

Highlighting the link between Autism and Suicide

A Briefing for Frontline Staff

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Background and objectives

In the new Suicide Prevention Strategy for England, 2023-2028, autistic people have been named as a new priority group off the back of data, evidence and engagement with experts. In addition, NCISH's 2024 Report selected Autism and ADHD as a topic of focus, highlighting that such conditions are becoming a more significant factor in suicide prevention activity, particularly within mental health services aimed at younger people.

The current message is simple. To help reduce the overall number of suicides, tailored and targeted support must be provided to the needs of these identified groups.

The Kent & Medway Suicide Prevention Programme would therefore like to raise understanding of the increased suicidal risk for those either diagnosed with, awaiting assessment for, or showing strong traits of autism. Embracing understanding of autism itself is key to this.

Whilst we recognise that neurodivergence is a broad subject area, we feel this focused look at autism can act as a key starting point to pave the way for further research and understanding. We also believe that many of the findings and tools within this paper can be applied more widely on account of overlaps with other mental health issues, such as isolation, anxiety, trauma, and self-esteem struggles.

Our aim from this paper is that frontline professionals can feel better equipped in spotting possible ASC in others, be more aware of how to tailor their communications, and know how and where to facilitate access to diagnosis pathways and support.

Acknowledgements

The K&M Suicide Prevention Programme does not claim to be an expert in autism, and so in our efforts to explore and understand it, it was necessary to collaborate with a number of specialists. Our particular thanks go to the following for sharing comments, advice and insights for this briefing paper:

Emilymay Miles - Kent Autistic Trust

Tony Coggins - Thrive Wellbeing Consultancy

Tristan Kluibenschadl - STAK.Life

Lisa Mortimer & Jacqueline Murray - KCC Adult Social Care

We have also compiled a list of other useful and relevant resources that can be found towards the end of this paper.

Autistic Spectrum Condition (ASC) - Key Facts



Autism Spectrum Condition (ASC) is a group of neurodevelopmental conditions that affect the way that people communicate and experience the world around them. It can bring many strengths, but also difficulties if needs are unmet.



It is crucial to remember that every autistic person is different.



Most people are able to learn, live and work independently, whilst around 15-30% have learning difficulties that require specialist support.



Some common strengths among autistic people include attention to detail, creative talent, mathematical and technical abilities, and the ability to learn and memorise things quickly.



The current needs and challenges for autistic people are perhaps best summarised in the 2030 Goals of Autistica, the UK's leading autism research and campaigning charity.

The vision includes:

- All autistic people will have support from day one if they need it
- The employment rate for autistic people will double
- Autistic people will have proven treatments for anxiety
- Public spaces will be more accessible for neurodivergent people
- Every autistic adult will be offered an annual, tailored health check
- Attitudes to autistic people will change



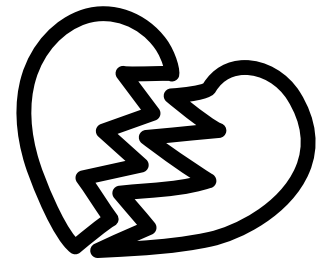
Suicide & Autism - What We Know So Far

Initial studies indicate that there is a significantly increased risk of suicide for autistic people, and whilst there is still much to be done in terms of research, it is important to acknowledge what is already understood:



More than 3 in 10 autistic adults have attempted suicide, and autistic children and young people are 28 times more likely to think about or attempt suicide (Oliphant et al, 2020)

Autistic women are three times more likely to die by suicide than non-autistic women (Kirby et al, 2019)



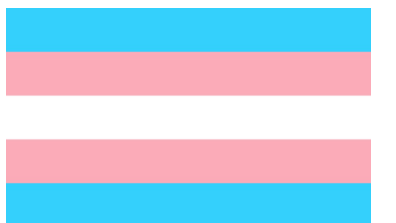
Adverse Childhood Experiences (ACES) such as bullying and abuse, micro aggressions and accumulative trauma by exposure to harmful sensory environments are factors found to increase suicidality

There are higher rates of suicidality in transgender people with autism (Strauss et al. 2021)



Although the literature is sparse, there is evidence to suggest that some ethnic minority groups may be at higher risk of suicide

Suicide rates for non-autistic people in the most deprived areas of England are almost double those in the least deprived (Baker, 2022). However, evidence is mixed regarding the effects of socio-economic position and suicidality in people with autism.

