NHS
North East and
North Cumbria

Suicide Prevention Toolkit for Autistic People

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Executive Summary

Autistic people are at higher risk of suicide than non-autistic people due to several factors.

- Many autistic people are unidentified, so the risk is difficult to quantify and manage.
- Many services are not autism aware or confident, so services seem hard to access for autistic people, including crisis services.
- Diagnosis can take some years due to capacity of services; many adults have had the diagnosis missed or misdiagnosed so support may have been misdirected.
- Many autistic patients have co-occurring physical health and mental health conditions, and many are not in employment. Some have co-occurring learning disability.
- The national strategy and its local implementation should help all sectors of society, health and care be more autism aware and create environments in education, employment health care and justice services that are more accepting and adapting.
- Reasonable adjustments and communication support can help.

Please feel free to use the place based resources as a guide and adapt them to your local area

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Autism and Suicide Rates - Overview

Trigger warning – this content discusses suicide

- Autism is a condition which affects how people communicate and interact with the world.
- A significant number [likely more than half] of autistic people are not identified either to themselves or to health/care professionals.
- It is estimated that around 50% of people who are autistic also have a learning disability and 71% of people who are autistic may experience a mental health problem such as anxiety, depression, attention deficit hyperactivity disorder (ADHD) or obsessive-compulsive disorder (OCD).
- Research suggests that 70% of autistic people have one mental health condition, and that 40% have two or more.
- Autistic people are up to four times more likely to have anxiety disorder, and twice as likely to have depression. Early research has showed that 66% of adults recently diagnosed had contemplated suicide in their lifetime, and 35% had planned or attempted suicide (Cassidy et al. 2014).
- Research has shown that autistic people are more vulnerable to negative life experiences, such as difficulty as navigating friendship groups causing social isolation, which may also impact their mental health.
- Compared to the general population, autistic people report having a lower quality of life, and suicide is a major cause of early mortality in autistic people.

Autism and Suicide Rates – Overview (cont.)

- People with a learning disability and or autism are at risk of deteriorating mental health/suicidal thoughts and may not be able to articulate that to get the services they need.
  - More than 6 in 10 autistic people have considered suicide.
  - More than 3 in 10 autistic people have attempted suicide.
  - 7 in 10 autistic adults have a mental health condition

Why are autistic people more likely to have self-harm and suicidal thoughts?

There are lots of things that make autistic people at risk of self-harm and suicidal thoughts and behaviours. Some of these are part of who an individual is, their cognitive and behavioural functions and some are based on the environment. Research findings include:

- Many autistic people have “sticky thinking” meaning they can focus on a particular train of thought. This can mean that suicide feels like the only escape.
- Autistic people are often forced to modify their autistic behaviours to cope in a society that is set up for non-autistic people. We call this “camouflaging/masking”, and it can increase feelings of loneliness and not being accepted.
- Autistic people often don’t have access to appropriate support because services may not be set up for their needs, and therefore, more likely to feel isolated, alone, and hopeless.
- Autistic people are more likely to experience difficult life events, which can increase their risk of attempting suicide.
- Clinicians have felt significantly less confident asking about suicide planning for their autistic compared to their non-autistic clients meaning important information and planning may get missed.

Why are autistic people more likely to have self-harm and suicidal thoughts? (cont.)

- Often strong links with co-occurring psychiatric conditions meaning an increased risk of suicidal ideation.
- Autistic adults are also significantly more likely to experience non-suicidal self-injury (NSSI) compared to the general population. NSSI is associated with increased risk of suicidality in this group.
- Autistic people often feel they aren't believed when they ask for help, or their distress is underestimated, because they can manifest depression and crisis differently.
- Parental education, restrictive and repetitive behaviours, IQ, and adaptive behaviour, affective and conduct problems, and medical concerns all increased risk of suicidality in the autistic young people researched.
- Routines and stimming are more often supportive of autistic mental health than not but changes in these behaviours might be an indicator of problems.
- Emotional dysregulation is associated with increased risk of suicidality. Low mood and overactivity/impulsivity also predicted the presence of self-harm. Stimming may aid regulation.
- Alexithymia meaning those with difficulty identifying and describing their emotions have been associated with further increased risk of suicidality.

