

12 Autism Spectrum Disorder (ASD)

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12.1 About this chapter

This chapter includes the population needs of citizens with Autism Spectrum Disorder. There are separate chapters for learning disabilities and mental health.

What is meant by the term Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition which typically emerges early in childhood (often, but not always, clearly evident by three years of age). The condition is life-long, however, the presentation of the core features may change as the individual develops. ASD impacts on three broad areas of functioning:

- Social understanding and reciprocal social interaction
- Communication – in particular reciprocal communication in a social context
- Difficulties relating to restricted interests, repetitive behaviour, significant sensory difficulties

ASD is a condition which presents across the ability range from those with severe/profound learning disability to those who are extremely able intellectually (such as those with a high IQ in the superior range).

Over time a number of labels have been used to describe the condition, including Autism, Childhood Autism, High Functioning Autism, and Aspergers Syndrome. As all of these conditions share the core areas of difficulty outlined above it is now current practice use the global diagnostic category of ASD. Currently there is also a debate as to whether it is a more appropriate to use the Autism Spectrum Condition (ASC), as opposed to ASD, however, the latter term is employed in current diagnostic manuals.

Safeguarding

It is known that adults with a learning disability are vulnerable to maltreatment and exploitation, which can occur in both community and residential settings (NICE, 2015), this would also include people who also have ASD. Staff have identified that there are significant safeguarding issues in relation to the use of the internet by people with ASD and a concern around radicalisation. Bullying is also an issue for people with ASD and particularly young people in mainstream schools who have Aspergers Syndrome. There may well be higher risks of Child Sexual Exploitation in people with ASD/Aspergers Syndrome.

12.2 What we know about the population

In 2011 it was thought that between 0.6% and 1% of the UK population had ASD with a male: female ratio of 4:1. Estimates of the prevalence of ASD have significantly increased over the last few decades and some studies attribute this to the broadening of the concept of ASD and increased awareness of the condition rather than a true increase in incidence, although this cannot be ruled out.

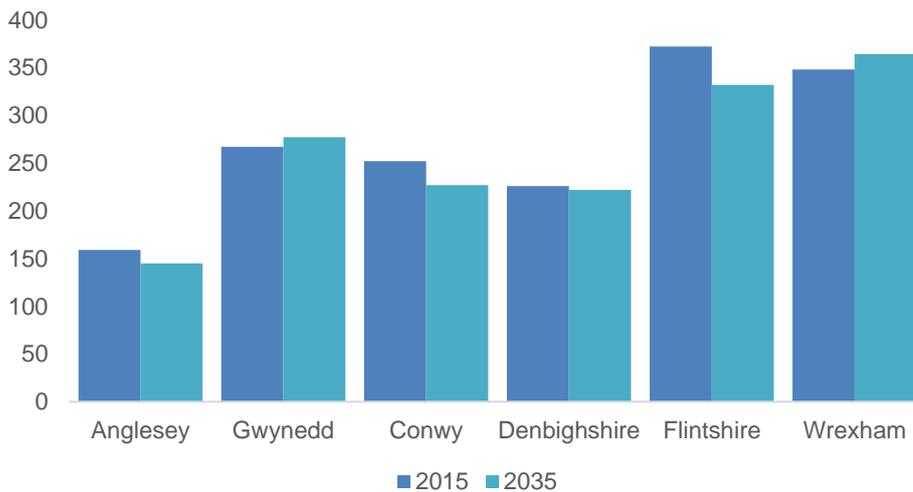
The population prevalence of ASD in 2011 showed:

- 1.1% in people age 16 to 44
- 0.9% in people age 45 to 74
- 0.8% in people age 75 and over

There is a strong suggestion of missed cases of adults with ASD; the assessment of ASD only became available in the early 1990's and has largely focussed on children.

Figures for the total number of people age 19 years over estimated to have ASD in North Wales together with future predictions are shown below. These show an increase in the predicted number of people with ASD in North Wales aged 18 plus.

