



**Partneriaeth**  
Ranbarthol  
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West  
Glamorgan  
Regional  
**Partnership**



POPULATION NEEDS ASSESSMENT  
2022 – 2027

AUTISM

If you require this information in an alternative format, please contact the  
West Glamorgan Transformation Office via email at  
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## 1. WHAT IS MEANT BY 'AUTISM'?

According to Autistic UK:

*“Autism is a neurological variation that occurs in about one percent of the population and is classified as a developmental disability. Although it may be more common than previously thought, it is not a new condition and exists in all parts of the world, in both children and adults of all ages.*

*The terms “autistic” and “autism spectrum” often are used to refer inclusively to people who have an official diagnosis on the autism spectrum or who self-identify with the autistic community. While all autistics are as unique as any other human beings, they share some characteristics typical of autism in common”.*

Some defining characteristics include:

**Different sensory experiences.** For example, heightened sensitivity to light, difficulty interpreting internal physical sensations, hearing loud sounds as soft and soft sounds as loud. This can be either painful or pleasurable depending on the sensory stimulus, and can often be both depending on the autistic person’s anxiety levels, mental and physical health at the time, and whether or not they have control over the stimulus. E.g. an autistic person can be hypersensitive to the noise of other people, yet can enjoy listening to their own music at a very loud volume.

**Non-standard ways of learning and approaching problem solving.** For example, learning “difficult” tasks (e.g. calculus) before “simple” tasks (e.g. addition), difficulty with “executive functions”, or being simultaneously gifted at tasks requiring fluid intelligence and having a verbal reasoning learning disability. It is important that autistic people are given the tools they need to learn in the way that best suits them. There isn’t a “one size fits all” approach, and each autistic person should be consulted individually – including autistic children who (where possible) should always be involved in their educational planning.

**Deeply focused thinking and passionate interests in specific subjects.** “Narrow but deep”, these “intense interests” could be anything from mathematics to ballet, from doorknobs to physics, and from politics

to bits of shiny paper. These interests often bring intense joy to the autistic person and should not be discouraged.

**Atypical, sometimes repetitive, movement.** This includes “stereotyped” and “self-stimulatory” (stimming) behaviour such as rocking or flapping, and also the difficulties with motor skills and motor planning associated with apraxia or dyspraxia. Stimming is often used by an autistic person to regulate or express their emotions, or to feel where they are in relation to the space around them.

**Need for consistency, routine, and order.** For example, holidays may be experienced more with anxiety than pleasure, as they mean time off from school and the disruption of the usual order of things. Autistic people may take great pleasure in organising and arranging items.

**Difficulties in understanding and expressing language as used in typical communication, both verbal and non-verbal.** This may manifest similarly to semantic-pragmatic language disorder (newly termed as Social Communication Disorder). It's often because a young child does not seem to be developing language that a parent first seeks to have a child evaluated. Autistic adults often continue to struggle to use language to explain their emotions and internal state, and to articulate concepts (which is not to say they do not experience and understand these). Autistic adults (as with children) can be speaking, non-speaking, or sometimes speaking. Most autistic people, however, are able to communicate if they are provided with the right tools, such as communication boards, Augmentative and Alternative Communication (AAC), Picture Communication System (PCS), and various sign languages including British Sign Language (BSL) and Makaton.




**Difficulties in understanding and expressing typical social interaction.** For example, preferring parallel interaction, having delayed responses to social stimulus, or behaving in a socially expected manner to the “norms” of a given social context (for example, not saying “hi” immediately after another person says “hi”).

Autism is diagnosed based on observation by a diagnostician or team of diagnosticians (e.g. neuropsychologist, psychologist, psychiatrist, licensed clinical social worker, etc.)”.

Source: [About Autism | Autistic UK CIC](#)

In summary, autism is not a learning disability, but around half of autistic people may also have a learning disability.

There are three common features of autism, which might affect the way a person:

-  interacts with others in a social situation
-  is able to communicate with others
-  thinks about and deals with social situations.

A substantial proportion of autistic people, especially those with fluent language and average-range ability, are not identified in childhood and enter adulthood without a diagnosis.

Autistic UK strongly support and believe in the use of identity-first language (that is, using ‘autistic person’ instead of ‘person with autism’), as does the autistic community in general.

Identity-first language will be adopted in this chapter, but quotes lifted from other sources will retain their original wording for authenticity.

### **Strengths-Based Approach**

The Western Bay Integrated Autism Service (IAS) subscribes to a ‘strengths-based approach’.

This ethos is described below:

*“It is a serious problem that many individuals on the spectrum grow up regularly hearing about what their problems are. It can have a detrimental effect on how they see themselves. Using a strengths-based approach from the outset, so they also understand that they have amazing strengths, would help to give them a much more balanced outlook.*

- *Autistic people have strengths, abilities and interests that often exceed their more neuro-typical peers. Common autistic-related*

*strengths include, but are not limited to; attention to detail, visual perception, creative and artistic talents, mathematical and technical abilities (like programming and robotics). Autistic people may also have particular interests or expertise in 'niche' areas, and other desirable character strengths, such as honesty and loyalty.*

- *Despite these strengths, autistic individuals often experience poor outcomes in education, employment, community engagement, independence, and interpersonal relationships. On average, autistic people currently have a lower quality of life than non-autistic people and are more likely to experience mental health problems.*
- *Societies are neuro-diverse. No two brains are identical. Although the way some people's brains develop can be disabling, particularly when public spaces and services are not prepared for them, development can also enable different cognitive strengths and advantages. Teams, businesses and societies can benefit from embracing the diversity of abilities that autistic and other neuro-divergent people have.*
- *Service models focus too much on 'impairment'. Internationally, the way services diagnose, assess and support autistic people tends to focus exclusively on impairment and functional deficits. Most autistic people will face difficulties, but these difficulties should not define them or be the sole focus of the support available to them. Neglecting autistic strengths and abilities can inadvertently perpetuate stigma around autism and limit people's potential.*
- *Strengths-based approaches focus on harnessing a person's strengths, abilities and interests. Initial research suggests that strengths-based interventions could help autistic people improve their self-esteem, confidence, social engagement, relationships and life skills, in particular when focusing on activities aligning with autistic people's interests and encouraging personal autonomy. For example, designing and running coding clubs with autistic people who have an affinity for ICT has been explored as a way to support autistic people into employment and further education."*

Source: [FINAL-Strengths-Based-Approaches-ActionBriefing.pdf \(autistica.org.uk\)](#)

Increasingly, there is a move towards a strengths-based view of autism and how to support autistic people. Gaudion and Pellicano<sup>1</sup>, for example, talk about the 'Triad of Strengths' and taking three of the characteristics outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DMS V) to consider how they can be treated as strengths.

Summarising some recent research studies, Panzano<sup>2</sup> draws attention to some of the strengths that autistic people can often demonstrate:

- 🧩 Autism is associated with genius
- 🧩 Hawkeye attention to detail
- 🧩 Problem solving skills
- 🧩 Visual skills and strengths
- 🧩 Excellent memory skills.

A large-scale study<sup>3</sup> challenged prevailing deficit-based views of young people with intellectual and developmental disabilities, and offered a promising alternative for describing transition-age youth in terms of the strengths they bring to activities and relationships.

It is also worth noting that strengths-based approaches can be used in work with autistic people, even instances where their behaviour is challenging<sup>4</sup>.

## Regional Statistics and Projections

In the West Glamorgan region, future projections for autistic people taken from the Social Care Wales data platform for the under 17 year old age group suggest that by 2040, this cohort will only rise by 0.5%.

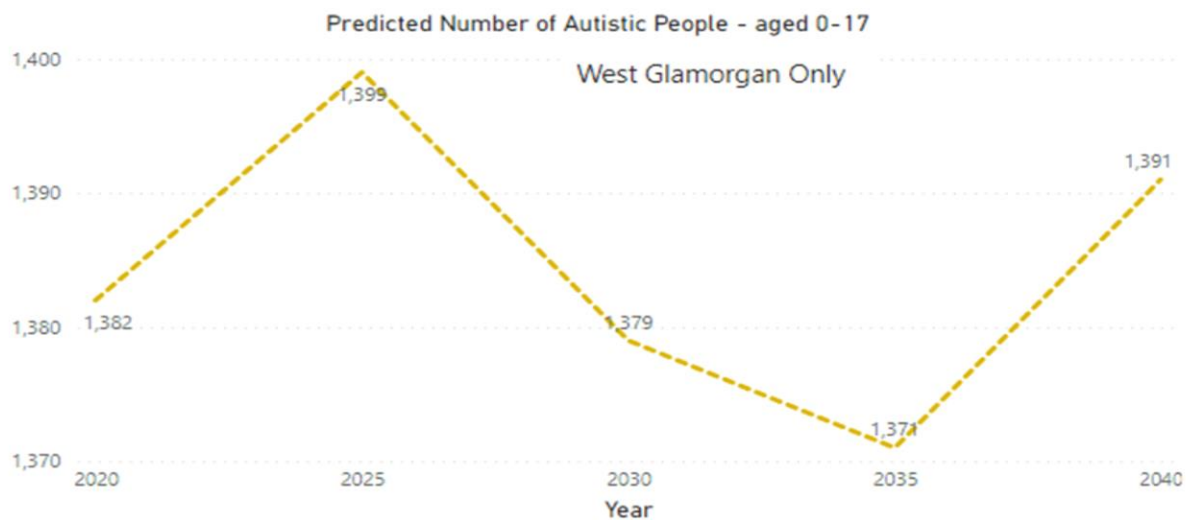
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<sup>1</sup> Gaudion K., Pellicano L. 'The Triad of Strengths: A Strengths-Based Approach for Designing with Autistic Adults with Additional Learning Disabilities. In: Marcus A. (eds) Design, User Experience, and Usability: Design Thinking and Methods. DUXU 2016. Lecture Notes in Computer Science, vol 9746'. Springer, Cham. (2016) [https://doi.org/10.1007/978-3-319-40409-7\\_26](https://doi.org/10.1007/978-3-319-40409-7_26) Accessed 6 December 2021