Why are autistic people more likely to have self-harm and suicidal thoughts? (cont.)

- Low self-esteem is also significantly associated with current suicidal ideation, and rumination with history of suicide attempts, suggesting that feeling sad, and trapped in the current situation may increase risk of suicide in autistic people regardless of diagnostic status.
- The contribution of poor sleep to suicidality in autistic people.
- The risk of crisis of mental health deterioration and suicidal thoughts/behaviours in difficult social situations is difficult to quantify. Carers are often left to cope with these scenarios, resorting to crisis teams who may not have specialists for autism or learning disability within them.
- Covid increased social isolation in general and affected more people living in supported accommodation with a mild learning disability, or in supported living with deteriorating mental health.
- Alcohol/substances. Autistic people may have a high use of alcohol/substance especially when there are other mental health conditions involved.

https://988lifeline.org/wp-content/uploads/2023/01/Warning-Signs-Resource-Sept-2021-2.pdf provides warning signs of imminent suicidal behaviour specific to autistic people.

Safety Planning

Safety Planning is a brief intervention to help prevent suicide

When people are suicidal, they can feel trapped in a moment of intolerable distress. These feelings often come and go, and the plan helps to ensure they do not act open their feelings in this moment of crisis.

This generic tool helps people to plan and think ahead of time about what might help them to safely navigate any future crisis

Autistic people have differences in social communication compared to non-autistic people. These differences could impact upon safety planning. For example, these differences might mean that imprecise language and broad questions are difficult for an autistic person to respond to, and might be a challenge for someone to generate alternative solutions

A few attempts may be needed to complete a plan, and it may need changing and updating regularly

Safety Planning (cont.)

Autism adapted safety plan:

Mental Health in Autism – Safety Plan (google.com)

https://sites.google.com/nihr.ac.uk/safetyplanstudy

Below is a useful link to produce a generic safety plan which could be adapted:

https://www.every-life-matters.org.uk/safety-planning/

https://prevent-suicide.org.uk/find-help-now/stay-safe/

Autism Friendly and Inclusive Environments

When Completing an Autistic Persons Safety Plan or supporting an autistic person in general, the first question should be:

- Is the environment in which you complete the plan or provide the support inclusive and engaging?

Options to support an autism friendly environment:

https://positiveaboutautism.co.uk/uploads/9/7/4/5/97454370/checklist_for_autism-friendly_environments_-september_2016.pdf

https://www.autismcrc.com.au/knowledge-centre/reports/guidelines-creating-autistic-inclusive-environments

Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings | British Journal of Hospital Medicine (magonlinelibrary.com) https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006

Sensory environment NHS England » Sensory-friendly resource pack

Reasonable Adjustment Campaign - https://necldnetwork.co.uk/work-programmes/reasonableadjustments

Autism Friendly and Inclusive Environments (cont.)

Communication support

Communication tips (autism.org.uk)

NHS Document Readability Tool (newcastlerse.github.io) tool to help make your documents reading age [UK average reading age 8-10] appropriate for the population.

Communication Top Tips for Healthcare Professionals « Learning Disability Network (necldnetwork.co.uk)

‘It’s Not Rocket Science’ meeting the sensory needs of autistic children and young people inpatient services: Sensory-Friendly-Ward-Principles.pdf

Autism Adapted Safety Planning

An autism adapted safety plan could utilise some of the challenges an autistic person may have and help them to identify coping strategies.

https://sites.google.com/nihr.ac.uk/safetyplanstudy

For example:

- Building upon where an autistic individual might have a particularly strong passions and interest.
- Directional questions that help autistic people to navigate their difficult feelings and distract from their suicidal thoughts until they pass.
- Space to think about warning signs of an impending crisis, internal coping strategies that might help, people and professionals they know and/or who they can reach out to for support, and ways to make the environment safer.
- Questions about how the autistic person would like to be communicated with when distressed, and whether they would like to share the safety plan with trusted people.
- The impact of external factors such as housing and housing support, employment etc.

