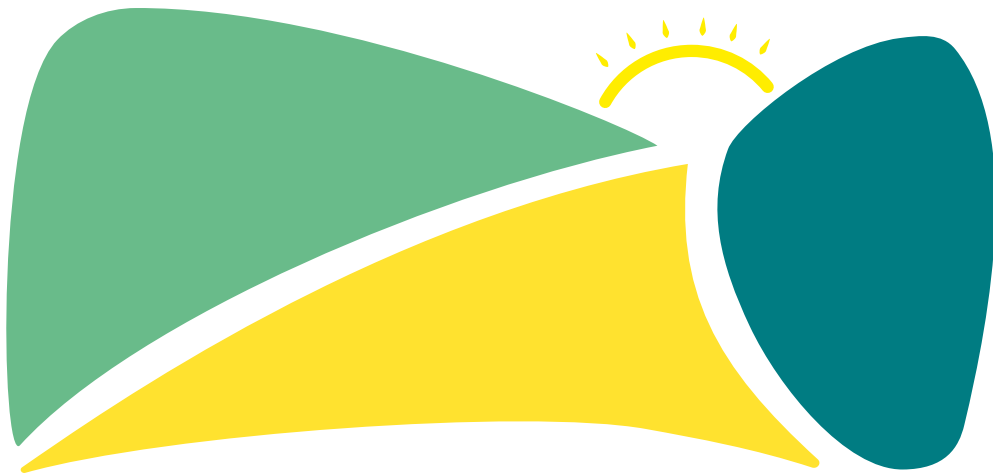




Presents

The Yellow Brick Road



A guide to services
for autistic people, their families, friends
and carers in Devon

Created by	Trish Darke Dimensions for Autism Co-Facilitator
With help from	Matt Grimsey Mark Evans Maria Waite Michael Everitt Katherine Last Ben Davey Guide Volunteers
With support from	Devon County Council
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Disclaimer

We at Dimensions for Autism CIC (DFA) have made every effort to ensure that the information in this guide is accurate and up-to-date, but details frequently change. Please make sure you are using the most recent version.

Neither DFA nor Devon County Council can guarantee the accuracy of the information about the organisations in this guide or the quality of the service they provide. Under no circumstances will DFA or DCC be liable for any loss, damage or injury arising out of any contact made by a private individual with any of the organisations included in this guide.

If you notice anything that is inaccurate, incomplete or out-of-date, let us know:
trishdarke.dimensionsforautism@gmail.com

Do you have any suggestions for additions to the guide? Great! Let us know:
trishdarke.dimensionsforautism@gmail.com

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About the Guide

This guide has been written with the support of adult Autistic members of Dimensions for Autism CIC (DFA). It was first published on the DFA website in April 2019.

DFA is an adult autism support group based in Devon. If you are an adult on the spectrum and want to add any information to this guide (when it is updated) then please email us at the following address:

✉ trishdarke.dimensionsforautism@gmail.com

Who is this guide for?

First and foremost, this guide is aimed at Autistic people, and those who believe they are Autistic, who live in the county of Devon, whether they have a formal diagnosis or not. It includes services and support in all three local authorities in the county - Devon County Council, Plymouth Council and Torbay Council.

This guide also includes information for the relatives, partners and friends of Autistic adults, as well as those who act as carers for someone on the spectrum.

Why the 'Yellow Brick Road'?

Being Autistic can have touch every aspect on a person's life, and interact with any co-occurring conditions in complex ways. Finding exactly the right support can often be challenging. This guide aims to provide a path through the confusion, from getting a diagnosis onwards, and to act as a series of signposts to point you in the direction of the specific services you may need.

So why a yellow road? Because the colour gold (chemical symbol 'Au') is often associated with autism - but our funding wouldn't quite stretch to a gold brick road, so we did the best we could with what we had.

How to use this Guide

To make this guide as easy to use as possible, it is split into sections that cover specific themes or types of services. Of course, some organisations offer a range of different services, so don't be surprised if you see the same name in several sections.

We've tried to provide as many different ways of contacting these organisations as possible, to help you get to the services you need. The contact info is symbol-coded, as in the example below.

Organisations

Each organisation included in the guide gets its own short description. We've tried to include as much information as we can about what is on offer, but it's a good idea to contact the organisation or visit their website for full details.



Website



Telephone number



SMS Text number



Email address

Groups

Some organisations have sub-groups for specific services. We've provided as many details about these as possible wherever we can.



Where the group meets



How often the group meets



Meeting times



Price for attending



Contact telephone number



Contact email address

What is Autism?

In brief, 'Autism' is the name given to a range of neurological and sensory differences. These differences are built into the brain and nervous system from the earliest stages of development, and are present for life, affecting the way Autistic people experience and interact with the world. While exact numbers are difficult to research, recent estimates suggest that Autistic people may be around 2% of the population.

While each Autistic person will have unique experiences, there are common factors that generally fall into two broad categories: sensory and executive function.

Sensory

Almost all Autistic people experience some sensory differences from the population at large. These can range from mild to intense, and include all the senses of the human body: the five well-known ones (sight, sound, smell, touch and taste) but also the sense of balance and acceleration (vestibular), the position of your body parts relative to each other and the world around you (proprioception), and the various internal bodily senses for things like heart rate, muscle tension, hunger, thirst and so on (interoception).

Sensory issues can include (but are not limited to):

- Being extremely sensitive to light, sound or touch
- Finding it hard (or even impossible) to tell when you are hungry, too hot or cold, or in pain
- Having specific preferences for (or against) food flavours and/or textures
- Appearing clumsy due to poor balance, spatial awareness and/or hand-eye coordination
- Actively seeking out specific sounds, textures etc. that you find especially enjoyable

Executive Function

'Executive function' broadly refers to the brain's ability to process, organise and respond to the information it receives. These functions often work differently in Autistic people, sometimes as a result of (or in combination with) dealing with an overload of sensory information (see above).

Executive function issues can appear as (but are not limited to):

- Having a poor short-term memory
- Finding it difficult to keep track of the passage of time
- Being extremely – sometimes painfully – sensitive to the emotions of others
- Becoming so absorbed in their interests that you cease to notice almost anything else
- Needing extra time to mentally prepare for starting and/or stopping an activity
- Having trouble identifying and/or describing your emotions (Alexithymia)

Autistic Behaviour

Because the neurological differences are (at time of writing) not directly observable, Autistic people have historically been identified through how their observed behaviour differs from the general population. Some of these are direct results of Autistic neurology, while others are learned coping strategies; many are a combination of both.

There are, of course, as many 'Autistic behaviours' as there are Autistic people, but some frequently noted behaviours are:

- Preferring consistency, familiarity and/or routine
- Intense fascination with specific subjects, people and/or sensory experiences
- Avoiding busy, crowded or fast-changing environments
- Making repetitive movements ('stimming') to relieve stress or for enjoyment

Autism and Socialising

While central to the classic diagnostic criteria, the social interaction challenges Autistic people often experience are better understood today as a side-effect of having a brain that is wired differently from the majority. They are still used as a core diagnostic category, though, and are often the most obvious sign to others.

While communication is, of course, a two-way activity, Autistic people do report some common issues:

- Focusing on the words that are spoken in conversations rather than non-verbal signals (facial expressions, body language, gestures)
- Difficulty following multiple, overlapping speakers in busy environments
- Preference for practical, goal-oriented interactions over 'small talk' and socialising for its own sake

While some Autistic people will avoid social situations, often due to past negative experiences trying to fit in by hiding their Autistic traits ("Masking"), being Autistic doesn't mean being inherently anti- or non-social. Many Autistic people actively want social connections, but struggle to form these bonds in a world that doesn't accept them as they are.

As these examples show, there is no single thing that is 'autism'. This makes it an extremely difficult term to summarise, because it encompasses a range of experiences as broad and varied as the number of Autistic individuals in the world.

The Spectrum

Talking about 'autism' as a single thing is hard, because the criteria used to identify and diagnose the condition have changed substantially since it was first codified in the 1940s. At the same time, our ideas about what 'autism looks like' and who can (and can't) be Autistic have moved away from the young, white male stereotype. A lot of individuals who identify as Autistic today don't fit neatly into the categories created by clinicians over the years; most straddle the gaps between them or shift from one to another throughout their lives.

The term 'Autistic spectrum' was coined to reflect this variability. While some might try to present this as a straight line between the 'worst' and 'mildest' cases, 'the spectrum' actually acts as an umbrella term to acknowledge the broad multi-dimensional range of Autistic experiences.

Today, most Autistic people who get a diagnosis are given the label 'Autism Spectrum Disorder' (ASD), although some prefer to use the more neutral Autism Spectrum Condition (ASC). This has mostly replaced a range of diagnostic categories that were previously used, though you may still encounter people who were given and/or identify with these labels:

- Asperger's Syndrome
- High-Functioning Autism (HFA)
- Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)

Co-occurring Conditions

While not every Autistic person experiences other issues, there are some conditions that are diagnosed more often in the Autistic community than in the general population.

The exact relationship between these other conditions and autism - whether they are an expression of the underlying sensory or executive function issues, or separate conditions altogether - is currently unclear, but regardless of the source, these often need to be considered when deciding how best to support the individual:

- Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)
- Dyslexia, Dyspraxia, Dyscalculia, Dysgraphia, and other specific learning disabilities
- Intellectual Disabilities (ID)
- Anxiety, depression, and other mental health issues
- Epilepsy and other seizures
- Obsessive Compulsive Disorder (OCD)
- Rejection-Sensitive Dysphoria (RSD)
- Pathological Demand Avoidance (PDA) (see appendix 5)

Neurodiversity

Coined in 1997 by Australian disability rights activist Judy Singer, the 'neurodiversity' refers to the idea that neurodevelopmental conditions like autism should be thought of not as defects in need of repair, but as a natural part of human variation. Building on the Social Model of Disability, the neurodiversity movement aimed to draw more attention to the social barriers faced by Autistic people, especially the prejudice of non-autistic 'neurotypical' people.

Though at first it focused mainly on the Autistic community, the neurodiversity movement has since grown to cover a wide range of conditions, and to greater recognition of the overlaps between them – for example, some people diagnosed with both autism and ADHD use the term 'AuDHD' to talk about their experiences.

Autism and the Law

Even after it was recognised as a distinct condition, autism continued to be treated as a sub-type of learning disability. More recently, however, the UK government has recognised that autism needs to be treated on its own terms. It has passed legislation aimed at addressing the requirements of Autistic people.