<sup>2</sup> Panzano, L, 'Five Research-Based Strengths Associated with Autism' <https://blog.stageslearning.com/blog/five-research-based-strengths-associated-with-autism> Accessed 6 December 2021

<sup>3</sup> Carter, E, Boehm, T et al, 'Known for My Strengths: Positive Traits of Transition-Age Youth With Intellectual Disability and/or Autism', Research and Practice for Persons with Intellectual Difficulties or Autism, vol 40, Issue 2, 2015, <https://journals.sagepub.com/doi/abs/10.1177/1540796915592158> Accessed 6 December, 2021

<sup>4</sup> Ayland, A, West, B, The Good Way model: 'A strengths-based approach for working with young people, especially those with intellectual difficulties, who have sexually abusive behaviour', Journal of Sexual Volume 12, 2006 - Issue 2: Young People with Harmful Sexual Behaviours, <https://www.tandfonline.com/doi/abs/10.1080/13552600600841680> Accessed 6 December 2021



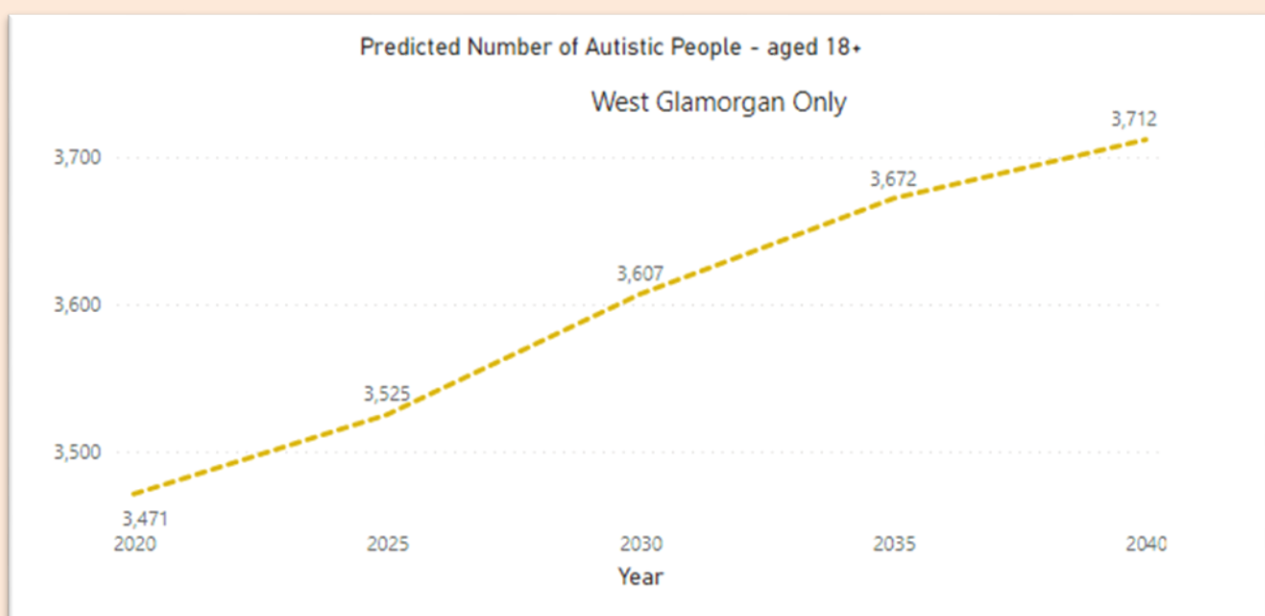
**Notes**

The prevalence of autism among children has been taken from the Special Educational Needs (PLASC) data return.

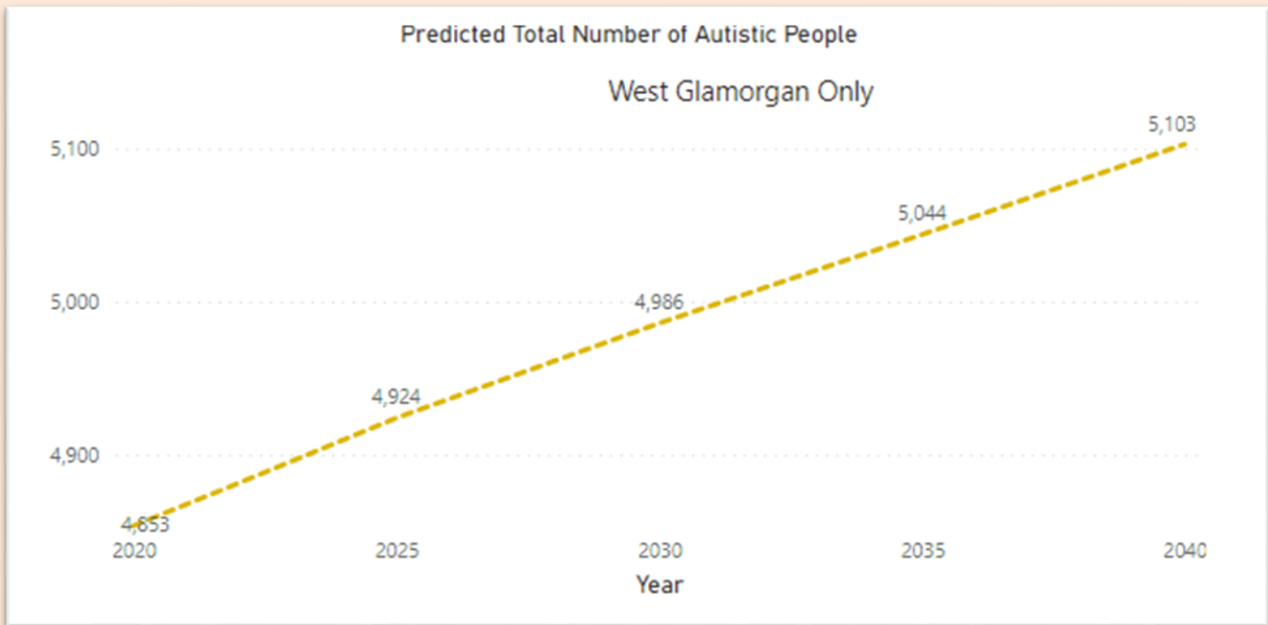
Prevalence data on autism among adults aged 18 years and over are taken from "Estimating the prevalence of autism in adults: Extending the 2007 Adult Psychiatric Morbidity Survey". The data from the 2007 Adult Psychiatric Morbidity Survey, (a household survey carried out in England), were combined with data from a further study of the prevalence of autism among adults with learning disabilities living in private households and communal care establishments in Leicestershire, Lambeth and Sheffield (Brugha et al. 2012).

For more information, please see the 'Methodology' tab. [Population Projections Platform \(socialcaredata.wales\)](https://socialcaredata.wales.gov.uk/population-projections-platform)

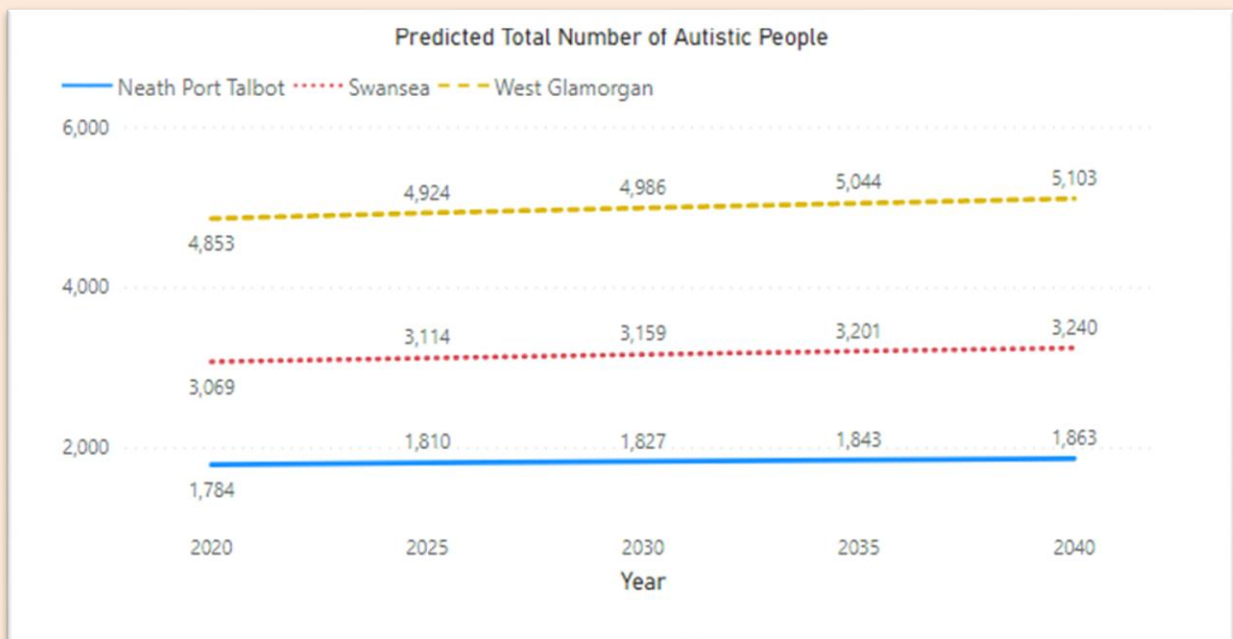
However, for autistic people over the age of 18 in West Glamorgan, the projected figure for the same time period rises by 6.5% to 3712 (see below).