GP Practice Guide for supporting autistic people below:

https://www.england.nhs.uk/wp-content/uploads/2017/09/guide-support-autistic-people.pdf

Avoiding Crisis and Escalation

An individual and their family can be supported to learn skills to help anticipate and turn around an escalating situation that seems to be headed in the direction of crisis.

Preparation and strategies for coping and staying safe in crisis situations is essential and it is important for the team, including the family, to develop a crisis plan together.

Hope boxes can add to a person's feeling of personalisation of their safety plan Hope-box.pdf (papyrus-uk.org)

Think about ways to reduce being overwhelmed, including planning rest and recovery time.

Supporting autistic people who are overwhelmed or having a meltdown | Autistica

Useful links

https://www.autismspeaks.org/tool-kit-excerpt/planning-crisis

https://www.autistica.org.uk/downloads/files/Crisis-resource-2020.pdf

https://www.autistica.org.uk/downloads/files/Autistica-Support-Plan.pdf

https://paautism.org/resource/crisis-intervention-de-escalation

Right medication at the right time for the right reason. Safer Prescribing in Children and Young People – STOMP & STAMP

STOMP stands for stopping the over medication of people with a learning disability, autism, or both with psychotropic medicines.

STAMP aims to make sure that children and families can access other treatment and support when children display behaviours that challenge.

People with a learning disability, autism or both are more likely to be given these medicines than other people.

People with a learning disability, autism or both should only be prescribed psychotropic medication when clinically indicated. Other therapies and support (including family support) should be offered before prescribing and while taking psychotropic medication.

The experience of parents, carers, clinicians, and young people indicate that psychotropic medication prescribed in childhood is often continued long past its original prescribing rationale. This could be because of poor monitoring and reviewing, and an unwillingness to challenge the originating prescriber about the appropriateness and/or efficacy of a particular psychotropic medication. Clinicians can also be reluctant to reduce long standing medication.

Right medication at the right time for the right reason. Safer Prescribing in Children and Young People – STOMP & STAMP (cont.)

Some medications may not be necessary as the young person grows into adulthood and the medication side effects may be detrimental to their health and wellbeing.

There is the risk that over medicalisation may increase the risk of suicide for at least some patients in particular children and/or cause other damaging side effects.

It should be noted that for some children and young people, medication can be useful in enabling them to function and help them to achieve their potential. However regular and timely reviews should be undertaken so that the effectiveness of the medication is reviewed and balanced against potential side effects and risk.

https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

https://www.england.nhs.uk/wp-content/uploads/2019/02/STOMP-STAMP-a5-leaflet.pdf

https://www.informationnow.org.uk/article/bottle-in-the-fridge-emergency-information-scheme/ - Bottle in the fridge scheme helps store your personal and medical information in your fridge door, so it can be found quickly by emergency services, if you have an accident or sudden illness at home. This simple and free idea could help to save your life.

General Prescribing Guidance for Suicide Prevention

- Think about practice opioid prescribing, attempt and manage any reduction safely.
- Think about gabapentinoids and other risk medications and review regularly.
- Think family – e.g. opioids available in the house in palliative care.
- 7 days [or less] only prescribing when risk is high [with signposting to prepayment certificate to reduce cost].
- Ask about alcohol and substance misuse.
- Use a single pharmacy for all prescribing [primary and secondary care]
- Consider proactive carer support.
- Consider proactive patient support in at risk times e.g. change of employment.