The Equality Act 2010

Welding together 116 existing pieces of legislation, this broad Act created a framework to define discriminatory treatment that targeted specific sub-groups of society, and to provide protection for these sub-groups.

At its core, the Act declares a number of 'protected characteristics', including (among others) age, race, gender identity, sexual orientation, religious belief and disability. With few exceptions, any behaviour that disadvantages anyone with one or more of these protected characteristics, whether direct or indirect, is unlawful. The act also outlaws harassment of these groups, and the victimisation of anyone who makes (or supports someone else in making) a complaint about discriminatory behaviour.

To try and ensure equal treatment of these protected groups, the act defines three main means of reducing or eliminating discrimination.

- **Positive Action** – this is mainly aimed at employers and empowers them to take active steps to encourage recruitment, retention and advancement people with protected characteristics ahead of those who do not.
- **Reasonable Adjustments** – this broader category covers any change an organisation can make to remove or reduce barriers protected people may face in accessing their services (see more about this in appendix 5)
- **Public Sector Equality Duty** – this places a specific requirement on public bodies, as well as private companies providing a public service (e.g. power and water utilities), to actively eliminate unlawful discrimination and promote equality and good relations between protected and non-protected groups.

While individual Autistic people may not consider themselves disabled, all autism spectrum diagnoses are considered to fall under the 'disability' characteristic. This entitles Autistic people to all the protections of the Equality Act.

The Autism Act 2009

The first piece of autism-specific legislation passed in the UK, and the only act targeted at improving services for one disability, the Autism Act laid out in law the government's duty to meet the needs of its Autistic citizens.

The act outlines two key requirements:

- The Government must create a strategy to meet the need of Autistic adults, including regular reviews.
- The Government must produce statutory guidance for local authorities to implement the strategy.

In practice, this meant that national government had to formulate a strategy to identify and diagnose Autistic adults in the community, and to provide appropriate support for them throughout their lives. Local authorities are then required to deliver on this strategy by providing diagnostic and support services, and by ensuring that medical professionals and frontline staff are given appropriate awareness training.

The Fulfilling and Rewarding Lives Strategy 2010

Published in the wake of the Autism Act a year earlier, this strategy set out general guidelines for implementing the act's requirements, with the overarching goal of enabling Autistic people to live 'fulfilling and rewarding lives' (hence the title) within their communities.

The strategy identified four key areas to be targeted for improvement:

- Increasing awareness and understanding of autism by creating training packages for those in health, social care and the criminal justice system
- Developing a clear, consistent pathway for diagnosis, and ensuring that those with a diagnosis are eligible for care and support
- Improving access to appropriate services and support for Autistic people, to help them live as independently as possible.
- Providing support for Autistic people to find and stay in employment, including raising awareness of autism with employers.
- Ensuring that local authorities set up autism-focused boards to implement and monitor these improvements, using the involvement of Autistic people and their carers to guide development of appropriate services.

To oversee these improvements, the government set up a National Autism Programme Board to help develop training for health professionals and provide guidance on the kinds of reasonable adjustments to be made to make services more accessible to Autistic people.

The 'Think Autism' Strategy 2014

Following a review of the Fulfilling and Rewarding Lives strategy, the government published an update in 2014. This 'Think Autism' document reinforced and extended the goals of the original, while also trying to address its shortcomings.

The main goal of the document was to extend the government's autism strategy beyond service providers and employers to build general awareness and acceptance in entire communities. It set up a temporary Autism Innovation Fund to support the development of community care and support, especially for those Autistic people who did not qualify for statutory services. To give shape to what a 'fulfilling and rewarding' life should be, it defined 15 priority challenges - also known as the '**I Want**' statements.

To ensure these goals were consistently implemented across the country, the document proposed improvements in data collection by local authorities about their Autistic constituents. It also stated that Autistic people should be able to access information about the services available to them, and be able to compare their locality's performance against that of others.

The Care Act 2014

While not directly autism-related, this act is important because it lays out the duties local authorities have to assess need for and provide care to (when appropriate) those constituents who require it.

It is an extremely long and complex piece of legislation, but in the broadest terms it states that:

- Local governments must provide needs assessments to anyone who seems to need some form of care and support, regardless of how likely they are to be eligible for support.
- They must also provide separate Carer's Assessments for individuals who meet the criteria as carers for a person with a disability (e.g. parents).
- Assessments must focus on the wellbeing and life goals of the person. They should involve the person directly, as well as their carer and/or someone else they nominate to assist them, wherever possible.
- Care should be provided with the goal of preventing the person's needs from becoming more serious, or at least delaying this as long as possible.
- Those assessed as needing support should be able to choose from a range of high-quality local providers to meet their requirements. Information on these care providers should be readily available to users.
- These rights apply regardless of whether the person being cared for is a child or an adult. A child who is about to turn 18 must be given a Child's Needs Assessment (CNA) to evaluate their probable needs as an adult, and their existing care left in place until this is completed.

If you believe you may be eligible for an Assessment of Needs or a Carers Assessment, it is worth researching important acts in more detail to find out how it might apply to your specific situation - see **Appendix 1** for links to further information.

The National Strategy for Autistic Children, Young People and Adults 2021-26

In July 2021 the UK government published a new report to update and replace the 2014 'Think Autism' Strategy (see above). While acknowledging that general public awareness of autism had increased substantially since the passing of the Autism Act in 2009, the report seeks to build on this work and expand it to areas not covered by previous documents, to ensure that Autistic people are able to fully participate in society.

The report lays out six key areas for improvement over the five-year period to 2026:

- Improving understanding and acceptance of Autistic people within society, especially for groups like minorities and non-male-presenting people, who have historically been under-diagnosed due to outdated stereotypes.
- Improving autistic children and young people's access to education and supporting positive transitions into adulthood, both within and outside of the school system.
- Supporting more Autistic people into employment and reducing the number who leave or are forced out of work due to insufficient workplace support.
- Tackling health and care inequalities for Autistic people and improving diagnostic pathways for both children and adults to reduce wait times for a diagnostic assessment.

- Building the right support in the community and supporting people in inpatient care, to reduce the number of Autistic people admitted unnecessarily to mental health inpatient care, and to improve care for those that are admitted.
- Improving support within the criminal and youth justice systems, by building understanding of Autistic people within police and other criminal justice staff and ensuring that the specific needs of Autistic people who come into contact with the criminal justice system are recognised and met.

The report lays out three core mechanisms for achieving these goals:

- Rebalancing research into autism to focus on how best to meet the needs of Autistic people within society, rather than on the physiological causes or mechanisms.
- Improving data collection and reporting, with a greater role for Autistic people, their families, and charities and other organisations that work with them.
- Strengthening governance and accountability, expanding the existing Autism Strategy Executive Group to include a greater representation of Autistic people and their families and carers from a wider range of backgrounds.

The report also acknowledges the substantial impact of the COVID-19 pandemic and associated lockdowns on the Autistic community, which both exacerbated pre-existing issues of loneliness and access to public services within the Autistic community, and greatly increased demand on diagnostic services for both children and adults.

The Health and Care Act 2022

The Health and Care Act 2022 is a large and complex piece of legislation that mainly focuses on overhauling the organisation and oversight of the NHS as a whole, and imposed a range of new considerations that NHS decision-makers must take into account. See **Appendix 1** for links to full information about the act.

Among its many provisions, the most relevant to Autistic people is Section 181, which requires all staff who provide NHS services to undertake mandatory awareness training on learning disabilities and autism.

The Oliver McGowan Mandatory Training on Learning Disability and Autism was developed as the standard package to be delivered to all NHS staff under this new requirement. The training package was developed in close collaboration with Autistic people, and the in-person training must be co-delivered by an Autistic person.

See **Appendix 2** for more details about the Oliver McGowan training.

Statutory Services

Diagnostic Services

If you suspect you are autistic, your first port of call is your GP. Under the **Autism Act**, local authorities must provide a pathway to diagnosis. This service is free, but you need to be referred to it by your GP. See **Getting a Diagnosis** for more details.

Assessments of Needs

Anyone who thinks they may need support may be entitled to a **Needs Assessment** (also called an **Assessment of Needs**) from their local authority. This service is free, and you can ask for an assessment yourself - you don't need to be referred by someone else. A formal Autism Spectrum diagnosis is helpful, but you don't need one: the assessment is about your needs as an individual, not a list of symptoms.

To refer yourself for an assessment, you will need to contact the care provider of the local authority for the area you live in:

Devon County Council



www.devon.gov.uk/adult-social-care/assessments/care-support-needs-assessments/



0345 1551 007



csc.caredirect@devon.gov.uk

Plymouth Council



www.plymouth.gov.uk/get-adult-care-or-support



01752 668000

Torbay Council



www.torbay.gov.uk/adult-social-care/assessments/



01803 219700

Disagreeing with the Assessment

The assessor should always discuss with you if you do not agree with the assessment and must record any differences of view.

Both you or your representative **must always be informed** of your right to make a complaint using the complaints procedure of your local authority (see below) if you remain unhappy with the assessment and decision.

For further details on eligibility and the eligibility criteria, please refer to:

- Section 13 of the Care Act 2014
- The Care and Support (Eligibility Criteria) Regulation 2014
- Section 6 of the Care Act Statutory Guidance

Carer's Assessments

Anyone who acts as a carer for an Autistic person may be entitled to their own separate **Carer's Assessment**, to determine what impact the caring responsibilities have on their lives and what support they might be entitled to.

As with Needs Assessments, you can refer yourself for a Carer's Assessment, but in some areas you will need to contact a different organisation:

Devon County Council



<https://www.devon.gov.uk/adult-social-care/carers-support/carers-assessments/>



0345 643 4435

Plymouth Council



01752 668000 or 01752 201890



customerservices@plymouth.gov.uk

caringforcarers@improvinglivesplymouth.org.uk

Torbay Council



www.torbay.gov.uk/adult-social-care/carers/carers-assessment/



01803 219700

Benefits

Autistic people are entitled to the same unemployment benefits as any other UK citizen. In England, the legacy benefits system has now been replaced with Universal Credit for all new claimants. You can find out more about the Universal Credit system using the following links:



www.gov.uk/universal-credit

www.understandinguniversalcredit.gov.uk/

On top of the standard benefits system, you may also be eligible for a **Personal Independence Payment (PIP)**, depending on how much your condition impacts your day-to-day living.

To request a PIP application form, or find out more about the application process:



www.gov.uk/pip/how-to-claim



0800 917 2222

The application process can be long and complex, so getting advice and support can increase your chances of success. Consider contacting your local Citizens' Advice Bureau (CAB) for guidance:



www.citizensadvice.org.uk/



03444 111444

If you are receiving benefits and also looking for work, your local Jobcentre may employ a **Disability Employment Advisor**. These can offer employment assessments to help identify

your skills and the kinds of work that might suit you. They may also be able to refer you to support schemes like Access to Work.