Figure 12.1 Children age 0 to 17 predicted to have ASD by 2035 in North Wales



Source: Daffodil

Table 12.1 Children age 0 to 17 predicted to have ASD by 2035

	2015	2020	2025	2030	2035
Anglesey	159	163	164	155	145
Gwynedd	267	265	268	271	277
Conwy	252	254	254	242	227
Denbighshire	226	232	237	231	222
Flintshire	372	373	368	349	332
Wrexham	348	365	373	368	364
North Wales	1,624	1,652	1,664	1,616	1,567

Source: Daffodil

Figure 12.2 Total population aged 18 and over predicted to have ASD by 2035

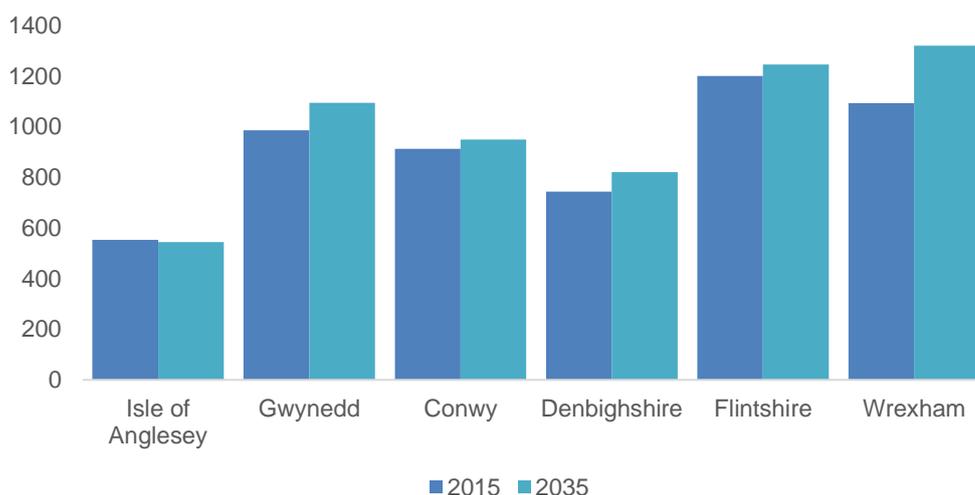


Table 12.2 Total population aged 18 and over predicted to have autistic spectrum disorders

	2015	2020	2025	2030	2035
Anglesey	553	550	547	546	544
Gwynedd	986	1,017	1,046	1,074	1,095
Conwy	913	923	932	942	950
Denbighshire	744	765	783	803	821
Flintshire	1,201	1,217	1,227	1,241	1,246
Wrexham	1,094	1,148	1,204	1,264	1,321
North Wales	5,491	5,620	5,739	5,870	5,977

Source: Daffodil

Welsh language profile

There is a variation across North Wales in the proportion of people with Welsh as their preferred language. This means that there are varying needs across North Wales for Welsh speaking support staff and to support the language and cultural needs of Welsh speakers with ASD. The need tends to be met better in areas where there are greater numbers of Welsh speakers, such as Gwynedd than in areas such as Denbighshire and Flintshire where recruiting

Welsh speaking support staff has proved to be difficult (CSSIW 2016). There is more information in the Welsh language profile produced for the population assessment.

12.3 What are people telling us?

Planning for ASD services is difficult. Traditional learning disability services are not flexible and responsive enough to meet the needs of people with ASD. The number of people being diagnosed has increased in the last 5 years however, the retirement of a dedicated doctor for ASD means that the services have not continued to develop in North Wales.

There is a high suicide rate among people with ASD and a high proportion in prison and this can be due to a mix of difficulties with the system and naivety.

Parents of children with ASD report that caring for a child with the condition is challenging due to behavioural issues. There is little support for emotional well-being for families so that they are able to continue to provide the care and have good family relationships. Parents would like the community to be more aware of autism (as it is hidden disability) and be more accepting.

Parents also cite inability to access advice in timely manner, lack of social activities leading to social isolation, lack of training, information and support to manage problems and behaviours.

Gaps in provision are a frustration for parents and adults with ASD and there is a pattern of unmet needs across all activities undertaken.

Many people with ASD, particularly those who are high functioning are often not eligible for mental health and social care services and support, but many will have often low level support needs which if not addressed could escalate into more serious mental health problems, homelessness and financial difficulties.