Safeguarding

Think About

- Understanding your local safeguarding reporting pathways and review process.
- Ensuring the individual and family concerned are involved in accepting and positive socialising/relationships, where the autistic person feels comfortable to be their autistic self without judgement. This advice could be applied counterproductively with increasing need for masking and reducing social recovery time
- Assess a person's quality of support and care.
- Education – support in enabling access to SEND and robust and supportive EDHCP (educational health and care plan)
- Ensuring there is adequate support for family carers.
- Ensure appropriately trained and skilled staff are involved in the individuals care and support.
- Ensure you work collaboratively with all services involved in an individual's support to share relevant information confidentially and provide holistic wrap around support.
- Consider the importance of planning enough rest and recovery time alone after challenging situations - gives time for overwhelm to reduce

Safeguarding (cont.)

Useful Links

https://www.safeguardingsolihull.org.uk/ssab/wp-content/uploads/sites/2/2021/09/Safeguarding-Practice-With-Autistic-People-1.pdf

https://www.local.gov.uk/our-support/partners-care-and-health/care-and-health-improvement/autistic-and-learning-disabilities/learning-disabilities/better-lives/7-supporting-adults-learning-disabilities-andor-autism-stay-safe

https://www.preventingexploitationtoolkit.org.uk/home/what-is-exploitation/what-is-vulnerability/autism-spectrum-conditions

https://adhdandautism.org/wp-content/uploads/2021/11/Safeguarding-Vulnerable-Adults-Policy-v03.pdf

https://www.beyondautism.org.uk/wp-content/uploads/2022/11/Safeguarding-Adults-at-Risk-Procedure-2022.pdf

https://www.autism.org.uk/shop/products/books-and-resources/safeguarding-young-people

https://www.england.nhs.uk/learning-disabilities/care/children-young-people/send

The National Autistic Society's education rights helpline can give advice about child's rights, education law and how to resolve problems at school call: 0808 800 4102.

Postvention and Bereavement Support

Patients bereaved by suicide are up to six times more likely to die by suicide themselves, we do not know how this affects autistic individuals.

Postvention support is an organized immediate, short-term, and long-term response in the aftermath of a suicide to promote healing and mitigate the negative effects of exposure to suicide

Useful Links

https://www.childbereavementuk.org/supporting-a-bereaved-child-who-is-autistic

Overview of our new guide: supporting people bereaved by suicide who are neurodivergent – Support After Suicide
https://www.ifucareshare.co.uk
All age therapeutic postvention support

https://www.mind.org.uk
1-1 counselling and in some areas, they provide Triple AAA group support for neurodiverse population

Holistic Care

As professionals it's important to think about the identification of trigger points and internal and external factors such as life events and behaviours that may influence an individual's mental wellbeing temporarily or longer term and could potentially escalate to a crisis point. These include:

- Transitions between services, life stages etc.
- Personal and professional relationships.
- Gender and sexual identity.
- Past trauma.
- Health Inequalities and access to services.
- Eating disorders /disordered eating.
- Misdiagnosis/additional diagnosis such as bipolar or personality disorder.
- Additional ADHD or sensory needs, Alcohol and Substance misuse.
- Employment - Difficulty in finding employment and further education and apprenticeship opportunities.
- Entering the criminal justice system and negative experiences within it.
- Sexual health.
- Poverty and financial hardship.
- Maternal/perinatal Mental Health.

Autism and Transitions

Useful Links

https://www.autism.org.uk/advice-and-guidance/topics/transitions

https://www.autismeducationtrust.org.uk/sites/default/files/2021-11/Supporting-learners-with-autism-during-transition.pdf

https://www.beyondautism.org.uk/blog/transitions-big-to-small/

https://www.autismtoolbox.co.uk/transitions/

https://www.tandfonline.com/doi/abs/10.1080/1045988X.2023.2207482

https://autismadhdconnection.com/10-ways-to-make-transitions-easier-for-your-autistic-child

LGBTQ+

Autistic people are more likely to exhibit diverse gender identities or gender variance than the general population.