If you have (or are about to start) a job, but feel you need adjustments that your employer can't (or won't) provide, the **Access to Work** department can provide assistance and support. If you are eligible, you may be given a grant in addition to your other benefits, to be spent on specialist equipment, a support worker or travel adaptations.

To find out more, and to apply to the Access to Work scheme:



www.gov.uk/access-to-work



www.disability-grants.org

0800 121 7479

Special Educational Needs

Every local authority is required to provide a **Local Offer**, a collection of all the education, health and social care services that are available to people with SEND aged 0-25.

Each local authority in the county of Devon has its own Local Offer:

Devon County Council



www.devon.gov.uk/educationandfamilies/special-educational-needs-and-disability-send-local-offer



sendlocaloffer@devon.gov.uk

Plymouth Council



www.plymouth.gov.uk/schoolseducationchildcareskillsandemployability/specialeducationalneedsanddisabilityandlocaloffer/specialeducationalneeds/localoffersendexpectations

Torbay Council



www.torbay.gov.uk/schools-and-learning/send/local-offer



SENDreforms@torbay.gov.uk

If regular SEND support is not enough, you can also apply to your local authority for an **Education, Health and Care Plan (EHCP)**. This is a transferable report that details the additional educational, health and social needs of the person, along with any assistance required to meet those needs.

Anyone who believes a child may need additional support can request an assessment for an EHCP, including the child themselves if they are aged 16 or over. Once in place, an EHCP can remain in force until the person turns 25.

For general information about EHCPs:



www.gov.uk/government/publications/send-code-of-practice-0-to-25

The National Autistic Society (NAS) also have an EHCP guide:



www.autism.org.uk/about/in-education/extra-help-in-school/england/ehc-plans.aspx

Advocacy

If you are struggling to communicate with or express your needs to service providers, you may be entitled to advocacy support. This may mean nominating a friend or relative to speak on your behalf, or you may be able to get support from an advocacy service or charity.

The **Devon Advocacy Consortium** is a partnership of six charities that offer professional advocacy services for any over-16s who need advice or representation in making a health or social care issue or complaint (there are strict criteria). To make a referral for advocacy you will need to speak to your Social Worker, as they are currently not accepting self-referrals.

For more information:



devonadvocacy@livingoptions.org



0845 231 1900

The Devon and Cornwall Autism Card

Devon County Council and Devon and Cornwall Police have collaborated to create the **Devon and Cornwall Autism Card** for residents of the two counties. The card is available for free to any resident of Devon or Cornwall who identifies as Autistic - a formal diagnosis is not required.

To find out more information, and to request a card, contact Dimensions for Autism:



<https://devonautismcard.info/apply>



07496 496651 (Voicemail only)



autismcard@dimensionsforautism.life

Getting a Diagnosis

Preparing for Diagnosis

At present, there is no definitive biological test for autism, so clinicians have to rely on observations of the person's behaviour and lifestyle. Some of this will be done during face-to-face assessments, but this is not always reliable, especially if the person has learned to conceal (mask) their Autistic nature.

Because of this, most diagnostic services will assess your behaviour against the following criteria:

- Issues with social communication, social interaction and/or social imagination (this is often referred to as the 'triad of impairments')
- Behaviours or interests that are repetitive, restrictive or obsessive
- Difficulties with everyday life
- All of the above were present from an early age

To help the clinician get a clear picture, it is a good idea to prepare and bring along some other sources of information to support your case, such as:

- Doctors' reports of any physical or mental health issues, or other diagnosed conditions, you may have
- Written testimonies about what you were like as a baby or young child, like reports from teachers or support workers
- In-person testimonies from relatives, friends, or anyone else who can provide insight into your life and behaviour, especially as a baby or young child

Public Diagnostic Services

Under the Autism Act, every UK citizen should have access to a publicly available diagnostic pathway. The service is free, but **you will need to be referred by your GP** to access the service - you cannot self-refer.

In Devon, the public diagnostic service is the **Devon Autism and ADHD Service (DAANA)**. At time of writing, the current waiting time between being referred to DAANA and the first assessment appointment is around 5 years.

Right to Choose

If you live in England and your GP refers you for an autism diagnostic assessment, you now have a legal Right to Choose to be referred to a private diagnostic provider instead of the standard NHS service, as long as the provider you choose is also providing autism assessments to the NHS in another part of England. This can be done when the GP makes the first referral, and the service will still be funded by the NHS at no additional cost to you.

The majority of people in Devon who opt for a Right to Choose will be referred to either Psychiatry UK or Problem Shared, the two main organisations that provide private Autism and ADHD assessments for the Devon area at time of writing.

There is still a waiting time between referral and first appointment with Psychiatry UK and Problem Shared due to the current high demand for autism and ADHD assessments, but it is generally lower than the waiting time for DAANA. Assessments are generally carried out remotely via video or telephone calls.

The form for requesting a referral from your GP for an autism diagnostic assessment via Right to Choose can be downloaded directly from the Psychiatry UK and Problem Shared websites.

Psychiatry UK

 <https://psychiatry-uk.com/right-to-choose-asd/>

Problem Shared

 <https://www.problemshared.net/right-to-choose>

Private Diagnostic Services

If you don't want to use the public diagnostic route, either through the NHS or Right to Choose, you can also seek an assessment directly from a private provider. These will usually offer shorter waiting times than the public service, but will charge for their services, ranging from £200 to over £1,000. Additionally, some service providers will only accept a formal diagnosis obtained from a public provider.

At present, there is only one private service based in the Devon area that offers diagnosis of autism spectrum conditions.

Clinical Partners, Plymouth

 www.clinical-partners.co.uk/for-adults/autism-and-aspergers

National Diagnostic Services

Lorna Wing Centres

These internationally-recognised diagnostic centres, named after the pioneering psychologist who coined the term 'Autistic spectrum', are operated by the **National Autistic Society (NAS)**. These are open to people of all ages and accept both NHS referrals and private applicants.

At present, there are two centres: one in Kent and one in Essex.

 www.autism.org.uk/services/diagnosis.aspx

The NAS also maintains a directory of assessment and diagnostic services available in the UK:

 www.autism.org.uk/directory

Support Organisations for Autistic Adults

There are a number of support groups available to Autistic adults living in Devon. Many of these allow anyone who identifies as Autistic to attend, regardless of whether they have a diagnosis. This can be a useful source of support and information for those who are waiting for an assessment or are thinking about getting one.

Dimensions for Autism CIC (DFA)

Dimensions for Autism is a Community Interest Company offering support for autistic adults, and those who identify as autistic, who live in the Devon area. You do not need an official diagnosis to become a member, but the organisation focuses on those who have few or no support needs. Full meeting details are available on request via email.



www.dimensionsforautism.life



trishdarke.dimensionsforautism@gmail.com

DFA Newton Abbot Group

A monthly group offering a mixture of information, topical discussion and social activities for Autistic people living in and around Newton Abbot.



Newton Abbot



Weekly, every Thursday (except when at Exeter or on community outings)



14.30 – 16.30



£3.00 suggested donation (optional)



Trish Darke trishdarke.dimensionsforautism@gmail.com

DFA Exeter Group

A group for autistic people living in Exeter.



Exeter



Monthly, fourth Thursday of each month (except December)



14.30 – 16.30



£3.00 suggested donation (optional)



Trish Darke trishdarke.dimensionsforautism@gmail.com

DFA Barnstaple Group

A monthly the North Devon area.



Barnstaple



Monthly, second Friday of each month



14.30 – 16.30



£2.00 suggested donation








Michael Everitt michael@dimensionforautism.life

Trish Darke trishdarke.dimensionsforautism@gmail.com

Dimensions for Autism CIC (DFA) *con't*

DFA Paignton Group

A monthly group for autistic people living in the Torbay area.

-  **Paignton**
-  **Monthly, last Monday of each month**
-  **14.30 – 16.30**
-  **Free**
-  **Trish Darke** trishdarke.dimensionsforautism@gmail.com







DFA Women's Group

A dedicated monthly group for autistic women.

-  **Exeter**
-  **Monthly, first Monday of each month**
-  **15.00 – 17.00**
-  **Free, but you will need to bring your own money for refreshments**
-  **Trish Darke** trishdarke.dimensionsforautism@gmail.com
-  **Lindsay Richardson** lr.dimensionsforautism@gmail.com




DFA LGBTQ+ ASC Group

An evening social group for autistic people who identify as LGBTQ+.

-  **Exeter**
-  **Monthly, third Wednesday of each month**
-  **18.00 – 20.00**
-  **£2.00 suggested donation**
-  **Martina Grace** wildgirlmartina@yahoo.co.uk
-  **Trish Darke** trishdarke.dimensionsforautism@gmail.com

DFA Young Persons Group

A dedicated monthly online evening group for young autistic adults (18+).







-  **Monthly, third Thursday of each month**
-  **19.00 – 20.30**
-  trishdarke.dimensionsforautism@gmail.com

National Autistic Society (NAS)

The National Autistic Society is the main autism charity in the UK. It has a number of local branches in the county, which operate support groups for autistic adults.






 www.autism.org.uk

NAS Exeter & District Adults' Support Group

-  Exeter
-  Monthly, third Monday of each month (term-time only)
-  10.30 – 12.30
-  Free, but donations welcome
-  www.nasexeter.simdif.com/
-  Penny Palmer (chair) exeter@autism.org.uk







NAS Tavistock & District Women's Aspergers Support & Social Group

An autistic women-only group for those with few or no support needs.

-  Monthly
-  Free, but donations welcome
-  www.nasbranch.org.uk/tavistockanddistrict
-  07436 544233
-  Wendy West (chair) tavistockanddistrict@NAS.org.uk




NAS Plymouth Autistic Adults Group

A Plymouth-based branch focused on Autistic adults.

-  Plymouth
-  Monthly, second Thursday of each month
-  17.00-19.00
-  www.autism.org.uk/what-we-do/branches/plymouth-and-district
-  0808 800 4104
-  plymouthadultaspergersbranch@nas.org.uk

NAS West Devon Autistic Women's Group

A group facilitated by NAS Plymouth & District for Autistic women.

-  www.autism.org.uk/what-we-do/branches/plymouth-and-district
-  0808 800 4104
-  plymouthadultaspergersbranch@nas.org.uk

Plymouth Autism Hub

Run by the charity 'Autistic Adults in Plymouth', the Plymouth Autism Hub provides a safe socialising space for autistic people aged 16 and over in the Plymouth area, with activities including card and board games, plus quiet spaces for those who need them.

