and counselling for people with ASD

| ASD challenge | Interventions |
|---|---|
| 1. Understanding the implications of an autism diagnosis | Post diagnostic discussion (s) and individualised counselling The provision of good quality education and information packs for individuals, families/carers along with appropriate verbal discussion at time of need. Use of visual props if needed. Signposting to useful websites and forums. |
| 2. Development of effective means of communication | Individualised language therapy assessment. Updated as required. Alternative and augmentative communication systems introduced where required. Work to ensure language system (regardless of form) is used functionally and is therefore effective on an individual basis. Teaching/learning on internet etiquette and supervision. |
| 3. Social communication | Targeted social communication programmes delivered either individually or in a group setting as required and appropriate to the individual to include internet etiquette and promotion of online safety. |
| 4. Developing and maintaining relationships | Work to assess the understanding of relationships and promotion of skills to develop relationships including sexuality issues and intimate relationships. Access to social groups, friendship circles etc. |
| 5. Social isolation for individual with autism | Accessible social groups and opportunities, support in the community. Befrienders. Respect the need to be alone at times. Acceptance by families that friendships can take many forms |
| 6. Social isolation for family | Family/ Partner/ Carer support, opportunity for respite. Access to autism friendly environments |
| 7. Learning to learn skills | A functional assessment of the person's cognitive abilities and learning style leading to a planned programme both directly with the individual and indirectly with the family, carers etc. Formal psychometric testing may be conducted if appropriate to inform intervention. |
| 8. Predicting and managing change | Timely individual direct work with individuals to teach methods where required. Family/carer /employer guidance/education in these methods Visual supports; timetables, timers, text alerts, choice boards etc. to be used as appropriate |

| ASD challenge | Interventions |
|---|---|
| 9. Behaviour and emotional regulation protecting wellbeing | Knowledge development in understanding behaviour in the context of ASD. Individual work with the individual on assessing behaviour, recognising triggers and developing and managing the implementation of strategies to help. Behaviour support plans, cognitive interventions, psychotherapy or counselling as required and indicated by life circumstances e.g. around transitions of all types including bereavement. Work with the individual's family/carers, criminal justice, social work, Police as appropriate. Autism Alert card possession |
| 10. Restricted and repetitive interests and behaviours | Assessment and positive day to day management on an individualised basis. Treatment by mental health clinician if required |
| 11. Motivation issues | Structured programmes as appropriate to the individual linking to the other core challenges as required. Career guidance, employer/HE/FE support. |
| 12. Sensory issues | Assessment of sensory difficulties. Identification and implementation of strategies. Environmental adaptation on an individual basis with individual control working towards reducing the impact of sensory sensitivities |
| 13. Daily living skills | Assessment of core life skills as required across the lifespan and to take account of changing needs at various transitions. Specific individual programmes to teach and maintain these skills where needed. Involvement of families/carers in assessment and implementation of new learning Education for families/employers/ care providers/housing dept re practical needs |
| 14. Co-existing conditions- examples | epilepsy, dyspraxia, dyslexia, disorders of attention, sensory impairment, anxiety, sleep disorder, addiction, anger management, depression, self-harm, psychosis, personality disorder, OCD, disordered eating patterns etc. These require assessment and treatment/management by appropriate specialist clinician. Joint working is crucial |

Source: The Scottish Strategy for Autism (2013)