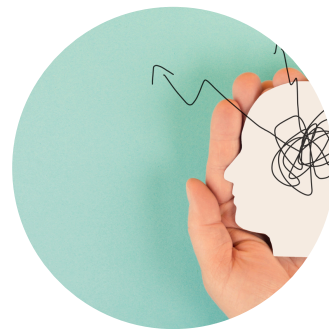


Risk Factors: Comorbidity

Comorbidity is the simultaneous presence of two or more medical conditions in an individual. What we know so far is that:



*There are high rates of **depression and burnout** in people with autism (Cleary et al., 2022). The two require very different kinds of treatment.*



*Having a **mental health condition** is a significant risk factor for suicidality in people with autism (Kloves et al., 2021). According to a 2019 survey, 76% of autistic adults reported reaching out for mental health support within the previous five years (All-Party Parliamentary Group on Autism, 2019).*



*However, it is **unclear** whether people with autism and an intellectual disability are at a greater or lesser risk of suicide than those people without an intellectual disability.*

Risk Factors: Characteristics of Autism



***Alexithymia** - a difficulty in articulating and identifying feelings in a neurotypical way - is present in up to 65% of neurodivergent people. This can make it harder to put coping mechanisms in place prior to crisis.*



***Camouflaging** - adapting behaviours to hide symptoms of autism in order to be accepted by peers can result in delays in diagnosis and access to help, and therefore increased risk of suicide (Cassidy et al,2020).*



People with autism interpret suicide assessment tools differently. Suicidality in people with autism is often missed in psychiatric health screenings (Jachyra et al, 2022).



***Rumination / Repetitive thoughts** - can be used as a way to try and find resolution to a past trauma, and can lead to mental distress if this resolution is not found.*



***Monotropism** - a tendency to focus attention on a small number of interests at any one time - can explain special interests and transition struggles (Milton et al, 2012).*

Risk Factors: Characteristics of Autism Continued:

Shutdowns and Meltdowns

Shutdowns and meltdowns can occur when an autistic person experiences sensory, social or informational overwhelm. They are uncontrollable and often misunderstood for tantrums. They can be terrifying and painful to an autistic individual. Initial research suggests they are linked to epileptiform events within the brain, but more research is required on this (Nicotera et al 2019).



Shutdowns - can look like an individual appearing quiet, withdrawn and unable to respond to things. Common triggers include unexpected changes in plans, social overload, emotional dysregulation, trauma and having sudden, additional demands placed on them.



Meltdowns - can include shouting, aggression and damage to property. They can occur when an autistic person is experiencing overwhelm and wants to get to a safer, quieter space where they can regulate this. They can be distressing both to the individual and to those supporting them.

An understanding of these characteristics will help individuals and frontline practitioners to tailor communication to the needs of the autistic person, and be mindful of the impacts of overwhelm and environments.

LeDeRs (Learning from Life and Death Review Programme) - Putting Autism under the Spotlight:

Source: <https://tinyurl.com/bdd78t8f>

NHS update to learning disability mortality review

📅 23 March 2021

Learning disabilities and autism

Autistic people will now be specifically included in an improved and expanded LeDeR programme to drive improvements in care, the NHS announced today.

"We welcome this crucial change from the NHS, which brings autistic people within the LeDeR programme and will help make sure lessons can be learned.

It's a tragedy for anyone's life to be cut short, and the NHS must be able to learn from what happened. This is particularly important for autistic people who face unacceptable health inequalities - often because of poor understanding of autism and the best way to support autistic people.