The following chart indicates that by 2040, the projected number of autistic people within the West Glamorgan region will rise to approximately 5103 - an overall increase of 4.9%.



It is estimated that there will be 3240 autistic people in Swansea and 1863 autistic people in Neath Port Talbot by 2040.












It is estimated that there are one in a hundred people on the autism spectrum (source: [www.autism.org.uk/advice-and-guidance/what-is-autism](http://www.autism.org.uk/advice-and-guidance/what-is-autism)), therefore based on the population figures recorded on Stats Wales for West Glamorgan, there are estimated to be around 4853 autistic adults and children within the region (as at 2020).








## **Children**

The NHS identifies signs of autism in both adults and children in the following:

Signs of autism in young children include:

-  not responding to their name
-  avoiding eye contact
-  not smiling when you smile at them
-  getting very upset if they do not like a certain taste, smell or sound
-  repetitive movements, such as flapping their hands, flicking their fingers or rocking their body
-  not talking as much as other children
-  repeating the same phrases.

Signs of autism in older children include:

-  not seeming to understand what others are thinking or feeling
-  finding it hard to say how they feel
-  liking a strict daily routine and getting very upset if it changes
-  having a very keen interest in certain subjects or activities
-  getting very upset if you ask them to do something
-  finding it hard to make friends or preferring to be on their own
-  taking things very literally – for example, they may not understand phrases like "break a leg".

## **Autism in girls and boys**

Autism can sometimes affect girls and boys in different ways. For example, autistic girls may be quieter, may hide their feelings and may appear to cope better with social situations.

This means autism can be more difficult to identify and diagnose in girls.

Source: 'Signs of autism in children' NHS,

[www.nhs.uk/conditions/autism/signs/children](http://www.nhs.uk/conditions/autism/signs/children) Accessed 6 December 2021.

## Diagnosis

Whilst these are general definitions of autism, the issue of obtaining a diagnosis of autism from the NHS is somewhat more complicated.

Obtaining a diagnosis from the NHS requires an assessment from a clinician who will use a variety of tools to determine whether or not a person meets the formal diagnosis of autism.

In terms of what an autism diagnosis entails, the [National Autistic Society](http://www.autism.org.uk) website includes a helpful guide with links to more detailed information. A key piece of information relating to diagnosis reads as follows:

*“Diagnostic manuals, ICD-10 and DSM-5, set out the criteria for autism to be diagnosed. These create the foundation for diagnostic tools such as the DISCO (Diagnostic Interview for Social and Communication Disorders), the ADI-R (Autism Diagnostic Interview - Revised) - the ADOS (Autism Diagnostic Observation Schedule) and 3Di (Developmental, Dimensional and Diagnostic Interview).*










*These, and other diagnostic tools, are used to collect information in order to help to decide whether someone is on the autism spectrum or not. This guide explains more about the manuals and criteria for an autism diagnosis.”*

Source: [www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-criteria/all-audiences](http://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-criteria/all-audiences) (Accessed 8 November 2021)

Information on diagnosis can also be found on the [NICE website](http://www.nice.org.uk).

## 2. LIFESTYLE FACTORS AFFECTING AUTISTIC PEOPLE

A recent report identified some key facts about autism that impact on the wider issues of health and care.

-  There are at least 700,000 autistic people currently living in the UK, which is around 1% of the population.
-  Autism is apparently much more prevalent in males than females, but part of this difference may be due to under-reporting of females.
-  Autism is a life-long condition for which there is no 'cure'. Indeed, the idea of a cure is deeply resented by many autistic people.
-  Autism causes difficulties with social communication and interactions, as well as a restricted and repetitive range of behaviours, activities or interests.
-  Many autistic people experience sensory-processing difficulties e.g. becoming overwhelmed by their environment, avoiding or not noticing certain sensations, or seeking out certain sensations. These difficulties may heighten their anxiety and stress, impact on their participation and at times cause pain.
-  80% of autistic people, at some point in their lives, have mental health problems such as anxiety and depression, and the majority rate their anxiety as the number one problem in their lives.
-  About one in 10 autistic adults has epilepsy, but among those with intellectual disability the prevalence is much higher - up to 30%.
-  Approximately one third of autistic people have learning or intellectual disabilities.
-  Autistic people are socially disadvantaged: they are more likely to be excluded from schools, to suffer poor healthcare, to be underemployed and to be badly served by the criminal justice system.

Source: <https://nationalautistictaskforce.org.uk/wp-content/uploads/2020/02/autism-dividend-report.pdf>

## Support

With support from the Welsh Government, the National Autistic Society (NAS) are delivering a project aiming to create new social groups for autistic adults across Wales. In 2020-21, a survey of autistic adults in Wales was undertaken to find out about current opportunities for socialising and the potential for setting up new peer support groups. 70% of respondents said they would like to participate in a group, and one in six would like to set up a group themselves. The NAS are now working closely with autistic adults and volunteers, learning from what already works well and supporting them to develop a range of sustainable, peer-support activities that meet the needs of autistic adults in Wales.




Source: [NAS AnnualReport 2021.pdf \(thirdlight.com\)](#)

## Education and learning

The [Additional Learning Needs and Education Tribunal \(Wales\) Act 2018](#) (ALNWA 2018) changes the way that children and young people aged 0-25 with additional learning needs (ALN) are supported in Wales. This came into force on 1 September 2021.

The legislation will have a phased implementation. The Welsh Government is determined that the new ALNWA 2018 regime will deliver a fully inclusive education system for learners in Wales, where needs are identified early and addressed quickly. It is intended that the planning under the new regime will be flexible and responsive, with the learner at the centre of everything.

The following changes have been introduced:

-  Introduce the term Additional Learning Needs (ALN) to replace the terms 'special educational needs' (SEN) and 'learning difficulties and/or disabilities' (LDD).
-  Legislation that covers the age range 0 to 25. This will replace the two separate SEN systems covering children and young people of compulsory school age and young people in post-16 education.
-  A single individual development plan (IDP) to replace the existing variety of plans for learners in schools and further education.

- 🌈 Increased participation of children and young people in the planning process, so planning is something done with them rather than to them.
- 🌈 High aspirations and improved outcomes. This will be the focus of the IDPs.
- 🌈 A simpler and less adversarial system. The process of producing and revising an IDP should be much simpler than is currently the case with statements of SEN and should avoid the adversarial nature of the existing approach.
- 🌈 Increased collaboration and information sharing between agencies. New roles are created to support this – Additional Learning Needs Coordinators in education settings; Designated Educational Clinical Lead Officers in health boards; and Early Years ALN Lead officers in local authorities.
- 🌈 Avoiding disagreements and earlier disagreement resolution about the IDP or the provision it contains.
- 🌈 Clear and consistent rights of appeal including a right of appeal to a tribunal where disagreements about the contents of an IDP cannot be resolved at the local level.
- 🌈 A statutory ALN code to set out the duties of local authorities and other organisations responsible for the delivery of services to children and young people with ALN.
- 🌈 A bilingual system where services must consider whether provision is needed in Welsh and take all reasonable steps to secure it.

Source: <https://gov.wales/additional-learning-needs-special-educational-needs>, (accessed November 2021)

## **Employment and vocation**

*“Around half of disabled people aged 16 to 64 years (52.1%) in the UK were in employment compared with around 8 in 10 (81.3%) for non-disabled people (July to September 2020); disabled people with autism were among those disabled people with the lowest employment rate.”*

Source: [Outcomes for disabled people in the UK - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk)

*“The Disability Employment Gap is still too wide, with around half of disabled people in work, compared to over 80% of non-disabled people. But the autism employment gap is even wider, with just 22% autistic people reported in paid work. We are really worried that out of all disabled people, autistic people seem to have the worst employment rate.*

*While not all autistic people can work, we know most want to. The Government must improve the support and understanding autistic people get to find and keep work.”*

Source: [New shocking data highlights the autism employment gap](#)

### **Impact of COVID-19**

There has been a significant impact on autistic people through the COVID-19 pandemic. Findings of the NAS survey undertaken in 2021 state:

*“The report was based on a survey of 4232 autistic people and families in the UK during June and July. We found that the disruption, uncertainty and pace of change triggered huge levels of anxiety and, for some, was made worse by the withdrawal of support from social care, education and mental health services.”*

Source: [NAS AnnualReport 2021.pdf \(thirdlight.com\)](#)

The Policy Innovation and Evaluation Research Unit of the London School of Economics was commissioned to undertake rapid research to improve understanding of autistic people’s experiences during the pandemic.

The research showed that the COVID-19 pandemic has exacerbated challenges many autistic people already faced, such as loneliness and social isolation, and anxiety. While reasons for this vary, the research found that many autistic people have struggled with understanding restrictions and practicing infection control measures. In addition, the pandemic has created new issues for autistic people, for example in being able to shop at supermarkets due to new social distancing measures.

At the same time, the research also showed the benefits of lockdowns for some autistic people, who have been better able to engage in virtual

spaces, have felt less societal pressure and have been able to go out more.