LGBTQ youths who have been diagnosed with autism were over 50% more likely to attempt suicide in the past year compared to LGBTQ youths who have never had an autism diagnosis, according to a research brief published by the Trevor Project, an organisation that provides crisis intervention and suicide prevention services to LGBTQ youth under 25

Useful Links

https://www.autism.org.uk/what-we-do/branches/lgbtq-online-branch

https://ww.autismspeaks.org/lgbtq-information-and-resources

https://www.mosaictrust.org.uk

https://stem4.org.uk/gender-sexuality-mental-health

https://mermaidsuk.org.uk

Impact of Societal Views and Trauma

Prejudiced beliefs against autistic people sadly may lead to many forms of discrimination, including but not limited to medical, education, and employment discrimination. These attitudes can be built into society, at a systemic level and can affect the individual deeply both in their ability to reach their full potential causing low self-worth, and in their physical and mental health and cause anxiety and depression as a result.

For example, if an autistic individual experiences trauma and bullying growing up, they are likely to have social anxiety and become easily overstimulated in social situations. This, in turn, can cause autism meltdowns, anxiety, and depression

- Think Trauma Informed Staff Training at all levels!

Useful Links

https://www.autismtoolbox.co.uk/social-and-emotional-wellbeing/trauma

https://www.e-lfh.org.uk/programmes/trauma-informed-care – e-learning modules

Disordered Eating

Autistic individuals may have highly selective eating requirements or be particularly sensitive to the textures, look, smell or sound of foods, which can lead to food aversions. "The social aspects of eating (such as sitting at a table with others, waiting until others are finished) can also be challenging." (“Eating disorders and autism”)

Useful Links

https://www.beateatingdisorders.org.uk

https://embrace-autism.com/autism-and-eating-disorders

https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/anorexia-and-autism

https://www.arfidawarenessuk.org/the-link-with-autism-1

Support for Avoidant Restrictive Food Intake Disorder (ARFID) - Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Employment

The Office for National Statistics (ONS) published data in 2021 that shows just 22% of autistic adults are in any kind of employment whilst three quarters of those who responded to a survey conducted by Autism.org.uk said they would like to be in suitable employment.

Work with people in crisis often centres around workplace challenges and/or failure to make reasonable adjustments.

Employment can help with a person's self-esteem, sense of worth and identity.

Useful Links

https://www.ambitiousaboutautism.org.uk/what-we-do/employment/toolkits

https://www.autism.org.uk/what-we-do/employment

https://www.employmentautism.org.uk

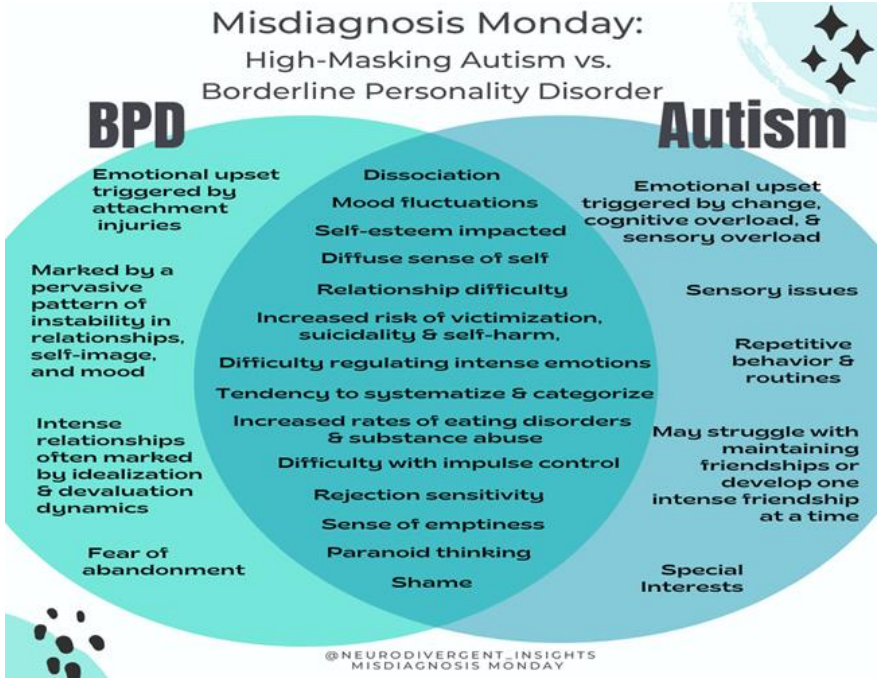
https://livingautism.com/employment-support-autistic-individuals