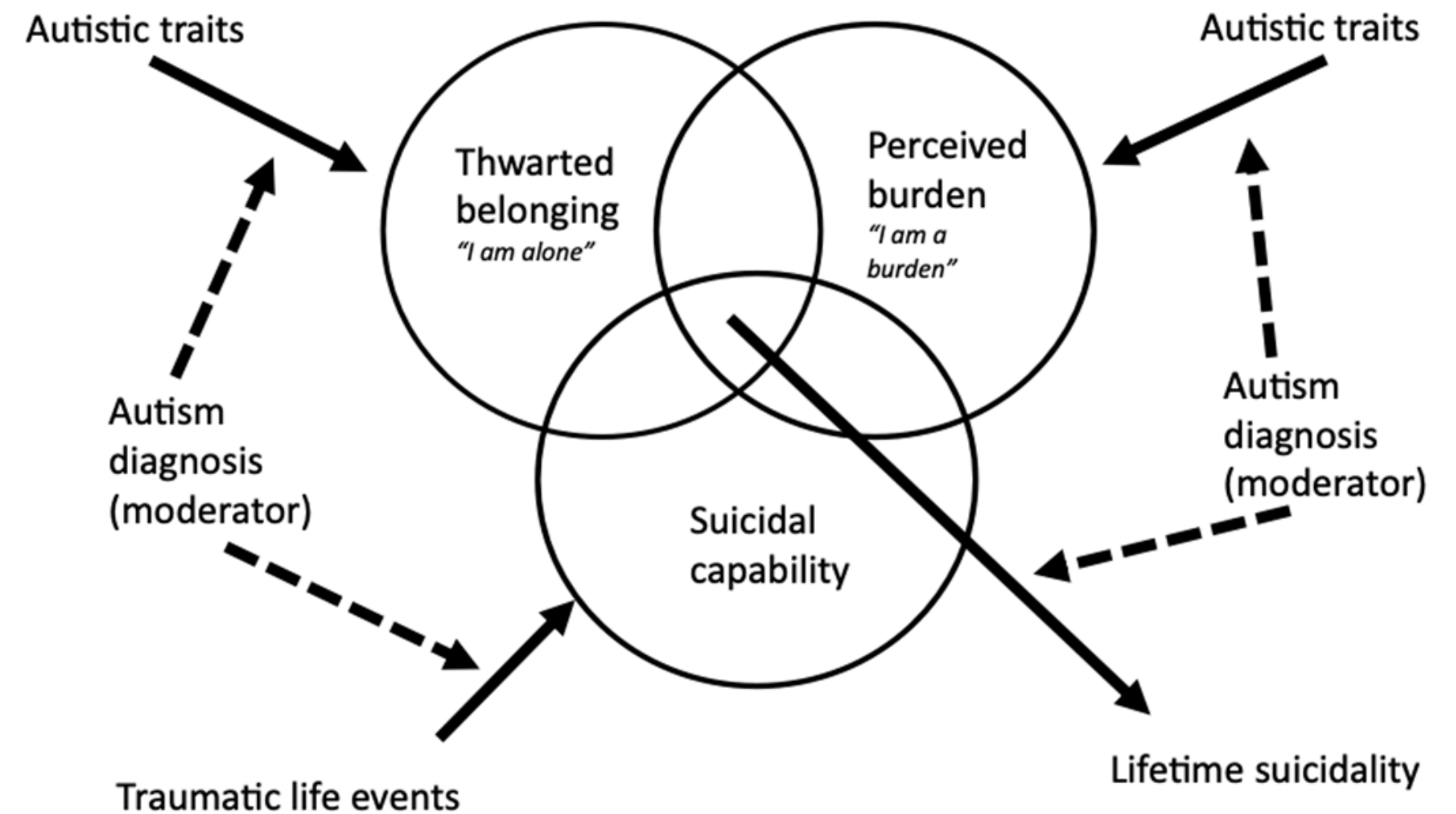
This change will be vital for the NHS' efforts to improve care for autistic people." - Tim Nicholls, Head of Policy at the National Autistic Society

The Interpersonal Theory of Suicide

*There are three factors that place individuals at risk of suicide-related behaviours. These are **perceived burdensomeness** (a belief that others are better off without you), **thwarted belongingness** (absence of reciprocal relationships with family, friends and society), and an **acquired capability in the development of suicide risk**.*

*A number of studies have used this theory to explain the higher rate of suicidality in people with Autism. Autism is characterised by **challenges in social communication and maintaining relationships** which can lead to higher rates of perceived burdensomeness and thwarted belongingness. Risk factors include a perceived lack of social support from family and peers, isolation and bullying.*

By embracing understanding of how to communicate with autistic people, all neurotypes can play a role in reducing the impact of these challenges.



(Source Pelton et al., 2020)

Protective Factors

Protective factors can take many different forms and will be individual to each person, but in broadest terms the following are considered to be the most important:



Resilience-building, a sense of self worth, emotional awareness and having strategies to manage emotions (Costa et al., 2020; Pelton et al.2022).



Social support and social connections also act as important protective factors (Hedley et al., 2018).

The National Autistic Society advocates the SPELL framework (Structure, Positive, Empathy, Low-arousal and Links) to understand and respond to the needs of autistic people and support the development of the protective factors above. For more information, see <https://tinyurl.com/2p9ny2s9>



Service Challenges

Despite growing understanding of the links between autism and suicide, there are still many challenges to providing effective support that services currently face. These include:

- *Suicide awareness and prevention programmes that are available for the general population may not be suitable for people with ASC (O'Halloran et al., 2022).*
- *There is a lack of specific suicide prevention resources and interventions for people with autism (Horowitz et al., 2018; McDonnell et al., 2020).*
- *There is a divide between services for autism and service for mental health (Cleary et al. 2022).*
- *There are low levels of understanding of autism in mental health services (Camm-Crosbie et al., 2019).*
- *There is a lack of evidenced based assessment tools to identify suicidality in people with autism (Cassidy et al., 2022).*