The key concerns were identified as:

- 🧩 **Communication from Government:** Government communication regarding COVID-19 was difficult to understand and follow for many autistic people. Clear communication and transparency of decision-making from government are important and can help autistic people follow advice and guidance.
- 🧩 **Schools and education:** Access to education for autistic children during lockdown was not consistent. Continued input from schools and maintaining contact with parents and families are vital if schools need to be closed in the future.
- 🧩 **Grocery shopping:** Accessing groceries during lockdown was a struggle for many autistic people. Ensuring everyone has access to necessary grocery shopping, especially vulnerable groups like autistic people, must be a priority.
- 🧩 **Mental health and access to medical care:** COVID-19 and its consequences affected the mental health of autistic people in a range of ways. Mental and physical health care should be accessible to all members of the population. This is particularly the case for autistic people who are more likely to have mental health problems and may find it harder to access services.
- 🧩 **Caring responsibilities and respite:** Renewed support for family members and carers is needed. Many were exhausted during lockdown, especially when external support and respite care were stopped or reduced.

Source: PIRU, 'The Impact of COVID-19 on Autistic People in the United Kingdom', 2021, <https://piru.ac.uk/projects/current-projects/the-impact-of-covid-19-on-autistic-people-in-the-united-kingdom.html> (accessed November 2021).

## **Mental health and wellbeing**

An article in the Nursing Times looked at the impact of the environment on autistic people. Many will have sensory difficulties, causing them to avoid crowded areas or going out on bright days. Others may be

hyposensitive to pain and may not realise how serious an injury is because their pain threshold is so high.

When combined with a learning disability or a mental health issue, autistic people who are hypersensitive to noise may, for example, find even a ticking clock irritating and this can potentially lead to challenging behaviours.

In terms of mental health, autistic people are more likely to experience problems than the general population. Approximately 70%–80% of autistic children and adults experience mental health problems, most commonly depression and anxiety. The same report shows that it is difficult to determine the true rates of depression and anxiety in autistic people, because many features of autism (e.g. social withdrawal, sleep problems) overlap with symptoms of depression and anxiety, and it may be difficult for autistic adults to identify that they are experiencing these conditions.

Source: Nursing Times, Innovations, 'Creating accessible healthcare environments for people with autism', <https://www.nursingtimes.net/roles/hospital-nurses/creating-accessible-healthcare-environments-for-people-with-autism-03-12-2019/> (accessed November 2021)

## **Housing**

The ONS published several different pieces of data together in the "Outcomes for disabled people in the UK: 2020". This included several different national surveys that the ONS has run. For the first time, some of these surveys asked respondents if they are autistic. The results that were published included reference to housing:

"Of the autistic adults responding, 75% lived with their parents, compared with 16% of disabled people generally. There could be lots of different reasons for this figure, including if responders were younger or still in education. These are new figures and we will keep looking at future publications. There are other autism-related figures in the data, but because they were only answered by small number of people, the findings should be treated with more caution."

Source: [New shocking data highlights the autism employment gap](#)



## **Access to help and support**

“Even before the pandemic, too many autistic people struggled with their mental health and lacked the support they need, and things are even worse now. Our 2019 report, Autism Act: 10 years on, showed 76% of autistic people have reached out for mental health support in the past five years, with only 14% believing there are enough mental health services in their area to support their needs. Services are often impossible to access and even when people are able to get support, it’s often not tailored to the individual and their autism, which only compounds the situation.”

Source: [NAS AnnualReport 2021.pdf \(thirdlight.com\)](#)

## **Transition to adulthood**

A research project carried out in 2020 looked at the parental perspective on having a son or daughter going through transition. In addition to undertaking research with parents it also included a review of literature relevant to transition and identifying how it feels for both parents and their children. It references, for example, the worry parents experience as they attempt to navigate complex pathways and confusing systems. They also reference the need for a systematic transition process, a lack of support for parents and support to handle the legal and financial procedures associated with young adults with profound intellectual disability reaching adulthood (18 years old).

Source: Codd, J, Hewitt, O, ‘Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective’, British Journal of Learning Disabilities, March 2021, <https://onlinelibrary.wiley.com/doi/full/10.1111/bld.12327> (accessed November 2021)

## **Autistic parents**

Whilst there is a considerable amount of literature available regarding the parents of autistic children, there is a paucity of material relating to autistic parents. Much of the material that is available is anecdotal and written from personal experience. Whilst that clearly has value any suggestions within it are largely invalidated and cannot be generally applied. Swenson has written a helpful article on this issue that also notes the general shortage of material.

Source: Swenson, S 'When You Suspect a Parent May Be on the Autism Spectrum' Goodtherapy, 2016, <https://www.goodtherapy.org/blog/when-you-suspect-parent-may-be-on-autism-spectrum-0610164> (Accessed 6 December 2021)

## **Older Carers**

Carers and employment has already been discussed above. Whilst most authorities have clearly worked out approaches for carers generally, it is worth considering the carers of people with learning disabilities and autistic people separately. The family carers of adults with behaviours that challenge can lead particularly complex and stressful lives. Their caring role can leave them isolated and unsupported.

The paper goes on to explore the benefits of engaging carers in mindfulness and other such courses.

Source: Cook, T et al, 'Mindfulness-based practices with family carers of adults with learning disability and behaviour that challenges in the UK: Participatory health research'. Health Expectations, 2019, <https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12914> Accessed November 2021.

Good future planning is important to older carers and can help alleviate feelings of stress and anxiety. Consideration of the future role of siblings as carers as also an important issue. The report also refers to 'Managing changing reciprocities' with the carer and the person with learning disabilities becoming more co-dependent.

## **Gender dysphoria**

There is some emerging research suggesting that there is a higher number than average of people with gender dysphoria that also have autism, and as such services need to be mindful of a person's gender identity.

Source: [www.autism.org.uk/advice-and-guidance/what-is-autism/autism-and-gender-identity](http://www.autism.org.uk/advice-and-guidance/what-is-autism/autism-and-gender-identity)

## **Mortality**

Although an American study, research by Smith Dewalt et al<sup>5</sup> shows that people with autism experience high rates of early mortality. They identify that:

*“...6.4% died during the 20-year follow-up period, and the average age at death was 39 years. These individuals died an average of 38.5 years prior to their life expectancy. Causes of death were diverse, including chronic conditions (such as cancer and seizures), accidents (such as choking on food and accidental poisoning), and health complications due to medication side effects. Our results build on previous research that has indicated that individuals with ASD have a higher risk for mortality than the general population”.*

Smith Dewalt et al (ibid).

In a research article produced by Autistica Organisation, it stated: ‘Many families and autistic individuals have raised concerns over early deaths in autistic people. Ground-breaking new research now confirms the true scale of the mortality crisis in autism: autistic people die on average 16 years earlier than the general population. For those with autism and learning disabilities, the outlook is even more appalling, with this group dying more than 30 years before their time.’

The article also states:

‘Autistic adults with a learning disability are 40 times more likely to die prematurely due to a neurological condition, with epilepsy the leading cause of death.

Autistic adults without a learning disability are 9 times more likely to die from suicide.’

Source: [Personal-tragedies-public-crisis-ONLINE.pdf \(autistica.org.uk\)](#)

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<sup>5</sup> Smith Dewalt et al, ‘Mortality in Individuals with Autism Spectrum Disorder: Predictors over a 20-Year Period’ Autism, 2019, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6713622/> Accessed 17 November, 2021.

## Health Status and Needs

National Institute for Health and Care Excellence (2016)<sup>6</sup> guidance on autism in adults states that health professionals should:

*“In all settings, take into account the physical environment in which adults with autism are assessed, supported and cared for, including any factors that may trigger challenging behaviour.”*

An article in the Nursing Times<sup>7</sup> looked at the impact of the environment on people with autism. Many will have sensory difficulties, causing them to avoid crowded areas or going out on bright days. Others may be hyposensitive to pain and may not realise how serious an injury is because their pain threshold is so high.

When combined with a learning disability or a mental health problem people with autism who are hypersensitive to noise may, for example, find even a ticking clock irritating and any high-pitched noise distressing and this can lead to challenging behaviours.

In terms of mental health, people with autism are more likely to experience problems than the general population<sup>8</sup>. Approximately 70%–80% of autistic children and adults experience mental health problems, most commonly depression and anxiety. The same report shows that it is difficult to determine the true rates of depression and anxiety in autistic people, because many features of autism (e.g. social withdrawal, sleep problems) overlap with symptoms of depression and anxiety and it may be difficult for autistic adults to identify that they are experiencing these conditions.

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<sup>6</sup> NICE, ‘Recognition, referral, diagnosis and management of adults on the autism spectrum’, 2016, <https://www.nice.org.uk/guidance/cg142/evidence/full-guideline-186587677> Accessed 17 November, 2021.

<sup>7</sup> Nursing Times, Innovations, ‘Creating accessible healthcare environments for people with autism’, <https://www.nursingtimes.net/roles/hospital-nurses/creating-accessible-healthcare-environments-for-people-with-autism-03-12-2019/> Accessed 17 November 2021

<sup>8</sup> Crane, L et al, ‘Something needs to change’: Mental health experiences of young autistic adults in England’, Autism, 2018,

<https://journals.sagepub.com/doi/full/10.1177/1362361318757048> Accessed 17 November 2021

Also, characteristics associated with autism may affect the way mental health problems present themselves in autistic adults. As the report notes:

*“Yet, while the rates of mental health problems in autistic people are difficult to determine, the consequences are not. Autistic adults who are experiencing episodes of depression, for example, report high rates of suicidal thoughts, and suicide plans or attempts.”*

Crane et al (ibid).

### **The voice of autistic people**

An interesting starting point here is the language often used when discussing autism. A research report<sup>9</sup> from the US lists unhelpful terms and alternatives, as set out below. A similar point may be made with regard to learning disability terminology.