The group also organise community outings roughly once every three months.



<https://aaplymouth.org.uk/what-we-do/>

AAiP Social Club

A social meet-up for autistic people aged 16 and over.



Oasis Cafe, 28 Manor Street, Stonehouse, Plymouth PL1 1TW



Weekly, every Tuesday



14.00 onwards



07429 900530



contact@aaplymouth.org.uk

AAiP Community Outings

Social events autistic people aged 16 and over. People who attend will need to self-fund travel, venue entry and all other costs.



Various – suggestions welcome



Roughly once every three months



Various – attendees will need to self-fund

PANDA

Operating in North Devon, Promoting Autism NeuroDiversity Awareness seeks to elevate the voices and views of autistic people, and to assist them in accessing the services and support they need. They offer online advice and guidance to autistic people and service providers.



www.pandacharity.org

Autism In Totnes

A friendly group of Autistic adults who meet in Totnes every month for tea and coffee, games, optional socialising, and occasionally cake.

Autism In Totnes monthly meet-up



Totnes United Free Church, 56 Fore Street, Totnes, TQ9 5RU



Monthly, third Wednesday of each month



11.50 – 13.45



Minimum £1.00 donation for venue hire costs



autisticafterhours@gmail.com

Autism After Hours

A social support group for Autistic adults without a learning disability, which meets every month in Paignton. Tea and coffee are provided, along with a selection of board games and playing cards, but attendees are welcome to bring their own activities along.

Autism After Hours monthly meet-up





-  **The Methodist Church, 27 Palace Avenue, Paignton TQ3 3EQ**
-  **Monthly, second Saturday of each month**
-  **15.00 – 17.00**
-  **Free, but donations welcome**
-  autisticafterhours@gmail.com

SOCOPS

Social Opportunities is an Exeter-based charity that supports young people with an Aspergers or High-Functioning Autism diagnosis. They run two groups, one for children aged 8-15 years and another for young adults aged 16-23 years.

SOCOPS Plus

A facilitated group that organises community social activities at various locations around Exeter for young Autistic adults aged 16-23. Full details can be requested using the contact information below.

-  **Exeter – various venues**
-  **Fortnightly, usually Tuesdays**
-  **Usually 19.00 – 21.00 (exact times vary depending on activity & venue)**
-  **07713 499212**
-  socopsplus@hotmail.co.uk

Education Support

Since autism is officially classified as a disability, Autistic people who are in education are entitled to assistance to support them during their studies.

The Local Offer

Each local authority maintains a public database, called the Local Offer, that details all services available in its area to those who have Special Educational Needs or Disabilities (SEND).

See **Statutory Services** for full information.

EHCP

If general SEND support does not meet your child's needs, you may be able to get an Education, Health and Care Plan (EHCP) from your local authority. This will identify the child's health, education and social needs, and lay out the support they require.

See **Statutory Services** (page 11) for full information.

Disabled Students Allowance (DSA)

A financial support scheme for students in higher (university) education with a mental health issue, long-term illness or any other disability, the Disabled Students Allowance scheme provides grants to pay for specialist equipment, support staff, extra travel costs or any other health-related expenses.

The grants do not need to be repaid, however, can only be used for costs that are directly related to your course. The amount you receive will depend on an assessment of your needs.



www.gov.uk/disabled-students-allowances-dsas



www.ucas.com/finance/additional-funding/disabled-students-allowances-dsas

Preparing for Adulthood (PfA)

A national programme supported by several different organisations, this organisation works with local authorities to promote SEND education that emphasises life skills, employment and independence from an early age. Their website has downloadable information documents on a wide range of subjects, from education to health to independent living.



www.preparingforadulthood.org.uk



01225 789135



info@preparingforadulthood.org.uk

Information, Advice and Support Services

Each of the local authorities has an advice service dedicated to SEND service provision in its area, offering free advice and support via telephone and face-to-face, as well as online resources.

DIAS

Devon Information, Advice and Support service; the service for the Devon County Council area.



www.devonias.org.uk/



01392 383080



info@sendiasstorbay.org.uk

PIAS

Plymouth Information, Advice and Support service; the service for the Plymouth City Council area.



01752 258933 or 0800 953 1131



pias@plymouth.gov.uk

SENDIAS Torbay

The SEND Information, Advice and Support service for the Torbay Council area.



01803 212638



info@sendiasstorbay.org.uk

College SEND Support

Most colleges in Devon have their own dedicated support teams for students with additional educational needs. You will need to contact the college to find out exactly what support they offer, but it is also helpful to speak to the team directly if possible.

South Devon College - Additional Learning Support Team



0800 038 0123



enquiries@southdevon.ac.uk

City College Plymouth Learning Support Team



www.cityplym.ac.uk/help-advice/studying-with-disabilities/



01752 305300



info@cityplym.ac.uk

Bicton College



www.bicton.ac.uk/student-support/supporting-your-learning/



01209 617523



learning.support@cornwall.ac.uk

College SEND Support *con't*

PETROC College



www.petroc.ac.uk/support-help/additional-learning-support



01884 235200



guidancecentretiverton@petroc.ac.uk

University of Exeter AccessAbility Pathway

One of the wide range of support services offered by Exeter University to its students, AccessAbility is a team of disability specialists dedicated to providing support to students who have a disability or long-term condition that may impact on their study experience. This includes mentoring specifically for autistic students (see below).



www.exeter.ac.uk/wellbeing/accessability/support/



Accessability@Exeter.ac.uk

AccessAbility Specialist Mentoring for ASC

A mentoring service for students who have been diagnosed with an autism spectrum condition, including Aspergers Syndrome, tailored to the individual needs of each student.



www.exeter.ac.uk/media/universityofexeter/wellbeing/documents/AccessAbility_leaflet_-_ASC_Mentoring.pdf

National Autistic Society (NAS)

Among its many other roles, the NAS provides a range advice and information for young autistic people who are, or intend to be, in education.



www.autism.org.uk/services/education.aspx

NAS Student Support Services

This scheme offers personalised advice and support for university-level students with an ASC diagnosis. This can include preparation for higher education and living independently, mentoring during studies, and discussions with university staff about meeting the person's needs.

The support is not free, but the costs can be included in any Disabled Students Allowance you may be eligible for.



www.autism.org.uk/services/education/further-education.aspx



studentsupportreferrals@nas.org.uk

Eat That Frog CIC

Based in south Devon, Eat That Frog is a Community Interest Company that offers training courses for young people who have Special Educational Needs (SEN), providing a combination of academic and employability skills. They also provide support and one-to-one mentoring for those already in an apprenticeship. These services are open to anyone aged 16-18 with SEN of some kind, as well as those aged over 18 who have an active EHCP.

The charity has training centres in Torquay, Paignton and Newton Abbot, which are also open to those who need support or internet access to search for jobs.



01803 551551



Gail Rochelle info@eatthatfrog.ac.uk

Employment Support

As with education support, Autistic people in employment are entitled to a number of support schemes and protections.

National Careers Service

A government website that provides online resources for those who need general careers advice (though not disability- or neurodiversity-specific resources).



nationalcareersservice.direct.gov.uk



0800 100 900



Textphone: 08000 968 336

JobCentre Disability Employment Advisers

Disability Employment Advisers are specialist work coaches in UK Job Centres to support jobseekers who have a health condition or a disability that affects their ability to work. They can carry out assessments of your specific employment needs, provide signposting to local Disability Confident employers, and can work with employers to identify barriers and arrange Reasonable Adjustments.

Every UK job centre should have a DEA, and you can request an appointment for specialist advice and coaching.



<https://www.jobcentreguide.co.uk/about-disability-employment-advisors>

Disability Confident Employers

The Disability Confident scheme is designed to help employers recruit and retain disabled people and people with health conditions for their skills and talent. Information about organisations that gain one of the three 'Disability Confident' levels will be shared via this scheme, with an aim being that the scheme will also provide information to those who have disabilities about Disability Confident Employers.



www.gov.uk/government/collections/disability-confident-campaign

Access to Work

If you are currently in work, or are about to start a new job, the Access to Work scheme can help you organise any reasonable adjustments you may need if your employer can't (or won't). This can include a non-repayable grant that can be spent on equipment or support services, depending on your eligibility.



www.gov.uk/access-to-work



01202 858863

ACAS

The Advice, Conciliation and Arbitration Service provides free, impartial advice about employment law and workplace relations to employers and employees. They have published some articles focusing specifically on neurodiversity in the workplace.



www.acas.org.uk/

ACAS Helpline

A free, confidential helpline for anyone who needs advice or support about UK employment or workplace law. The service also has a separate contact email address for anyone who is unable to use the helpline directly due to specific accessibility needs.



08.00 – 18.00 Monday to Friday (excluding bank holidays)



0300 123 1100



accessibleservices@acas.org.uk

Fit For Work

This government-funded initiative offers free, impartial advice for those with a health condition that is affecting their current employment, or those that are currently on sick leave. This advice is available via web chat and online resources as well as their free advice telephone number.



www.fitforwork.org



0800 032 6235

Benefits and Work

If you are currently receiving benefits, starting employment may affect the amount you receive. This organisation provides online advice about the eligibility rules for the UK benefits system.



www.benefitsandwork.co.uk/

The Gov.uk website has a calculator to help you work out how employment might affect your entitlements:



www.gov.uk/benefits-calculators

CSW Group

Formerly Careers South West, this not-for-profit enterprise provides 'transition support', including advice and signposting for young people into employment.



cswgroup.co.uk/

Devon County Council Supported Internships

Designed to build workplace skills and provide a transition into employment, supported internships provide work placements with local employers lasting 6-12 months. Each internship is designed around a development programme personalised to suit the person's goals and needs.

You don't need to have any qualifications, and there are no completion requirements, but you do need to be aged 16-24 and have an Education, Health and Care Plan (ECHP).

www.devon.gov.uk/educationandfamilies/special-educational-needs-and-disability-send-local-offer/preparing-for-adulthood/employment/apprenticeships-traineeships-and-supported-internships



Workways

A free service provided by NHS Devon Partnership Trust, Workways offers support and advice for those whose mental health issues make it harder for them to get and/or keep a job. This includes assistance in finding work, help for you and your employer once you have a job, and supported voluntary placements for those who need a step in between.