Implications for Practice - General Recommendations

Population characteristics must be considered when designing interventions. In particular:

 *Raising understanding among those who work with autistic people of the increased risk of suicide.*

 *Awareness of the waiting lists and timescales for assessment.*

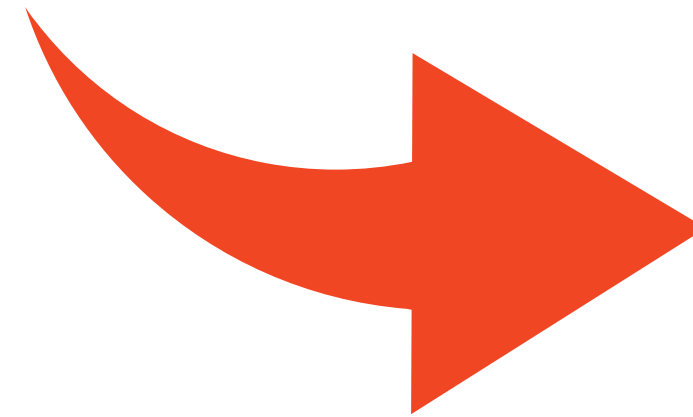
 *Considering how to communicate better with autistic people, including exploring whether they use a Communication Passport.*

 *Understanding the impact of bullying and intersectionality on autistic people and considering ways to address this.*

 *Providing tailored support to young transsexual autistic people.*

 *Increasing the understanding of clinicians working with autistic transsexual people of the heightened risk of suicide.*

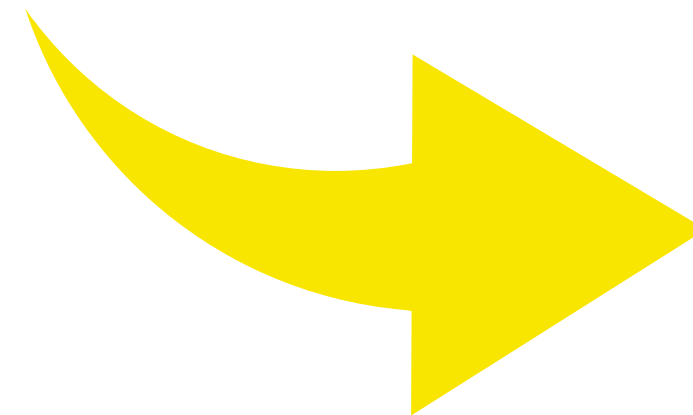
Promoting Mental Health



Providing programmes that build self-worth and emotional wellbeing for autistic people is an effective way to address perceived burdensomeness.



Supporting autistic people to engage in structured activities with clearly defined roles and expectations can help in the development of peer relationships.



Facilitating activities with peers with common interests can help reduce a sense of thwarted belongingness (Hedley et al.,2018).

Implications for Practice - Professionals

The main implications for professional practice centre around heightened understanding of the following:



There is an increased risk of suicide in autistic people.



Suicidal thoughts and feelings may present differently in an autistic person.



Some risk factors can have more impact on an autistic person, such as bullying and social acceptance.



There should be increased screening for suicide among autistic people and a comorbid mental health condition.



Autistic traits such as alexithymia and camouflaging can make identification of suicidal thoughts and behaviours more difficult.

Assessing Suicide Risk

There are no assessment tools for depression or suicidality that have been developed specifically for autistic people. However, there are some helpful things to consider:



Listen to and believe the autistic person.



Ask clear and specific questions, using visual supports if necessary. Verbal communication is often reduced if an individual is overwhelmed.



Give time for the autistic person to process the question.



Be curious and understanding of the individual's life experiences, in appropriate low arousal settings.



Check that the autistic person has interpreted and understood the question as intended.



Use accessible tools to help autistic people monitor and report on their mental health.

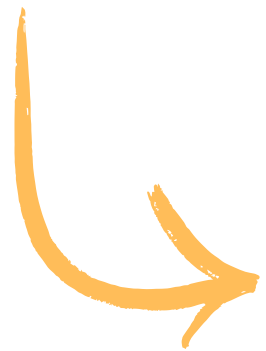
The Zero Suicide Alliance have produced a free training session around Autism & Suicide, which can be accessed here:

<https://www.zerosuicidealliance.com/autism-suicide-training>

Implications for Practice - Safety Planning

Safety plans are a tool used to support and guide someone when they are experiencing thoughts of self-harm or suicide, to help keep themselves safe. They differ from risk assessments and should be an early consideration as opposed to one at the point of crisis. Anyone in a trusting relationship with the person at risk can help draft the plan; they do not need to be a professional.