<b>Patronising language</b>	<b>Alternative language</b>
Special interests	Areas of interest or areas of expertise, focused, intense, or passionate interests
Special needs	Description of specific needs and disabilities
Challenging behaviour / disruptive behaviour / problem behaviour	Meltdown (when uncontrollable behaviour), stimming (when relevant), specific description of the behaviour (e.g., self-injurious or aggressive behaviour)
Person-first language (to refer to autism)	Identity-first language; ‘on the autism spectrum’

<sup>9</sup> Bottema-Beutel, K, et al, ‘Avoiding Ableist Language: Suggestions for Autism Researchers’ Autism in Adulthood, 2021, <https://www.liebertpub.com/doi/full/10.1089/aut.2020.0014#B112> Accessed 18 November 2021/

<b>Patronising language</b>	<b>Alternative language</b>
<b>Medicalised / deficit-based language</b>	
High/low functioning; high/low severity or support needs	Describe specific strengths and needs, and acknowledgment that the level of support needs likely varies across domains (e.g., requires substantial support to participate in unstructured recreation activities, but minimal support to complete academic work)
'At risk' for ASD	Increased likelihood/chance of autism
Burden of/suffering from autism	Impact, effect
Co-morbid	Co-occurring
Autism symptoms	Specific autistic characteristics, features, or traits
Treatment	Support, services, educational strategies (when applicable)
Healthy controls/normative sample	Non-autistic (if determined via screening), neurotypical (if determined via extensive screening ruling out most forms of neurodivergence), comparison group (with description of relevant group characteristics)
Psychopathology	Neurodevelopmental conditions, neuropsychiatric conditions, developmental disabilities, mental illnesses (or specific mental health condition)

At the same time, there have been significant changes in recent times as to how autism is perceived and this has greatly impacted upon how autistic people are viewed and view themselves.

As Leadbetter<sup>10</sup> observes:

*“A central premise of the neurodiversity movement is that variations in neurological development and functioning across humans are a natural and valuable part of human variation and therefore not necessarily....Neurodiversity as a social justice and civil rights movement intersects with the wider disability rights movement...The most significant premise of both is that disability is not simply a defect in the individual, but arises from the interaction between a non-standard individual and an unaccommodating environment (the social model of disability).”*

Leadbetter, ibid

Borrowing from US academic practice, UK Autistic identify three types of advocacy for autistic people<sup>11</sup>:

- 🧩 Self-Advocacy – advocating for yourself
- 🧩 Individual Advocacy – advocating for individuals g. assisting someone in a medical appointment
- 🧩 Systems Advocacy – advocating to change policies or laws to benefit the wider community.

They also identify four important aspects to giving autistic people a voice:

- 🧩 Engagement (with those people)
- 🧩 Representation
- 🧩 Co-production
- 🧩 Participation.

Williams, K (ibid)

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<sup>10</sup> Leadbetter, K, et al, ‘Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice’ 2021, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8075160/> Accessed 16 November, 2021.

<sup>11</sup> Williams, K, Untitled, UK Autistic 2020, <https://autisticuk.org/advocacy-and-autistic-uk-cic/> Accessed 18 November 2021

It should be noted that a suite of resources designed to support services and organisations to co-produce effectively has been produced by the West Glamorgan Co-production Group and comprises a framework, toolkit and charter: [Click here to view.](#)

Some legislation makes provision of independent advocacy to autistic adults a legal duty in specific circumstances<sup>12</sup>.

When someone is detained under the Mental Health Act (2007), whether they are in hospital or on a Community Treatment Order, they have a right to an Independent Mental Health Advocate. This advocate can advise them of their rights and help them get their voice heard.

When someone has been assessed as lacking capacity to make a decision, they have a right under the Mental Capacity Act (2005) to an Independent Mental Capacity Advocate. This advocate represents the wishes of the individual if there are no family or friends to do so.

### **3. SERVICES USED BY AUTISTIC PEOPLE**

Autistic people are a very diverse group. Whilst some people need 24-hour support others have limited or no social care support. The process of accessing social care and health care services can be complex. Both social care and health care are dealt with under different legislation, and it is not uncommon for local authorities and health boards to disagree about which organisation is responsible for providing services<sup>13</sup>. The Welsh Government acknowledges these challenges in their plan for health and social services - A Healthier Wales<sup>14</sup> (updated October 2021). They outline their ambition to improve how health and social services work together, so that they are designed and delivered around the needs

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<sup>12</sup> Watts, G, 'Adult autism advocacy in the UK: a policy review', 2017, Tizard Review, <https://www.emerald.com/insight/content/doi/10.1108/TLDR-10-2016-0029/full/pdf?title=adult-autism-advocacy-in-the-uk-a-policy-review> Accessed 18 November, 2021.

<sup>13</sup> Accessing Social Care and Health care services in Wales (Mencap, 2017)

<sup>14</sup> A Healthier Wales: Our Plan for Health and Social Care (Welsh Government, 2021)



and preferences of individuals, with a much greater emphasis on keeping people healthy and well.

A review of inequalities in access to health services for disabled people in Wales<sup>15</sup> published in 2015 found that:

- 🌸 only 24% of people with depression and anxiety disorders had received any form of treatment
- 🌸 many deaf and hard of hearing people were forced to make contact with their GP in a method that was not optimal and 90% of GP surgeries in Wales did not offer suitable alternatives for making appointments. There were also barriers to arranging interpretation or communication support
- 🌸 there are significant geographic variations in access to healthcare services for disabled people across Wales, particularly in terms of mental health and rehabilitation services
- 🌸 there are seen to be negative and disproportional impacts on the health outcomes of disabled people as a direct result of the Welfare Reform Act.
- 🌸 The review also highlighted 'a severe lack of published evidence in terms of access to healthcare services for disabled people in Wales'.

There is clear evidence that many autistic people particularly those without a co-occurring learning disability or significant mental health issue who are not eligible for tier 2 and 3 services, often fall into gaps between statutory mental health and learning disability services. As a consequence, they are unable to access emotional, behavioural, low level mental health and life skills support<sup>16</sup>.

Wales was the first country in the world to create an all-age strategy for Autism, with The ASD Strategic Action Plan for Wales published in 2008. The Plan created a number of funded actions on how local services can

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<sup>15</sup> Review of Evidence of Inequalities in Access to Healthcare Services for Disabled People in Wales: Executive Summary (Welsh Government, 2015). Accessed: 12 November 2021.

<sup>16</sup> Integrated Autism Service Supporting Guidance (National Autism Team, not publishing date, approx. 2016)

best meet the needs of young people and adults with ASD. One of the key achievements has been the increased profile and awareness of autism. There is a wide range of information and resources available to help people with autism and their families and carers, as well as resources for professionals. We have also established a national co-ordinator as well as ensuring there are local leads. Their focus has been on raising awareness and working to ensure there is information, advice and improved services and support available across Wales.

The strategy was refreshed and a new Strategic Action Plan was developed in 2016, in response to what people with autism, their families and carers said is important to them. The Plan has three key priority areas:

- 🧩 Awareness raising, information and training;
- 🧩 Assessment and diagnosis; and
- 🧩 Meeting support needs.

In March 2016, as part of the refreshed Autistic Spectrum Disorder Strategic Action Plan (ASD SAP), the Welsh Government announced that it would be funding a new national Integrated Autism Service (IAS) to help fill gaps in assessment and diagnostic services for adults and in post-diagnostic support for adults and support for parents and carers. Children and young people's ND services and the IAS were developed in parallel.

### **Western Bay Regional Integrated Autism Service**

The Western Bay Integrated Autism Service (IAS) works with autistic adults, their family members and anyone with a supporting role (including professionals). They also offer support to the parents/carers of autistic children and young people. Anyone can refer into the Integrated Autism Service.

Western Bay includes Swansea, Neath Port Talbot and Bridgend, however for the purposes of this PNA, only data referring to Neath Port Talbot and Swansea is presented.

The Integrated Autism Service provides direct support for autistic adults. We also provide advice, support and signposting for parent carers of autistic children, young people and adults. Adults can self-refer for an assessment if they think they may be autistic.

Autistic adults who have received a diagnosis at any point in their life can access the service for:

- 🧩 support to understand autism
- 🧩 short-term direct support
- 🧩 support to access other services which may include employment, education, health, leisure and recreational activities.

Professionals from any service can contact the IAS for:

- 🧩 consultation, advice and support on how to tailor interventions in an autism friendly way.
- 🧩 training for staff teams about how autism impacts on individuals and how to incorporate reasonable adjustments into working practice.

The Integrated Autism Service also offers:

- 🧩 Post Diagnostic Support Courses
- 🧩 Autism Advice Hubs –these are accessible for anyone with an autism related query.