https://www.cntw.nhs.uk/services/individual-placement-support-ips-employment-service - CNTW Individual Placement Support Service

Co-occurring Diagnoses?

Borderline personality disorder is a common misdiagnosis for autistic women and genderqueer people.

It is also commonly co-occurring, and an autistic person is more vulnerable to developing it.



Substance Misuse

Autistic individuals are twice as likely to develop an addiction problem than their non-autistic peers. An estimated 1 in 5 teens and young adults receiving substance abuse treatment may have undiagnosed symptoms of Autism.

Useful links

https://www.addictionhelp.com/addiction/autism

https://www.autism.org.uk/advice-and-guidance/topics/mental-health/addiction

https://addictionsuk.com/blogs/autism-and-addiction

Justice System

Compared with non-autistic individuals, autistic people may have higher rates of interactions with the Criminal justice System throughout their lifetime.

Autistic people are potentially more likely to be caught for their criminal behaviour, to confess during police interviews, to enter a guilty plea, or to have difficulty advocating for their rights in court.

Autistic people are more prone to being manipulated into involvement in crime and can sometimes perceived as aggressive when in meltdown and arrested rather than helped.

Autistic people who offend may be sentenced more harshly, or there is a possibility that a lack of autism sensitive forensic rehabilitative programmes and risk assessments may contribute to longer stays within forensic settings

Useful Links

https://www.autism.org.uk/advice-and-guidance/topics/criminal-justice/criminal-justice/professionals

https://livingautism.com/two-different-worlds-collide-autism-spectrum-conditions-criminal-justice-system

http://www.mhldcc.org.uk - Mental Health, Autism & Learning Disabilities in the Criminal Courts. Information for magistrates, district judges and court staff.

General Considerations

Anxiety/low mood and other mental health issues– is the person receiving the right support from NHS mental health services? E.g. practice primary mental health workers, social prescribing link workers, NHS talking therapies

Voluntary organisations, Mental Health Support teams in school, School Health Nursing teams.

Sleep Hygiene -is the person accessing help for any sleep problems? Sleep and autism

Crisis Management – has the person got access to the local crisis team numbers including SHOUT, SHOUT the Samaritans, Samaritans and Papyrus Papyrus and do they have a safety plan?

What are the effects of hormonal changes and menstruation/menopause Autistic people and menstruation (autism.org.uk), Menopause (autism.org.uk) and other physical health problems?

Is the person socially isolated or physically unfit? Social Prescribing link workers/locality support planners can help an individual to access. support/activities within their local community health and wellbeing hubs.

Debt and Poverty are a key area of concern and can have an impact on a person's mental health and wellbeing. Access to independent advice and support around finances such as Citizens Advice Bureau, Citizens Advice Bureau to ensure they are receiving the benefits and financial help they are entitled to and practical support via foodbank referrals, social care support.

General Considerations (cont.)

Is the person addicted to gambling or alcohol/substances? Linking them to local gambling support services gambling support services and local substance misuse services can help.

Is the person pregnant or a recent new parent and struggling? They could access the local family hub, for additional support.

Is the person young and at risk of an inpatient admission? have they and their family had access to family support workers, Autism Keyworkers or other relevant local support, are they on the local dynamic support register? dynamic support register

Carer support local carer charities carer charities and link workers/support planners can help.