The service is free and will last for as long as you need it, but you will need to be referred to the service by either your GP or your recovery/care coordinator.



www.workways.org.uk/



01392 677050



General enquiries: info@workways.org.uk

Application and Referral queries: dpt.workwaysadmin@nhs.net

Working Well with Autism

A co-operative social enterprise based in Plymouth, this charity aims to support autistic people into education and employment not just by preparing the person for the workplace, but also by altering the workplace to suit the individual. They offer in-work support for employed autistic adults, as well as awareness and acceptance training for organisations.

Their individual support is not free, but may be included as part of an Access to Work grant if you are eligible.



www.workingwellwithautism.org/?q=supporting-employees



01752 283953



info@workingwellwithautism.org

Travel Support

As the presence of Autistic people in the wider community has become more visible, providers of public transport have gradually improved their provision for passengers on the spectrum.

Blue Badge

Recent legislation changes have opened the national Blue Badge scheme to applications from people with 'hidden disabilities', including autism. Eligibility is determined by your Local Authority (Devon County Council, Plymouth Council or Torbay Council).

A Blue Badge allows the holder to use disabled parking spaces, plus the ability to park in no-parking areas like double-yellow lines for up to three hours.



[new.devon.gov.uk/roadsandtransport/parking/blue-badge-parking/](https://www.new.devon.gov.uk/roadsandtransport/parking/blue-badge-parking/)

The government website has an online guide about how a Blue Badge can be used:



www.gov.uk/where-registered-disabled-drivers-can-park

Disabled Persons Railcard

A national railcard that gives a 33% discount on travel for yourself and another adult. It is available to anyone receiving PIP or DLA payments.



www.disabledpersons-railcard.co.uk



0345 605 0525



disability@raildeliverygroup.com

National Bus Pass

Available from Devon County Council, this pass grants free 'off-peak' bus travel. You will need to check when 'off-peak' fares apply with your local bus service.



www.traveldevon.info/bus/national-bus-pass



01392 383688 or 01271 38368



nationalbuspass@devon.gov.uk

Devon Access Wallet

An initiative run by Devon County Council to improve access to transport for anyone with communication issues. It can be used on any bus or train, and uses pictures and word cards to help the user communicate where they want to go and what help they need.



www.traveldevon.info/accessibility/devon-access-wallet/



01392 383509

Southwestern Railway Disability Travel Support

Southwestern Railway offers travel assistance at all stations it operates, for anyone who needs help navigating the station or getting on or off the train. This does not need to be booked in advance, but it is a good idea to let the station staff know ahead of time what your needs are.



www.southwesternrailway.com/travelling-with-us/assisted-travel



0800 5282100 or 0345 6000 650

Ring and Ride

Available in most towns and rural areas in the county, the Ring and Ride scheme provides flexible transport for those who struggle to access the public transport system. This can be booked in advance, and users can be picked up and returned directly to their home.

For more information, and to find the Ring and Ride scheme for your area:



www.traveldevon.info/accessibility/community-transport/ring-and-ride/

Supported Living, Daily Support and Enabling

For Autistic people who need support with everyday living, there are a number of organisations that offer a range of options, from short mentoring courses to fully supported accommodation.

National Autistic Society (NAS)

The NAS provides a range of living support services for autistic people across the country, from residential housing to social support and mentoring.

To find out exactly what services are available in the south west, you will need to refer to the NAS website:



www.autism.org.uk/southwest



01278 760555



sw.services@nas.org.uk

Garland Support

A supported-living company that operates two residential properties in Exeter, and also offers training courses in a wide range of life skills, from cooking to accessing services.



www.garlandsupport.co.uk



01392 757303



info@garlandsupport.co.uk

Passmore Care Services

A private family-run organisation that offers supported accommodation, living support and day services to people with intellectual disabilities, including autistic people. A referral is required to access their services.



www.passmorecareservices.co.uk



01392 270227



neil@passmorecareservices.co.uk

SameAsYou (SAY)

An enabling support charity based in Tiverton, offering day support services for people with intellectual and learning disabilities, or any other additional living needs.



www.sameasyou.co.uk



eliza@sameasyou.co.uk


Mental Health Support

Crisis Support

If you have a mental health crisis and need emergency support, the following organisations can provide care and assistance at any time of the day.

The Samaritans

This national charity runs a **free, confidential 24-hour telephone helpline** for those who urgently need advice or support:

 **116123**

For those who prefer not to communicate via telephone, they also offer an **email service** which is guaranteed to respond **within 24 hours**:

 jo@samaritans.org

For more information, visit:

 www.samaritans.org/

NHS First Response Service (111)

If you need specific mental health crisis support, you can contact the NHS First Response Service. To do this, **dial 111** and select the 'mental health' option.

Emergency Services (999)

You can also contact your local Accident and Emergency department or Police force if you need to. To do this, **dial 999** and ask for the service you need.

Out-of-Hours GP Service

Your GP's surgery will operate an **out-of-hours telephone service**. To get the number, you will need to **telephone your GP's surgery** and listen to the pre-recorded message.

NHS Primary Mental Health Care

The NHS offers mental health services as well as healthcare. These services are accessed via a referral via your GP.

You can also get advice online through NHS Direct:

 www.nhs.uk/conditions/stress-anxiety-depression/

Non-Crisis Support

Talkworks

Formerly known as the **Depression and Anxiety Service (D&AS)**, Talkworks is the dedicated NHS mental health support provider. You can self-refer to the service, and they may then refer you to specialist support services if needed.

To find out more about Talkworks:



www.dpt.nhs.uk/locations/talkworks-depression-and-anxiety-service-south-and-west-devon



0300 555 3344 (Ask for 'Talking Health Team')

The Moorings @ Devon

The Moorings offer drop-in mental health support at three sites across Devon. They provide safe, non-judgemental and non-clinical spaces with experienced staff who can offer emotional, social and practical support for people who are experiencing, or who believe they may be heading towards, a mental health crisis. They can also help with creating Staying Well and Crisis plans, as well as signposting to other organisations.

Support can also be provided over the phone or via video call. Calls received outside of opening hours will be directed to an answerphone; any messages or emails will be responded to as soon as possible during open hours.

The Mooring @ Exeter



Wonford House, Dryden Road, Exeter EX2 5AF



10.00 – Midnight, Monday – Friday (including bank holidays)

12.00 – Midnight, Saturday – Sunday



07990 790920



devonexeter.mhm@nhs.net

The Mooring @ Torquay



Torbay Business Centre, Lymington Road, Torquay TQ1 4BD

10.00 – 18.00, Monday – Friday (ONLINE ONLY)



18.00 – Midnight, Monday – Friday (including bank holidays)

12.00 – Midnight, Saturday – Sunday



07483 991848



devontorquay.mhm@nhs.net

The Mooring @ Barnstaple



The Voice Meeting Rooms, Belle Meadow Court, Albert Lane, Barnstaple EX32 8RJ



18.00 – 23.00, Thursday – Monday



07850 927064



devonbarnstaple.mhm@nhs.net

Time to Talk

A free, confidential telephone service run by the charity Living Options Devon, this project aims to reduce isolation and loneliness among those living in Devon who are deaf or have a disability. There are several contact options on offer, including a webcam service for BSL users and an email address for those who prefer not to use the telephone.



www.livingoptions.org/support-help/time-talk



0300 303 3691



time2talk@livingoptions.org

Torbay Community Helpline

A volunteer-led service that can provide support and advice for a range of situations, including loneliness, isolation and other mental health issues. You can also call on behalf of someone else if needed.

An online contact form is available on the Torbay Community Helpline website for those who are unable to access the helpline directly.



Monday to Friday: 10.00 – 13.00 and 15.00 – 18.00 (except bank holidays)
Saturday: 11.30 – 12.30



www.torbay.gov.uk/adult-social-care/community-helpline/



01803 446022

Paignton Community Hub

A meeting place run by a local non-profit community organisation that can provide in-person support with a range of issues, including mental health in cooperation with the Helpline.



Paignton Library & Info Centre, Great Western Road, Paignton TQ4 5AG



Monday to Friday (except bank holidays)



09.30 – 13.30



07562 780102



info@paigntoncommunityhub.org.uk

Torbay Community Café & Help Hub

A locally-run social space where people can get help and advice as well as a good meal.



4-8 Temperance Street, Torquay TQ2 5PU



Monday to Friday (except bank holidays)



10.00 – 15.00



www.facebook.com/torbaycafehelphub/

New Leaf

Part of NHS Devon Partnership Trust's Vocational Rehabilitation Service, this organisation provides supported employment for adults with a mental health condition, providing the skills and environment to help them to work towards gaining or returning to paid employment.



www.dpt.nhs.uk/our-services/adults/vocational-services/new-leaf

MIND

This national charity is dedicated to mental health support and advice. They offer a range of free remote services countrywide.



www.mind.org.uk

Infoline

A general advice service about mental health issues and the services available to help.



0300 123 3393 - Mon-Fri 09.00-18.00 (except bank holidays)



info@mind.org.uk

Legal Line

A general advice service about mental health issues and the services available to help.



0300 466 6463 - Mon-Fri 09.00-18.00 (except bank holidays)



legal@mind.org.uk

The Samaritans

As well as their crisis support, the Samaritans provide a general telephone service for those who need an empathetic ear. The charity also has five local branches in Devon.



www.samaritans.org



08457 909090



07725 909090

Every Mind Matters

An online portal provided by the NHS that offers a range of self help resources relating to mental health and wellbeing, mainly focused on Cognitive Behavioural Therapy (CBT) and related Mindfulness techniques.

The website also provides a separate section for those supporting someone else with mental health issues, as well as links to crisis support services.



www.nhs.uk/every-mind-matters/

Rethink Mental Illness

A national mental health charity that provides information and advocacy support. They run a number of informal support groups around the county, both for those affected by mental health issues and for their family and friends.

Their website provides signposting to local resources supported by the charity.



www.rethink.org

Devon Advocacy Consortium

The Devon Advocacy Consortium is a partnership of six charities that offer professional advocacy services for any over-16s who need advice or representation in making a health or social care issue or complaint (there are strict criteria). you will need to discuss with your Social Worker or Care coordinator for a referral for advocacy.



www.devonadvocacy.org.uk



0845 231 1900



devonadvocacy@livingoptions.org

The Advocacy People (Plymouth)

The Advocacy People is a charity partnership between three organisations to provide a wide range of advocacy support for people living in Plymouth.