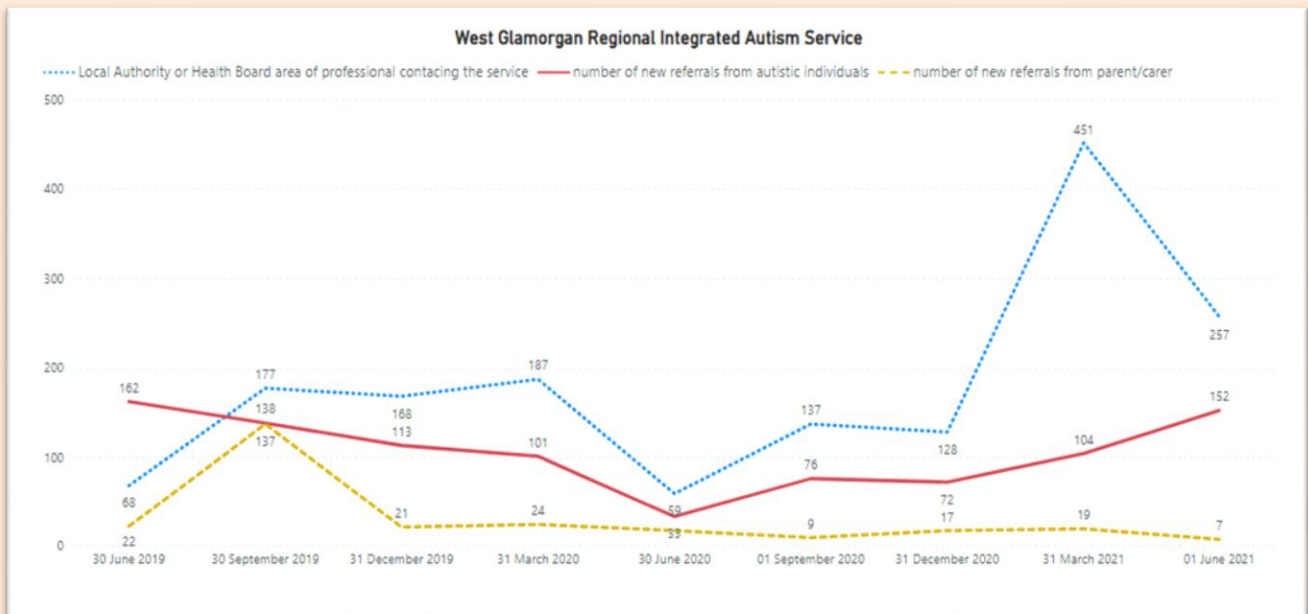
The service will not accept referrals for:

- 🧩 direct work with children
- 🧩 emergency or crisis intervention
- 🧩 respite care
- 🧩 diagnostic assessments for people under 17 years 9 months
- 🧩 prescription or monitoring medication
- 🧩 long-term input or care management.

Other services are available to help with these issues.

The time period for the graph below shows the number of referrals into the service from Neath Port Talbot and Swansea only. The period of

collection is based on the quarterly returns to DataCymru between April 2019 and June 2021.



## Social Care

In both Neath Port Talbot and Swansea, there are opportunities for children and young people to participate in fun, interesting and safe activities, providing a break for both children and family members with caring responsibilities.

In Swansea, Action for Children (AfC) is a service that offers support via a Short Breaks Programme to children aged 0 to 18 years old. The activities are provided by Ty Laura, which is a residential setting in The Mumbles and also offers the opportunity to have some respite in their recently acquired new 8-berth caravans, providing extra capacity and importantly a “holiday” setting located on a premier site on the Gower. These facilities are available in the day, evening, overnight and the weekend, providing much needed and invaluable resource to families who are in need of help and support with disabled families. Another facet of the Action for Children support is access to Family Link Carers who are able to provide similar services and activities in their own homes on the same availability as Ty Laura.

In Neath Port Talbot, a variety of short break services are provided to children in the form of daytime and overnight short breaks. Short break services include a 'Positive Outcomes Play Service' (POPS) which provide group based and bespoke play based activity sessions during evenings, weekends and school holidays. Overnight short breaks are provided through 'Park House', a purpose built overnight stay facility located near the beach in Port Talbot and through a 'Family Link' service which provides overnight stays within the homes of approved Family Link Carers. These services are annually reviewed in conjunction with children and their families which informs the service design, service delivery and monitoring of service quality.

In Neath Port Talbot, there is a placement of Autism and Neurodiversity Local Lead role within Social Services, providing consultation support to case managers, supporting the delivery of training across the sector. The officer represents Neath Port Talbot at regional and national level in respect of Autism Spectrum Disorder (ASD) and Neurodevelopmental disorder (NDD) linking local, regional and national partnerships and influencing service delivery. Additionally working with Autism Wales in the delivery of the new Training Framework across services, and providing specific training to local businesses, retail establishments, and community support groups.

The local Autism Lead will be responsible in delivering the Autism and Neurodiversity strategic plan for Neath Port Talbot. The role leads on a multi-agency planning and steering group which include carers, service users and Third Sector parties. The local Autism Lead will facilitate and co-ordinate the involvement of people with Autism and Neurodevelopmental disorders, parents and carers in local service development and have their views heard in local, regional and national policy/practice development.

There is also work continuing on a revised and updated NPT Neurodiversity Strategic Action Plan.

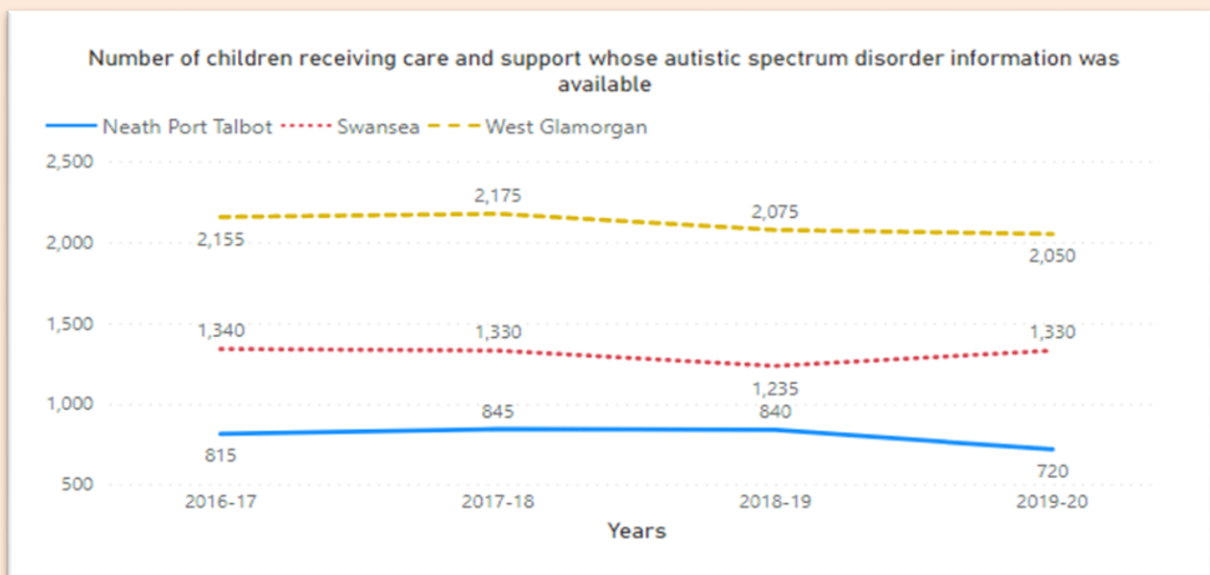
In Swansea, there is a local co-ordination group chaired by Head of Child and Family Services, with representatives from social services training, adult services, child and family services and education. The

aim of this group is to ensure Swansea have the right training and staff development in place in each of these service areas, and that they are compliant with the code of practice. It is anticipated that, where needed, there will be further developments where Swansea will seek to enhance existing specialist roles to offer consultations along with information, advice and assistance to the wider workforce.

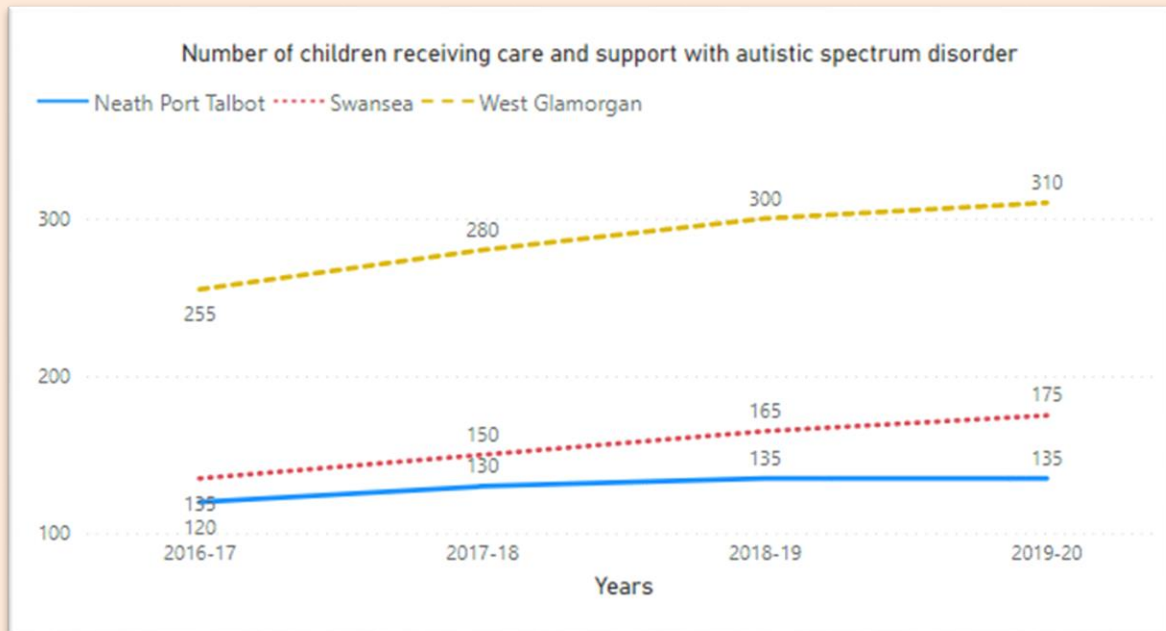
The establishment and utilisation of the Regional Autism Strategy Group, chaired by the Autism Lead, is a community stakeholder and partnership working across the area helps in the co-production and support of services, linking between IAS, NPT, Education Social care and 3<sup>rd</sup> Sector.

There is pending delivery of National Autism Training Framework for Wales (under development with the National Autism Team – [AutismWales.org](http://AutismWales.org)) this will be adopted in the training products for the IAS, and provide continuity of training for all current and new staff across Education, Health and Social Care in Wales.