Resources

Resources

https://learningdisabilitieshealthnetwork.org.uk

Suicide Prevention Practice Process for Primary Care. This has several useful pointers and stages to consider together with some important contact details, this can be adapted where necessary to support an individual with autism.

https://www.bild.org.uk/wp-content/uploads/2021/02/Trauma-Informed-Care-Toolkit-pdf-SABP.pdf

(bild.org.uk) Trauma informed care a useful part of autism and learning disability suicide prevention.

https://our.learningdisabilitieshealthnetwork.org.uk/t/adapted-gad-7-and-phq-9-measures-of-anxiety-and-depression/2297

Services are not always adequately reasonably adjusted, or equipped to deal with patients who present, there is now a reasonably adjusted set of tools to help Adapted GAD-7 and PHQ-9 measures of anxiety and depression - and a lot of easy read information for patients and families.

https://positiveaboutautism.co.uk/uploads/9/7/4/5/97454370/checklist_for_autism-friendly_environments_-september_2016.pdf

Example of a checklist to help ensure an autism friendly environment in which an autistic person may feel more comfortable in engaging.

Resources

https://livingautism.com/create-autism-friendly-environment

Creating an autism friendly environment.

http://nspa.org.uk

North East and North Cumbria Suicide Prevention Network.

https://hubofhope.co.uk

UK mental health support database, provided by national mental health charity, Chasing the Stigma, brings local, national, peer, community, charity, private and NHS mental health support and services together in one place.

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

Mental Health wellbeing tips and self-help apps/guides.

www.gov.uk

Suicide prevention: resources and guidance & National strategy for autistic children, young people, and adults: 2021 to 2026 - GOV.UK.

https://mencap.org.uk/ Treat me well top 10 reasonable adjustments.pdf.

Resources

https://www.autism.org.uk/what-we-do/news/adapt-mental-health-talking-therapies

Adapting talking therapies for autistic people.

https://www.england.nhs.uk/wpcontent/uploads/2022/10/B0467_i_sensory-friendly-resource-pack.pdf

The National Autism Trainer Programme | Anna Freud

Autism Specific National Charities

https://www.autistica.org.uk

https://www.autism.org.uk

https://www.ne-as.org.uk

https://www.ambitiousaboutautism.org.uk

https://www.childautism.org.uk

https://www.keyring.org

https://www.beyondautism.org.uk

https://www.autism-alliance.org.uk

National Suicide Strategy

https://www.gov.uk/government/publications/suicide-prevention-strategy-for-england-2023-to-2028

Place Based Support - Northumberland

https://www.ifucareshare.co.uk - Postvention Suicide Support (All Age)

https://www.ne-as.org.uk

https://www.everyturn.org

https://www.mhm.org.uk/talking-therapies-northumberland

https://www.tynesidemind.org.uk

https://www.journeyenterprises.co.uk

Diagnostic/education support

https://www.cntw.nhs.uk/services/children-young-peoples-service-northumberland

https://www.cntw.nhs.uk/services/learning-disability-and-autism-services/adults-services-for-people-with-learning-disability-and-or-autism/adult-autism

https://www.northumbria.nhs.uk/our-services/childrens-services/special-educational-needs-and-disability-send-support#2177900b

https://barnardos-parenting.org.uk/cygnet-programme

https://www.northumberland.gov.uk/Children/Needs/Autism-Service.aspx#:~:text=Autism%20Support%20Service-,The%20Autism%20Support%20Team%20offer%20school%2

Place Based Support – Northumberland (cont.)

Post diagnostic support

https://www.ttht.org.uk

https://autisminmind.com

https://www.autism.org.uk/what-we-do/branches/north-northumberland

https://northumberlandrecoverycollege.co.uk/events/autism-peer-support-group-online-3

https://www.daisychainproject.co.uk

https://www.splintergroup.uk

https://www.cygnussupport.com

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