They can provide advice and signposting for advocacy relating to NHS physical and mental health, social care, children and young people, and adults who have been assessed as lacking capacity.



www.theadvocacypeople.org.uk



0330 440 9000



info@theadvocacypeople.org.uk

Police Non-Emergency Service

For non-emergency situations, the police have a separate contact number: **101**

You can also contact the Devon and Cornwall Police 101 service by email:



101@devonandcornwall.pnn.police.uk

Addiction Services

The NHS Devon Partnership Trust offers a specialist service for adults suffering from severe alcohol or drug issues.



www.devonpartnership.nhs.uk/Addiction-services.64.0.thml

LGBTQ+ Information and Support

Since a disproportionately large percentage of Autistic people identify as LGBTQ+, we felt it was worth including a dedicated section specifically for them.

Intercom Trust

A specialist charity that works with LGBTQ+ communities across the South West, offering information, support, counselling, consultancy and advocacy. They run a number of support groups, and also offer a six-week Compassionate Mindfulness course for anyone who is, or thinks they might be, LGBTQ+.



www.intercomtrust.org.uk



0800 612 3010



helpline@intercomtrust.org.uk

Proud2Be

Based in Totnes, this social enterprise supports LGBTQ+ people, and their families, living in and around the South Devon area through a range of social evenings, youth groups and one-off events throughout the year.

They are also an activist group, running a number of campaigns, a volunteer programme and awareness training courses.



www.proud2be.co.uk



01803 864321

Proud2Be Social Evening

An evening social group open to LGBTQ+ people and allies.



Totnes



Monthly, second Thursday of each month



18.30 – 21.30



Free

X-Plore

A Devon-based charity that runs a number of youth groups across the county, providing safe spaces for young people who identify as LGBTQ+ or are questioning their gender identity. They work closely with Intercom.



www.lgbtgyouthdevon.org.uk/



0800 612 3010



xplorencharity@gmail.com

Transilience

A charity based in north Devon run by neurodivergent trans people, focused on providing 1-to-1 support and resources for trans young people living in the area, as well as trans awareness training for local organisations.



www.transilience.org.uk



beki@transilience.org.uk

Other Services

Citizens' Advice Bureau (CAB)

This national organisation offers advice to UK citizens on benefits, employment, housing, law, debt, and many more areas. The advice is free and delivered by experienced volunteers, although they may not have any specific knowledge about autism.


Anyone applying for a Personal Independence Payment can get assistance from the CAB when completing the application form.

 www.citizensadvice.org.uk/

CAB Exeter

The CAB has an office in Exeter, which runs free drop-in sessions. There are a limited number each day, and they tend to fill up fast, so it is worth arriving before the centre opens to ensure a place.

 www.citizensadviceexeter.org.uk


 **Devon Advice Line: 03444 111 444 - Monday-Friday, 10.00-16.00**

Healthwatch

A national organisation that provides a platform for people to provide feedback about their experiences with public health services. Each of the local authorities has its own dedicated Healthwatch organisation.

Healthwatch Devon


 healthwatchdevon.co.uk

 **0800 520 0640**

 info@healthwatchdevon.co.uk

Healthwatch Plymouth


 www.healthwatchplymouth.co.uk

 **0800 520 0640**

 info@healthwatchplymouth.co.uk

Healthwatch Torbay

 healthwatchtorbay.org.uk

 **0800 052 0029**

 info@healthwatchtorbay.org.uk

Social Prescribing

As well as their usual medical referrals, most GP surgeries can now refer people to Social Prescribing Link Workers who can help to meet practical, social and emotional needs that are affecting your wellbeing.

Social Prescribing Link Workers can work with their patients to create personalised care and support plans to help them manage their day-to-day health and wellbeing. They can also refer people directly to local community organisations for advocacy and advice, or to help alleviate loneliness and form social support connections.

For more information about Social Prescribing, contact your local GP surgery.



www.england.nhs.uk/personalisedcare/social-prescribing/

Devon Health and Wellbeing

An organisation set up by Devon County Council to bring health and social care organisations together with community representatives. It aims to encourage collaboration between services to ensure that service providers are meeting the needs of Devon residents.

The organisation's website has useful resources about needs assessments.



www.devonhealthandwellbeing.org.uk

CoLab Exeter

An 'integrated wellbeing and innovation hub' that aims to aid the recovery and social reintegration of people who have experienced homelessness, addiction, criminality or mental health issues. They bring together representatives from statutory and voluntary service providers to deliver holistic care plans. This organisation mainly covers the Exeter, East Devon and Teignbridge areas.



www.colabexeter.org.uk



01392 284280



enquiries@colabexeter.org.uk

Transitions Project

A project to provide volunteers and mentors to help with transitions that vulnerable people may be going through. At present this service is accessed via a referral from a Social Worker, Community Care Coordinator or Support Worker.



www.transitions.eci.org.uk



01392 284280

Living Options Devon

A county-wide charity dedicated to improving the lives of Deaf people and those with disabilities. They provide a range of free support, signposting, advocacy and mobility services to reduce social isolation and enable clients to live the life they want to.



livingoptions.org



01392 459222



07958 517919



info@livingoptions.org

Beyond Limits

A Plymouth-based organisation that supports people with intellectual and learning disabilities, mental health issues and other needs. It was founded with support from Partners for Inclusion, an award-winning Scottish personalised support organisation.



www.beyondlimits-uk.org



01752 546449



info@beyondlimits-uk.org

Devon People First

Part of Involve (a support organisation for voluntary action in Mid Devon), Devon People First is a semi-independent group run by and for people with intellectual disabilities, aiming to encourage and develop self- and peer-advocacy among its members.



involve-middevon.org.uk/projects/devon-people-first/



01884 251769



office@involve-middevon.org.uk

Shared Lives Plus

A national charity that facilitates shared-living arrangements between carers and people who need live-in support, providing training and guarantees for the carers.



www.sharedlivesplus.org.uk/



0151 227 3499



info@sharedlivesplus.org.uk

Westbank Health Walks

Part of the Stepping Out Exeter initiative, offering a programme of group walks around the Exeter area. A range of routes of varying difficulty are on offer every day of the week except Sunday. Participation is free.



www.westbank.org.uk



Claire Ridge 01392 824752



claire.ridge@westbank.org.uk

Young Devon

The largest young people's charity in the south west, providing advice, support, counselling and training for Devon residents aged 25 and under.



www.youngdevon.org



01752 691511



info@youngdevon.org

Youth Enquiry Service (YES)

A series of centres run by Young Devon, offering free confidential advice on a range of subjects. Drop-in sessions are available at various times - see the website for full details.

YES Exeter



01392 331666



yes.exeter@youngdevon.org

YES Newton Abbot



01626 202530



yes.newtonabbot@youngdevon.org

YES Ivybridge

Drop-in Only

North Devon Sunrise CIC

A grassroots community organisation providing support, services and activities to people with diverse identities (minority ethnic groups, disabled people, LGBTQ+) living in rural North Devon.

They also offer diversity awareness workshops for local businesses.



www.northdevonsunrise.org/



01271 328915



sarah.vingoe@northdevonsunrise.org.uk

FIGS South West

The local arm of a charity set up to increase the visibility of autistic women and girls, and to improve recognition by diagnosis services and support providers.



figsuk.org



Helen Bates (South West Lead): figscampaignuk@gmail.com

Devon Age UK

The local arm of a national charity that provides support and information to people aged over 50.



www.ageuk.org.uk/devon/



0333 241 2340

Devon Faith and Belief Forum

A local organisation that aims to bring together representatives of different faiths and traditions to promote mutual understanding and appreciation.



devonfaiths.org.uk

Hikmat Devon CIC

A Community Interest Company that supports and promotes minority ethnic communities in the county.



www.hikmatdevon.co.uk/



01392 757220 or 07837 577814

Exeter Picturehouse

This cinema offers regular autism-friendly screenings for autistic people and their friends, families and carers.



www.picturehouse.co.uk/cinema/exeter

Devon & Cornwall Police Diverse Communities Team

A small team of specialist officers and staff who focus on maintaining and developing confidence in the police within minority communities.



devon-cornwall.police.uk



DiversityDevon@devonandcornwall.pnn.police.uk

Support for Families and Carers

The following groups offer advice and support for family members and those who act as carers for an Autistic person.

National Autistic Society (NAS)

Alongside their work with autistic people, the NAS also provides advice and support for those who care for them. Some of the local NAS branches run dedicated support and social groups for parents and carers. These groups are free to attend.



www.autism.org.uk/services/home/parents-carers.aspx



0808 800 4104



supportercare@nas.org.uk

NAS Exeter & District Parent/Carer Group



Exeter



Monthly, third Monday of each month (term time only)



10.00 – 12.00



Free, but donations welcome

NAS Plymouth Parent/Carer Group



Plymstock



Monthly



19.00 – 21.00



Free, but donations welcome



plymouthparentsupport@nas.org.uk

NAS Tavistock & District Parent/Carer Group



Tavistock



Monthly



Free, but donations welcome



www.nasbranch.org.uk/tavistockanddistrict



tavistockanddistrict@NAS.org.uk

Children & Family Health Devon

An online hub that provides a variety of services for parents and carers of autistic children and young people living across Devon (excluding Plymouth), including diagnostic services and mental health support.



<https://childrenandfamilyhealthdevon.nhs.uk/>

DAANA

The Devon Autism and ADHD diagnostic service runs a support and information group for friends and family. This group is free to attend but is **only open to relatives or carers of those who have received a diagnosis from the DAANA team.**

Exeter Parent Carer Network

An informal collective of parents and carers living in and around the Exeter area, who have come together to offer mutual support and encouragement.



exeterparentcarer.co.uk

Exeter Parent Carer Cafe

An informal space for parents and carers of children with additional needs to meet each other, share experiences, and relax. There are always biscuits.



Wonford, Exeter



Weekly, every Tuesday and Thursday



10.00 – 12.00



Free, but donations welcome



info@exeterparentcarer.co.uk

North Devon Forum for ASC and ADHD

As a parent- and carer-led group, the North Devon Forum for Autism Spectrum Conditions and ADHD offers plenty of support and guidance for carers of autistic people in the North Devon area. Alongside their regular support groups, they host regular talks by professionals and experts.

You will need to apply for membership to attend any of the groups or events.



www.ndfautism.co.uk/index.php/join-us/parents

For more information:



www.ndfautism.co.uk/



07923 481332



info@ndfautism.co.uk

NDF Coffee Mornings

An informal social and support group for members, both autistic adults and parents/carers.