The latest data from Social Care Wales shows the number of children aged 0-17 years receiving care and support from local authorities whose autistic spectrum disorder was available has remained stable since 2016/17.



However, of those children where the information is available, the number of children with an autistic spectrum disorder receiving care and support is increasing in the Region from 255 to 310.



Services provided by Local Authorities are integrated with various teams across the care spectrum.

The numbers of active cases in Neath Port Talbot as of December 2021, in each category, are included in the table below.

Year	Month	Area	Team	ADHD	Autism	Dual Diagnosis	Pathway Referral	Team Total
2021	December	Neath Port Talbot	Adult Complex Needs Team	0	48	2	1	51
2021	December	Neath Port Talbot	Child Care Disability Team	11	111	10	20	152
2021	December	Neath Port Talbot	Children's Community Teams	3	5	0	8	16
<b>Total</b>				<b>14</b>	<b>164</b>	<b>12</b>	<b>29</b>	<b>219</b>

The information directly relates to those individuals who are 'open' to the various Social Worker teams, and/or services within the County.

The data presently does not include directly those individuals who are linked with Social Services in a Mental Health Capacity.

This information may well be an anomaly that sits with both Health and Social Services.

Swansea were unable to provide the number of active cases for the same period but will be looking to provide this information for future iterations of the Population Needs Assessment.

### **Education PLASC Data**

The data recoded by Welsh government in the Pupil Level Annual School Census (PLASC) returns show that the number of autistic spectrum disorders is increasing.

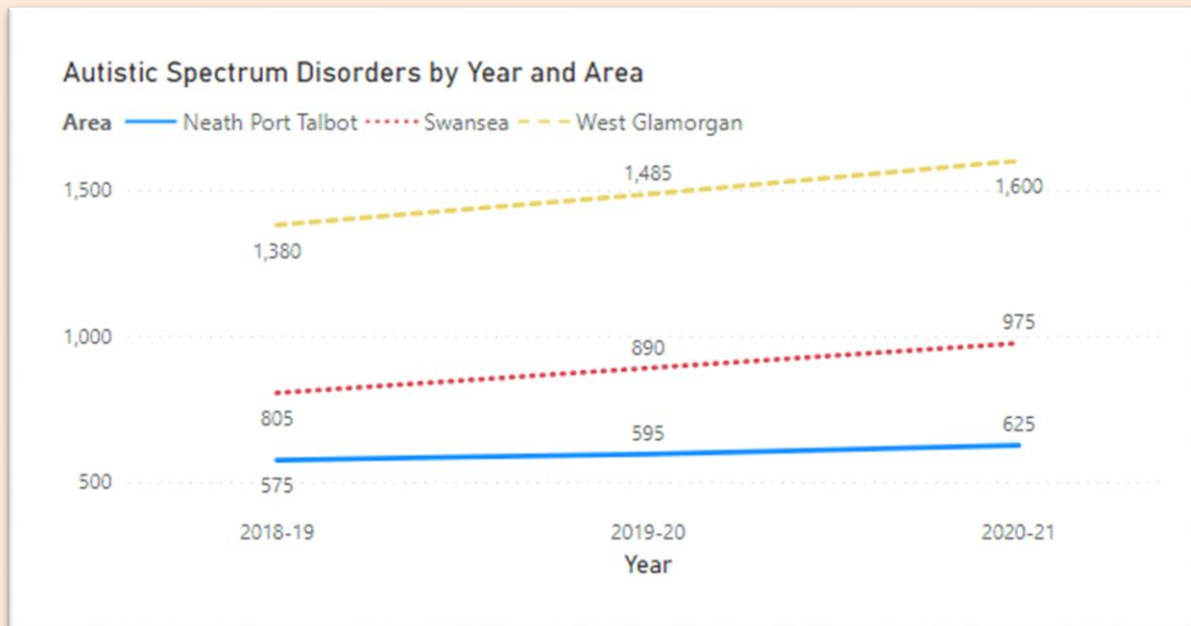
Likewise, the ADHD figures are also increasing.

Number of Special Educational Needs (SEN) by local authority and type of need.

Year	Area	Autistic Spectrum Disorders (1)	Attention Deficit Hyperactivity Disorder (1)
2018-19	West Glamorgan	1,380	345
2019-20	West Glamorgan	1,485	355
2020-21	West Glamorgan	1,600	380

The number of children that are recorded in West Glamorgan in schools show a growth of approx. 16% over the last 3 years for Autistic Spectrum Disorders. This data is taken from the Annual PLASC survey from all schools in the West Glamorgan region.





### Third Sector

There are a wide range of services and organisations to support Autistic people in the community. A list of examples can be found in Appendix 1.

### Swansea University

When students apply to university, they can declare a disability via the following codes:

- A. No disability
- B. You have a social/communication impairment such as Asperger's syndrome/other autistic spectrum disorder
- C. You are blind or have a serious visual impairment uncorrected by glasses
- D. You are deaf or have a serious hearing impairment
- E. You have a long standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
- F. You have a mental health condition, such as depression, schizophrenia or anxiety disorder
- G. You have a specific learning difficulty such as dyslexia, dyspraxia or AD(H)D
- H. You have physical impairment or mobility issues, such as difficulty using your arms or using a wheelchair or crutches

- I. You have a disability, impairment or medical condition that is not listed above
- J. You have two or more impairments and/or disabling medical conditions.

Swansea University currently has 202 enrolled students under code B, however, this by no means gives the full picture unfortunately as it is not possible to separate out the data for code J (319 enrolled students) where autism spectrum condition (ASC) may be one of the concurrent conditions. This data also only covers students who formally declared ASC at application, or took the step to have their university record updated if they received a diagnosis during their time at university.

The University Wellbeing Service has a specialist ASC Practitioner and Mentoring service for students with an ASC diagnosis or who are querying an ASC diagnosis. Since September 2021, this service has delivered 1039 appointments to 208 students who fit the criteria (this does not cover email queries from students with ASC).

Swansea University and Western Bay Integrated Autism Service (IAS) have been working together to provide better outcomes for autistic students. The team are looking to make approximately 30 new referrals into the IAS. The numbers of ASC students accessing the service has risen significantly over the last few years:

Academic Year	2016/17		2017/18		2018/19		2019/20		2020/21	
	Appointments	Students	Appt	Stu	Appt	Stu	Appt	Stu	Appt	Stu
<b>ASC Practitioner</b>	541	116	814	171	921	216	836	231	809	215
<b>ASC Mentor</b>	397	36	924	72	1310	91	2217	139	2449	131

\* An individual student may have appointments with both a Mentor and a Practitioner

## 4. WHAT NEEDS TO BE DONE TO ENSURE AUTISTIC PEOPLE ARE ADEQUATELY SUPPORTED?

The Welsh Autism Code of Practice aims to set out what is legally required of local authorities, health boards and other public bodies that provide services to support autistic people and their families in Wales. It has the potential to strengthen the rights of autistic people, and to improve the services available to them. Along with hundreds of autistic people, their families and professionals, in 2020 responded to the consultation on the Code of Practice to ensure it delivers the improvements in services and support that are needed.

Preventative services should enable autistic people in their daily lives, and should be agreed with the individual to meet their own identified needs. They should be co-designed and delivered to prevent the need for more intensive support. These services can include:

### Children

- i. providing advice to family or carers
- ii. promoting and facilitating involvement in local community groups and/or recreational activities
- iii. engagement with a range of health and social care practitioners.

### Adults

- i. encouraging involvement in the local community, daily living and healthy lifestyles
- ii. facilitating access to mainstream preventative services and or adaptations to accommodate their needs
- iii. supporting involvement with housing and employment services
- iv. engagement with a range of health and social care practitioners.

Source: [Code of Practice on the delivery of autism services | GOV.WALES](#)

The National Institute for Health and Care Excellence (NICE) has produced and recently updated guidance on the management and support of children and young people on the autism spectrum. The full guidance is some 700+ pages and there are a raft of recommendations

that cover 11 pages. Overall it does provide a comprehensive guide on a range of best practice with regard to children with autism.

Source: The NICE guideline on the management and support of children and young people on the autism spectrum' Updated 2021,  
<https://www.nice.org.uk/guidance/cg170/evidence/full-guideline-pdf-248641453>

### **National Autistic Society (NAS) 'Left Stranded' Report**

The NAS Left Stranded report was referred to in First Minister's Questions in the Welsh Parliament. The First Minister acknowledged the impact of the pandemic on autistic people and provided an update on what the Welsh Government was doing to improve the support available. This included a commitment to make a further statement on the proposed Code of Practice on the Delivery of Autism Services, detailing plans for publication.

Source: <https://www.autism.org.uk/what-we-do/news/coronavirus-report>  
[NAS AnnualReport 2021.pdf \(thirdlight.com\)](#)

### **Welsh Code of Practice on the Delivery of Autism Services**





The Autism Code of Practice came into force on 1 September 2021. Its purpose is to secure the implementation of Welsh Government's autism policy priorities, currently published in the Autistic Spectrum Disorder Strategic Action Plan 2016. It sets out what autistic people, their parents and carers can expect from public services in Wales and how the Welsh Government intend to adapt the way they organise society to be more aware and more attune to neurodiversity. It gives clarity to local health boards, local authorities and regional partnership boards on the Social Services and Well-being (Wales) Act and/or the NHS (Wales) Act 2006 and the responsibilities and services they are required to provide to support autistic people in their day to day lives. The code is supported by a Delivery Plan 2021-22, which outlines how this will be delivered and by who. This outlines the first year of priorities including a focus on recovery of services following the COVID-19 pandemic, inclusion of the Welsh Language in service delivery and support for autistic people who identify as Black, Asian or Minority Ethnic.