In relation to ongoing support and provision the most frequently reported areas of unmet need across children and adults are:

- support for emotional/behavioural issues;
- support for ASD specific issues and life skills;
- access to social and leisure opportunities within their own communities; and,
- respite support for families.

As well as lack of support it is reported that ASD aware education provision is frequently an issue for children with ASD and a lack of support for employment is an unmet need for adults.

The national work in 2015 reported that across all areas of need and all ages, there are three emerging themes.

- Staff within many generic and community services lack the skills and knowledge to support individuals with ASD.
- Eligibility criteria for tier 2 and 3 services mean that individuals with higher functioning ASD (and their carers) fall into gaps between mental health and learning disability services and so cannot access emotional, behavioural, low level mental health and life skills support.
- Existing generic community support and services need to be adapted in order to be suitable for many individuals with ASD due to their specific needs.

12.4 Review of services currently provided

Services and support for children with ASD appear to differ across counties and are provided from different organisations depending on the age of the children. For example, in Gwynedd children are currently assessed by Derwen integrated team for disabled children who are under 5 but by CAMHS if they are over 5. If these children also have a learning disability they would be attending Derwen.

In April 2008, the Welsh Assembly Government issued an Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales. The aim of the plan was to set out how to meet the needs of individuals with ASD, their families and carers and each local council was required to develop their own local plan.

The majority of support available for people with ASD is provided by third sector organisations. There are national organisations that provide a service in North Wales such as Autism Initiatives and also more local support groups such as Gwynedd and Anglesey Asperger/Autism Support Group. The National Autistic society also provide a domiciliary care service.

Nationally, the ASD Strategic Action Plan for Wales was refreshed and in 2015 an interim delivery plan was published to enable further development work to be undertaken to inform policy development. The plan contained a commitment to undertake a scoping exercise examining existing provision to address the gap in services in Wales. Unmet need was also examined as part of the evaluation of the ASD Strategic Acton Plan. Further evidence was gathered through stakeholder consultation during 2015 and highlighted gaps in services and identified demand for low level preventative support. As a result of the most recent research Welsh Government has committed to the development of an integrated autism service, which would involve further development of adult diagnostic assessment provision and lifelong support for individuals with ASD and those who support them. This service will be funded from Welsh Government's Intermediate Care Fund. This new ASD service will

be an integrated service model and it will sit within and support existing structures.

12.5 Conclusion and recommendations

Children and adults with ASD report unmet needs in respect of:

- behavioural/emotional support;
- ASD specific issues and life skills; and,
- access to social and leisure services and opportunity in the community.

Children and adults with ASD may or may not also have a learning disability or mild learning disability. Children and adults with ASD may have or may develop moderate mental health difficulties if support is not available to them at an early stage.

There is a national Autism service being developed, funded from Welsh Government Intermediate Care Funding, and the service will be developing in North Wales in the next year or so as part of the 3 year programme of roll-out. This service will be built on best practice and research and will be all-age.

It is also important that the support currently available in North Wales through the range of third sector organisations that operate in the area are continued and that these compliment the national service. The availability of such support services should be advertised widely so that they can be accessed by those who require the support.

There are gaps in awareness raising around ASD for the public, employers, staff and other areas of public services such as leisure centres and public transport.

Although there is a comprehensive range of information on the web, there is no way of knowing whether people are using this – raising the profile of the availability of services and support on such websites as DEWIS is required.

Training is required to improve the understanding of the effects and implications of ASD, particularly in relation to behaviour management and coping strategies and this needs to be across sectors and particularly within education services. It is also identified that the police service needs to be trained to identify if a person has ASD. Ideally this training should be jointly developed across health and social care and includes specifically:

- managing special interests,
- the transition into adulthood,
- housing and community living,

- employment and training,
- post diagnosis support for partners and family members,
- social isolation, developing social skills and maintaining relationships,
- keeping safe/anti-anti-victimisation interventions,
- autism in females,
- men and autism,
- keeping well and healthy and managing anxiety,
- challenging behaviour and anger management.

Finally, there is a new neurological developmental pathway which will be a service available for children and young people who do not fit into CALDS/CAMHS pathways for diagnosis and support established early in 2017 in Conwy/Denbighshire – if this is successful it should be available across North Wales.

References

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