Barnstaple



Monthly, last Thursday of each month (except December)



10.00 – 12.00



Free, but donations welcome



info@ndfautism.co.uk

Devon Carers

A service that provides information, support and signposting for carers living in the Devon County Council area (but not the Plymouth or Torbay areas). They provide advice via a telephone helpline and a 'live-chat' feature through their website.



www.devoncarers.org.uk



03456 434435



info@devoncarers.org.uk

Affinity

A Tiverton-based group for young people aged under 25 and their parents, carers and/or family. The group offers support both during and after diagnosis, helping carers share their experiences and strategies, and allowing children to meet and socialise with each other. They also invite professionals and experts to give presentations.



www.affinitysupportgroup.org



07917 188911



affinity.tiverton@gmail.com

Affinity Support Group

A support group run on the first two Wednesdays of each month, with one in the morning and one in the afternoon to give parents every opportunity to attend.



Tiverton



Monthly, first two Wednesdays of each month

Community Links SW CIC

A social enterprise based in Okehampton that offers professional support for families of children with additional educational needs. They focus on early-years intervention and one-to-one mentoring for parents.

Their services are not free, but subsidised rates are available subject to eligibility.



www.communitylinks-sw.co.uk



01837 55105



info@communitylinks-sw.co.uk

Okehampton Autism/ADHD Parent Support Group

A free support group for parents and carers of children with autism and/or ADHD, with or without a formal diagnosis.



Okehampton



Varies - see website for dates



10.00 – 11.30



Free



www.communitylinks-sw.co.uk/events/

Torbay Carers Service

A service supporting all carers who live in the Torbay area, providing a dedicated Carer Support Worker at every GPs surgery, as well as Carers' Health and Wellbeing Checks, training, and other activities.

They also provide the Signposts for Carers helpline, offering support via telephone or email, plus a regular newsletter.



www.tsdfc.uk/carers



01803 666620



signposts@nhs.net

Torbay Carers Adult Autism Support

A new service for those who live in the Torbay area, that support or care for adults who are (or think they might be) on the autism spectrum, who don't have a learning disability.

They offer a limited one-to-one peer-support service for those who would like to discuss their caring role or concerns, online or over the telephone.



trishdarke.dimensionsforautism@gmail.com

Torbay Carers Adult Autism Support Sessions

A free drop-in support and advice session for parents and carers of autistic adults. No booking is required – just turn up.



Paignton Library



Usually the third Tuesday of each month



13.00 – 17.00



Free

Caring for Carers

A support and advice service for carers living in Plymouth, run with the support of Age UK. They offer a range of support groups, workshops and social activities, and also run a Carers Card discount scheme.



www.improvinglivesplymouth.org.uk/our-services/caring-for-carers



01752 201890



caringforcarers@improvinglivesplymouth.org.uk

Plymouth Mental Health Carers Support Group

A support group for anyone who cares for an autistic person, a person with a mental health issue, or someone with OCD.



Plymouth



Twice monthly, second and fourth Thursday of each month



01752 211243

Autism Central

A national organisation providing peer support for the families and carers of autistic people. They offer a wide range of resources, education courses and signposting informed or co-developed by autistic people and their families, as well as one-to-one support and local peer-support group meetings.



www.autismcentral.org.uk/



info@autismcentral.org.uk

Autism Central South West Branch (Bristol Autism Support)

The branch of Autism Central that covers the South West region (Cornwall, Devon, Somerset, Dorset, Gloucestershire and the Scilly Isles) is delivered by a partner charity, Bristol Autism Support. Their website provides signposting to a range of local courses, events and support groups across the region.



www.autismcentral.org.uk/hubs/south-west-delivered-bristol-autism-support



autismcentralsw@bristolautismsupport.org

Carers UK

A national charity that provides support and advocacy for carers across the country. The charity does not produce much autism-specific material, but their general services and advice can be useful to someone who cares for an autistic person.



www.carersuk.org



0808 808 7777



advice@carersuk.org

Contact

A national charity for families of children with disabilities. They offer advice and support online and via a telephone service, plus workshops and support groups nationwide. Their website has a search feature for services and events in your area.



www.contact.org.uk/



0808 808 3555



helpline@cafamily.org.uk

Tissues and Issues

A Torbay-based combination support group and coffee morning for family members, including siblings, of children with Special Educational Needs and/or Disabilities (SEND) or a disability. The group has an attached creche for the children. A formal or pending diagnosis is required.



www.tissuesandissues.org/home



07796 470009

Autism Training

If you, or your organisation, is looking to learn more about Autistic people, the following organisations offer training courses to help raise awareness and understanding.

NOTE: This section refers only to training that is generally available. See Appendix 2 for details of the Oliver McGowan Training for NHS and Social Care workers.

MindEd

A national training organisation focused on the mental health of children and young people, with a range of courses targeted at parents/carers and professionals. They also have some online resources about autism, which can be found by searching for 'autism' on their website.



www.minded.org.uk/

BIS-Net

Run by Exeter-based charity CEDA (Community, Equality, Disability Action), the Behaviour Intervention Support Network (BIS-Net) provides training in challenging behaviour, autism, PDA and ADHD for parents and professionals. They also offer two-day behavioural support workshops for parents and carers.



www.cedaonline.org.uk/bis-net



01392 360645



info@cedaonline.org.uk

Other Useful Links

These links didn't fit well into any of the main categories, but we still think they're useful, so we collected them here just in case you need them.

Derriford Hospital Autism Service

University Hospitals Plymouth NHS Trust has launched a specialist support service for Autistic patients, providing resources and communication support to help them get the adjustments they need to access the care they need.

They also offer training to all staff within the Trust to spread knowledge and best practice.



www.plymouthhospitals.nhs.uk/autism-service



Plh-tr.derriforddautismservice@nhs.net

The Royal College of GPs

This organisation has made autism a priority for training and awareness over the next three years, autism awareness training is to be made available to all mainstream healthcare professionals and disability employment advisers.



www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx

Family Dog Workshops

Workshops for parents/carers of a child aged 3-16 with a clinical autism diagnosis.



www.dogsforgood.org/family-dog

General Information

Resources intended to support Autistic people in developing their social skills



www.thegraycentre.org/get-help

Workshop information from Alongside Autism 'for Carers of Adults' on the spectrum



www.alongsideautism.co.uk/papa-presentations.html

General information on strategies and resources



www.autism.org.uk/about/strategies.aspx

Appendices

Further information on specific subjects

Appendix 1: Important Legislation about Autism

The Autism Act (Nov 2009)

www.legislation.gov.uk/ukpga/2009/15/contents

Fulfilling and Rewarding Lives Strategy –
Autism Strategy (March 2010)

This is an update of Autism Act (2009)

The Think Autism Strategy (2014) Autism Strategy update

assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

In March 2015, further new statutory guidance replaced the existing guidance from 2010, stating that local authorities and the NHS should provide autism awareness training for all staff, and must provide specialist autism training for key staff such as GPs.

webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

This is the Joint Commissioning Strategy for Devon (integrated Devon, Plymouth and Torbay) '**Living Well With Autism Strategy**'

[//irp-](http://irp-cdn.multiscreensite.com/daa5b68f/files/uploaded/Living%20well%20with%20autism%20-%20joint%20strategy%20update%20%282%29.pdf)

[cdn.multiscreensite.com/daa5b68f/files/uploaded/Living%20well%20with%20autism%20-%20joint%20strategy%20update%20%282%29.pdf](http://irp-cdn.multiscreensite.com/daa5b68f/files/uploaded/Living%20well%20with%20autism%20-%20joint%20strategy%20update%20%282%29.pdf)

The Care Act (2014)

www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Protection under the Equality Act 2010. Regarding **Reasonable Adjustments**, see Appendix (4).

The National Strategy for Autistic Children, Young People and Adults (2021 to 2026)

<https://assets.publishing.service.gov.uk/media/60f72556e90e0764c6eb39f5/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf>

This report supersedes the Think Autism Strategy 2014 (see above), but many of its key aims follow on from and/or expand points from the previous strategy.

This report **does not** supersede the NHS Statutory Guidance document from March 2015 (see above): that guidance remains in effect.

The Health and Care Act (2022)

<https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted>

<https://assets.publishing.service.gov.uk/media/6363d911e90e0705a8c35457/health-and-care-act-2022-summary-and-additional-measures-impact-assessment.pdf>

Section 181 of this act introduced a requirement for mandatory awareness training on learning disabilities and autism for all staff delivering NHS services.

Valuing People (2001)

This is a White paper that highlights **Rights, independence, choice and inclusion** for people with learning disabilities.

assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Appendix 2: The Oliver McGowan Training

In October 2016, Oliver McGowan was admitted to hospital for mild seizures. An 18-year-old Autistic man with cerebral palsy and a learning disability as a result of a post-natal meningitis infection, Oliver also had strong adverse reactions to antipsychotic medications. Yet despite being told this several times by Oliver and his parents, and despite being given a passport detailing Oliver's needs and how best to communicate with and help him, the hospital staff administered an antipsychotic that caused his brain to swell to the point that it caused irreversible brain damage.

Oliver McGowan died on 11 November 2016 when his life support was switched off.

In the wake of this tragedy, Oliver's parents, Thomas and Paula, launched a campaign to improve awareness and understanding of learning disabilities and autism for all healthcare staff, not just staff who specialise in these areas. They were especially critical of the hospital staff who ignored Oliver's express wishes, disregarded the documents provided to them about how to care for him, and failed to communicate with other care providers who knew Oliver and understood his needs even though they had plenty of opportunity to do so.

As a result of this campaign, the Health and Care Act 2022 introduced a statutory requirement that regulated service providers must ensure their staff receive learning disability and autism training appropriate to their role. The resulting training package, which bears Oliver's name, was developed in close collaboration with Autistic people and people with learning disabilities, as well as their families and carers.

Tier 2, the in-person training package, is also co-delivered by a representative from the Autistic and learning disability communities respectively. These lived-experience representatives are provided with training to lead the sessions, and are paid for their time.