To understand increasing demand for support, the Welsh Government has commissioned a review of all age neurodevelopmental services in Wales commenced in February 2021. The review will understand the




current situation across Wales, identifying the demand, capacity and design of neurodevelopmental services for children, young people and adults. This work is due to be completed by spring 2022 and will inform future decisions on advancements in service design and delivery.

The Welsh Government has also launched the Together for Children and Young People (T4CYP) Programme. The programme included a focus upon addressing the needs of children and young people with neurodevelopmental (ND) disorders, such as attention deficit hyperactivity disorder (ADHD) and autism. This led to the establishment of a national “assessment pathway” and ND teams in each Local Health Board (LHB).

Local Health Boards and NHS Trusts must:

-  Make arrangements to ensure that health services are aware of the autism services available in their local areas and have clear pathways for referral.
-  Ensure that staff receive appropriate training in autism and associated behaviour and sensory needs at a level appropriate to their involvement.
-  Ensure that people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from Children or Adults Mental Health Services. Consideration of core ASC indicators and their influences on individuals must inform the care and support offered and its outcomes.
-  Ensure IQ is not considered as part of the eligibility criteria.

Local Authorities must:

-  Ensure that as part of their Information, Assistance and Advice Service information is available on local autism services.
-  Ensure that IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act.
-  Ensure that practitioners assessing an autistic individual’s eligibility for social care services have sufficient knowledge and skills to understand the impact of autism on the individual’s ability to achieve the five elements of well-being without care and support.

Local Authorities with Local Health Boards and NHS Trusts must:

- 🧩 Ensure that autistic people are aware of the right to access a needs assessment. This should be offered at the diagnosis stage
- 🧩 Ensure that awaiting a diagnosis is not a reason to be refused support and other services.
- 🧩 Ensure that carers of autistic people are aware of the right to access a needs assessment. The process of obtaining one should align with the diagnosis process and be offered at the diagnosis stage and a referral made if needed.
- 🧩 Encourage innovation in the development of autism services.
- 🧩 Ensure that reasonable adjustments are in place for autistic people to ensure they are able to access services in the same way as everyone else.
- 🧩 Ensure that where needs for specialist service provisions are identified, where possible these are made available.
- 🧩 Ensure that health and social care support for autistic people detained in the secure estate is provided by appropriately trained practitioners.

Source: [Code of Practice on the delivery of autism services | GOV.WALES](#)

## 5. CONCLUSION AND GAPS IDENTIFIED

The key issues highlighted in this chapter are:

- 🧩 Availability of preventative services that would enable autistic people in their daily lives
- 🧩 Access to mental health and wellbeing services
- 🧩 Low rates of employment and vocation
- 🧩 Impact from COVID-19 for people with autism
- 🧩 Transition to adulthood is complex process
- 🧩 Large number of adults with autism who are still cared for at home by their older carers

The most significant gap identified in the development of the autism PNA chapter was the insufficient data for autism across all services. This means we are unable to clearly identify the gaps and demand for different services.

The limited data sources included do however evidence that there is a growing number of children with autism and data suggest that this will continue to rise. In terms of planning the following need to be considered:

- 🧩 Ensure a common understanding and consistency across the partners in the way the data is recorded and analysed
- 🧩 Carry out more analysis to plan for the needs of the population living in the region
- 🧩 Engagement with people with autism and their carers to inform future developments for autism services
- 🧩 Better sharing of information between partner organisations and people, particularly in terms of the services that are available across the region.
- 🧩 Empowerment to achieve effective and meaningful co-production, and the need to develop the ability for people to contribute to the social change of the services they receive.
- 🧩 Further planning in terms of the requirements from the ALNWA Act around a fully inclusive education service needs to continue.

In addition, further planning work needs to be undertaken in relation to the Welsh Code of Practice on the Delivery of Autism Services.

## Appendix 1:

### Groups and organisations supporting the autistic community in the West Glamorgan region

[National Autistic Society Swansea Support Group](#) - This is a support network and growing community for autistic people, parent/carers and their family & friends. Whether a person is diagnosed, on the pathway or suspect autism they are very welcome to access the charity for support, advice, appropriate and enjoyable events, courses and workshops.

**Chinese Autism Support @ (CIWAc)** is a project that is committed to advocate for the Chinese ethnic autistic children and their families living in South Wales. The project provides culturally sensitive, multilingual advocacy services to help resolve issues or concerns these children may have about their education, health and social services; also to assist in empowering families to break the cultural and ethnic stigmas to get an early diagnosis for the children and have a better understanding of how to improve their life skills.

[Swansea Autism Movement \(SAM\)](#) - The main aim of this group is to fundraise and connect with other families in Swansea who have a young person with ASD diagnosis or are on the pathway.

[SNAC \(Special needs activity club\)](#) – SNAC Port Talbot is a specially designed centre for children and young adults with special needs to relax, make friends and have fun in a secure setting.

[Discovery Swansea University](#) - Inside Out: Creative activities for children and young people with Autistic Spectrum Disorder.

[Play and Leisure Opportunity Library Play](#) and Leisure Opportunity Library are a registered charity providing specialist toys and leisure equipment for children and adults with a disability in a lending library service. For a small fee, members can have access to a range of over 500 items including an extensive stock of multi-sensory and specialist



equipment. Library stock can be borrowed for a month at a time but longer by arrangement. They offer a limited collection and delivery service to members living in the Swansea area.

**Circus Eruption** is a young person-centred charity with diversity inclusion, equality and fun at its heart. It harnesses the energy and commitment of young people, volunteers and staff to create a safe, playful, accessible and creative environment, free from discrimination and prejudice. Circus skills are used as a vehicle to challenge self-perceived and imposed limits enabling people to realise and believe in their own potential and the potential of others.

**Interplay** is a project aiming to integrate young people with special needs into play and leisure opportunities that are available to any child in their community. They take 2 - 19 as their age range and provide holiday, after school and weekend activities in Swansea, Neath and Port Talbot.

**ELI Project** provides love and comfort to families with special needs by hosting events in safe environments where they can come together and connect with others.

**KidStop** is a preschool Parent and Toddler group Lifepoint Centre Swansea.

**Diversity Group** runs on Monday evenings from 5pm to 7pm. It is a leisure opportunity for children with ASD and siblings. Parents and carers of children under 12 must stay. Contact [Amanda.lervy@localaid.co.uk](mailto:Amanda.lervy@localaid.co.uk)

**The Swans Community Trust** offer [pan-disability activities](#) that cater for children and adults with a range of disabilities. Autism Cwm Wanderers AFC, Bravehearts and Pontardawe ASD football academy provide an opportunity for children to be completely at ease with other children.

**Mixtup** is largely a youth run and focused club that aims to provide its members with the things that most young people want - independence

and freedom away from their day to day responsibilities and to just be themselves and have fun in a safe and stimulating setting.

[Friends of Young Disabled \(FOYD\)](#) is a Swansea based charity, established in 1985, which provides a centre for young disabled people and other members of the community to meet and use its facilities to promote learning opportunities, engage in social activities and have fun.

[Surfability](#) provides surfing lessons and experiences for people with additional needs due to disability, illness, injury or learning difficulties at Caswell Bay beach.

[BikeAbility Wales](#) provides a cycling opportunity for everyone to enjoy. It was set up to enable people of all abilities to enjoy the pleasures and health benefits of cycling. BikeAbility holds cycle sessions each week, with bikes to suit all ages and abilities.

[Swansea Bay and Beyond](#) is an online community, volunteer run, set up to centralise and signpost as many local events and activities as possible that are available for both children and adults with additional needs.

[CanDo Hub](#) provides a training provision and inclusive fitness classes catering for adults with additional learning needs and disabilities in Swansea.

[Action for Children Stepping Stones Children's Centre](#) provides services for pre-school children who have an emerging or diagnosed disability. At Stepping Stones, children take part in activities both in a group, and working one-to-one with a project worker. Play workers are also on site to facilitate play and learning opportunities and to be with children between one-to-one sessions.

[Mountain Movers](#) is an ALN friendly educational community providing services and support to families who are electively home educating.

[ASDES](#) are a team of professionals, including an assessor, job coaches / trainers, counsellors, psychologist and ASD consultant. ASDES have been helping people with autism access the job market since 2010.

## **Support for Parent Carers**

['Joining the Dots' Parent Carers](#) is a Wales wide vibrant online community of parent carers of a child, young person or adult with additional needs. It's a place for parent carers and families to connect and share practical advice as they navigate services. It is a supportive forum to ask advice relating to health, social care, education and the practicalities and challenges of everyday life.

[Swansea Parent Carer Forum](#) are a voluntary group of parent carers all with children with additional needs. The group works with, but are independent of the City & County of Swansea, with the aim of making sure that services meet the needs of disabled children, young people, adults and their families.

[S.A.N \(Support Additional Needs\)](#) are a peer-led voluntary community group offering support and friendship to parents, carers and individuals who have additional needs. During school term time, they meet to support each other, signpost, and also host a range of speakers and coffee mornings for families living in Neath and beyond.

## **Young Carers**

[YMCA Swansea Young Carers Service](#) provides support and information for young carers aged 8-18 in Swansea. With a holistic family approach to support, every young carer and their family receives an in-depth assessment of needs which helps inform an action plan of support that intends to build resilience towards being a young carer.

[Swansea Young Adult Carers Project](#) is a transition project that supports the Young Carers (aged 8-18) who attend YMCA Young Carers Service from children's services onto adult services. They are

supported to navigate the process of leaving one service and moving into another as they develop into adulthood.