You can read about Oliver McGowan's story on the Oliver's Campaign website:

www.olivermcgowan.org/

To learn more about the Oliver McGowan Mandatory Training scheme:

www.local.gov.uk/our-support/partners-care-and-health/care-and-health-improvement/autistic-and-learning-disabilities/training

If you are interested in becoming a lived-experience trainer for the Devon and Torbay areas, you can contact the following email address:

Devon and Torbay

✉ ommtdevon@livingoptions.org

Appendix 3: Housing

Universal Credit Helpline 0800 328 5644 (Monday to Friday, 8am to 6pm)

www.gov.uk/universal-credit/how-to-claim

Exeter City Council Housing Advice team Tel: 01392 265726 (during normal office hours) housing.advice@exeter.gov.uk **Housing Benefit and Council tax support** 01392 265440, Rents team 01392 265475, Benefit and welfare advice 01392 265440. exeter.gov.uk/benefits-and-welfare/how-to-claim-benefits/what-you-need-to-know-about-benefits/benefit-support-available/

For those on low income help with council tax (called Council Tax Support or Council Tax Reduction) should still be applied for to your Local Authority separately from any claim for Universal Credit.

exeter.gov.uk/benefits-and-welfare/how-to-claim-benefits/what-you-need-to-know-about-benefits/

Support for council tax in other areas

East Devon District Council Tel: 01395 517446

eastdevon.gov.uk/benefits-and-support/council-tax-support/

Mid Devon District Council: www.middevon.gov.uk/residents/benefits/council-tax-reduction/

North Devon Council: www.northdevon.gov.uk/council-tax/discounts-exemptions-and-support/

West Devon Borough Council: email benefits@swdevon.gov.uk
www.westdevon.gov.uk/article/1938/Apply-for-Council-Tax-Reduction

South Hams District Council: email benefits@swdevon.gov.uk
southhams.gov.uk/article/4327/Council-Tax-Reduction-if-you-are-on-a-Low-Income

Teignbridge District Council: email revandbens@teignbridge.gov.uk
www.teignbridge.gov.uk/council-tax/reduce-your-council-tax/council-tax-support/

Torridge District Council: Tel 01237 428700 email benefits@torridge.gov.uk
www.torridge.gov.uk/article/11057/Council-Tax-Support

Torbay Council: www.torbay.gov.uk/benefits/hb-cts/cts/

Plymouth City Council: Tel 01752 668000 (select 3)
www.plymouth.gov.uk/home/counciltax/counciltaxsupport

Appendix 4: Making Complaints

Citizens Advice national advice line: 03444 111 444 or see www.citizensadvice.org.uk/ CAB have local offices based across Devon.

Your **local Healthwatch** can help you find independent NHS complaints advocacy services in your area. **Healthwatch Devon**. Tel: 0800 520 0640 or write to Devon Communities Together, 1st Floor, 3&4 Cranmere Court, Lustleigh Close, Exeter, EX2 8PW.

Healthwatch Torbay Tel: 0800 520 029 or write to Free post RTCG-TRXX-ZKJ, Room 17 The Library & Information Centre, Great Western Road, Paignton, TQ4 5AG.

Healthwatch Plymouth Tel: 0800 923 0039 or write to Unit 37, HQ Building, 237 Union Street, Plymouth, PL1 3HQ.

Devon and Plymouth Patient Advice and Liaison Service (PALS) Tel: 0300 123 1672 or 01392 267665 or Text:07789 741099 Email: pals.devon@nhs.net or write to Patient Advice and Complaints Team (including you telephone number) Freepost, EX184 COUNTY HALL, TOPSHM road Exeter, EX2 4QL. Offer confidential advice, support and information on health-related matters. They provide a point of contact for patients, their families and their carers. You can find officers from **PALS** in your local hospital. Find your nearest PALS by calling NHS 111. Or contact the **Patient Experience Team** (PALS Complaints)

NHS England www.england.nhs.uk/contact-us/complaint/

You can also contact social services at your **local council and ask about advocacy services** www.nhs.uk/service-search/Local-Authority-Adult-Social-Care/LocationSearch/1918

Equality and Human Rights Commission. Provides information, including Equality Act guidance, including information on disability discrimination. www.equalityhumanrights.com

Age UK may have advocates in your area (if you are over 50). Tel: 0800 055 6112 or visit www.ageuk.org.uk/

Finding an MP - www.parliament.uk/mps-lords-and-offices/mps/

Appendix 5: Reasonable Adjustments and the Equality Act (2010)

The Equality Act (2010) applies to England, Wales and Scotland. Implementing the provisions of EU directive 2006/54/EC.

The full text of the act is available at www.legislation.gov.uk/ukpga/2010/15/contents

There are guidance notes from HM Government available at www.gov.uk/guidance/equality-act-2010-guidance

Here is a guide from the CAB www.citizensadvice.org.uk/law-and-courts/discrimination/about-discrimination/equality-act-2010-discrimination-and-your-rights

and a guide from **ACAS**, mostly concerned with employment www.acas.org.uk/media/pdf/1/0/Equality_discrim_understand_basics_Nov.pdf

Autism falls under the “protected characteristic” of “disability”. Whilst there is no need to have an official diagnosis this can be helpful.

The act defines the following as unlawful:

Direct discrimination: That is treating someone less favourably because they possess (or are assumed to possess) a protected characteristic. It doesn't matter if this is deliberate or not.

Indirect discrimination: That is where there is a rule, policy or similar which applies to everyone in the same way. But which places people with a certain protected characteristic at a disadvantage.

Discrimination arising from disability: This is where disabled people are treated unfavourably because of something connected to their disability. It may be difficult to tell this apart from indirect discrimination.

Harassment: Unwanted behaviour in relation to a protected characteristic which results in the recipient feeling intimidated, offended, degraded or similar.

Victimisation: This is where someone is treated less favourably because of making a previous complaint about discrimination or supported someone else in making such a complaint.

In certain cases, indirect and disability discrimination may not be unlawful. This is known as “objective justification”. What this means is that the organization in question needs to have a good reason for doing so and could not achieve this without discriminating.

The following are defined in the act.

Positive action: This mainly applies to employment. Enabling an employer to offer a job or promotion to an Autistic person over a non-Autistic person. Assuming that both are qualified and competent for the job in question.

Reasonable adjustments: These are changes organisations make in order to address discrimination arising from the protected characteristic of disability. These could include changing how things are done, including policies and procedures; changing physical features, including ambient light and sound levels or providing extra aids and services.

Since autism is a spectrum condition, applicable reasonable adjustments depend very much on the individual, thus any examples of reasonable adjustments should be considered a suggestion.

Also covered in the act is “public sector equality duty”. The organisations include central and local government, the NHS, police, regulatory authorities, the armed forces, schools & universities, as well as companies carrying out public functions, such as electricity, water, gas or telephone companies and housing associations. These have specific duties to consider how their policies and decisions affect people protected under the Equality Act. Specifically, to do the following: eliminate unlawful discrimination, advance equality of opportunity & foster or encourage good relations between people who share a protected characteristic and those who don't.

Chapter 18 of the book “PDA by PDAers”, by Sally Cat (ISBN 1785925369) covers several general reasonable adjustments.

These include: rewording and explaining rules and procedures, allowing the use of email (or similar) rather than the telephone, keeping people informed, giving clear rather than approximate times.

Although this chapter is written from the point of view from someone with a PDA profile of autism, it is likely to be useful to Autistic people generally, for example, many Autistic people dislike using the phone and this can become a barrier to access to services.

Healthcare

Here is some information in relation to reasonable adjustments in healthcare, this article mentions being able to email GPs, and other NHS staff, amongst many other adjustments

www.ambitiousaboutautism.org.uk/talk-to-others/2015-04-09/reasonable-adjustments-autistic-people-are-entitled-to-by-law-from

Education

Examples of direct discrimination, indirect discrimination, discrimination due to disability and reasonable adjustment in relation to Autistic pupils in a primary or secondary school environment, can be found here... www.autism.org.uk/about/in-education/resolving-disagreements/discrimination-gb.aspx

Disability Rights UK has a list of reasonable adjustments for Autistic university students. These may also be useful to other students.

Section 4 of www.disabilityrightsuk.org/adjustments-disabled-students

These include: Having access to a specific member of staff for support needs or concerns. Having course materials and exams in clear plain English, avoiding unnecessary use of metaphor and inference. Having a written transcript of information usually given verbally.

Work

Here is some information with regards to reasonable adjustments in the workplace, from Bristol Autism Support www.bristolautismsupport.com/reasonable-adjustments-at-work-for-autistic-adults/

These include: Headphones or access to a quiet area to avoid sensory overload, use of text messaging in place of phone or face to face meetings, flexible working hours and not having to take part in workplace social events.

Information can also be found via this TUC report “Autism in the Workplace” www.tuc.org.uk/sites/default/files/Autism.pdf

These include: avoiding variable shift patterns, having a quiet working environment, support in the case of changes being made, provision of a mentor and avoiding ‘hot desking’.

And from Autism Network Scotland:

employment.autismnetworkscotland.org.uk/information-for-employers/reasonable-adjustments/

These include: Clear job descriptions which avoid hyperbole and jargon and meeting agendas to be followed and distributed prior to meetings. Autism Network Scotland also make the point that, in practice, only a few adjustments may be required.

Appendix 6: Pathological Demand Avoidance (PDA)

This information is important, as different strategies are required for those who have PDA to those who have ASC. Typical autism strategies won't work with a PDA profile.

PDA as with other Autism profiles is a lifelong disability and PDAers need for support will change at different stages of their life, depending on how their condition affects them. Evidence so far, suggests that the earlier the diagnosis, with the appropriate support given, the more able and independent they are likely to become.

People with a demand avoidant profile share difficulties with others on the autism spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours (including sensory seeking or sensory avoiding behaviours).

However, PDAers are driven to avoid everyday demands and expectations to an extreme extent. This demand avoidant behaviour is rooted in an anxiety-based need to be in control of their environment and avoid other people's demands and expectations.

The demand avoidant profile is increasingly being recognised and it's important to understand the distinct behaviour profile as it has implications for the way a person is best supported. Those with the PDA profile will need tailored support, with a clear understanding of their needs. Strategies that tend to be successful for the other profiles on the spectrum tend not to work for those with the PDA Profile.

People with a demand avoidant profile may appear to have better social understanding and communication skills than others on the autism spectrum, which they often use this to their advantage. They may use manipulation, distraction, giving excuses and could even have Non-epileptic Seizures brought on by anxiety. However, they might not really have as good an understanding of social matters as it seems. At times the anxiety can be so intense, that even if they are aware of what they are doing, they are unable to change their way of behaviour as their brain goes into a coping strategy mode, which can turn into full blown meltdown and exhaustion. They can be confrontational and impulsive. PDAers may mask how they feel especially girls, which is why it goes undetected.

The distinctive features of a demand avoidant profile include: resists and avoids the everyday demands of life; uses social strategies as part of avoidance as described above, they may appear sociable, but can lack understanding; experiences excessive mood swings and impulsivity; may appear comfortable in role play and pretence or the obsessive behaviour is most often focused on people.

People with this the PDA profile can appear controlling and dominating, especially when they feel anxious. However, they can also be enigmatic and charming when they feel secure and in control. It's really important to acknowledge that these people have a hidden disability and that getting the appropriate support (which is different) to other ASC profiles as the strategies used for other ASC will not work for PDAers.