The Mental Health in Autism project has produced a safety plan adapted for people with autism which is free to use. The full plan can be found here:



MHAutism

My Safety Plan

This form is to help you plan for times when you have strong thoughts, feelings or urges to end your life.

There is also space for you to provide information about how people can best support you when you feel this way. Follow the steps below until you feel safe.

This form can be completed by the person experiencing suicidal feelings, or with support from a trusted friend or family member, health care professional, or support worker.

Name: _____

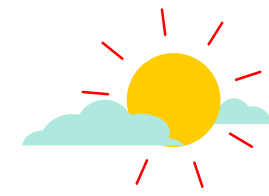
Date(s) of crisis: _____

My reason for living is:
(Please use this space to write a message to yourself for when you feel suicidal. You may also like to attach a photo to this form and/or something meaningful to you that you can focus on when you feel suicidal.)

<http://tinyurl.com/y3nrrp6hh>

What sort of things can a Safety Plan contain?

There is no nationally set structure for a Safety Plan. They should be meaningful to the individual and represented in a way that is appropriate for them. Some typical components include:



Reasons for living and/or ideas for getting through tough times.



Ways to make your situation safer.



Things to lift or calm your mood, including safety words and objects



Distractions, such as reading or other hobbies.



Sources of support (to include anyone you trust).

Safety planning helps to build and demonstrate understanding between an autistic person and the person supporting them.

The Local Offer in Kent & Medway

Assessment and Treatment Pathways:

For Children & Young People, click here.

For Adults, click here.

How do people access assessment and support?

- *All referrals must be from a health or social care professional, such as a GP or mental health specialist.*
- *Patients must be registered with a GP in Kent or Medway.*
- *Adults with a primary need for autism spectrum condition (ASC) and/or ADHD support.*
- *A transition service for young people 17-and-a-half years and older who are diagnosed as autistic or have ADHD, to support transition to the adult service.*
- *Adults who have signs or symptoms that may indicate ASC and/or ADHD, with no existing diagnosis or evidence of a learning disability.*

How can the services help?

- **Signposting, self-help, peer support groups and supporting access to other services.**
- **Assessment and diagnosis of neurodevelopmental conditions (autism and ADHD).**
- **Short-term structured support depending on the individual's needs.**
- **Providing pharmacological medication for ADHD, in line with Kent and Medway shared care guidance for adult ADHD enhanced service.**
- **Some ADHD support and assessment clinics are held virtually (online).**

Adult Autism and Attention Deficit Hyperactivity Disorder Service

A comprehensive expert assessment for adults with suspected Attention Deficit Hyperactivity Disorder (ADHD) and/or Autism Spectrum Disorder (ASD), as well as a variety of post-diagnostic support.

Kent CHT – Waiting Times (as of March 2024)

Appointment	Predicted waiting time
ADHD assessments	Up to seven years
Autism assessments	Up to three years
Medication reviews	Up to two years
Post-diagnostic support	Up to two years

What you can do while you wait for an assessment:



Find a local support group using the [National Autistic Society services directory](#) or at [AADD-UK](#).



Speak to your employer, HR or educational provider including (student support services or special educational needs (SENCO) staff).



Ask your local council for a [needs assessment](#) to see what support they can recommend.



Download and access the [Cogs App](#), which is free to access for 6 months, for those awaiting assessment.

(Source: [Kent Community Health NHS Foundation Trust](#))
(<http://tinyurl.com/yav487um>)

Interface of ASC and mental health- the local challenge of service provision

“Autism is not a mental health problem, but autistic people can have good and bad mental health like anyone else.” - National Autistic Society

Mental Health has been highlighted as the most important area for future research by the broader autism community ([James Lind Alliance](#)) yet people with ASC can sometimes feel that they are passed to disability services that lack mental health expertise ([Autistica, Camm-Crosbie et al, 2018](#)). Where this is identified, it is important frontline staff feel empowered to push for a referral into the right services.



What to do in a crisis?

Anyone experiencing an urgent mental health crisis can phone 111 and speak to a specially-trained mental health practitioner.

If there is a risk of immediate harm or risk to life, you must dial 999.

There are also Safe Havens in Canterbury, Medway, Maidstone, Folkestone and Thanet each evening between 6pm - 11pm. Anyone can attend and no appointment or referral is required. For more details, see here: <https://www.kmpt.nhs.uk/safehavenskentmedway>

Useful Resources:

Mental Health in Autism Project

Mental Health in Autism (MHAutism) is a research group exploring the challenges autistic adults face in relation to mental health problems, self-injury, and suicidality.

The Mental Health in Autism project has produced a simple suicidal behaviours questionnaire to better identify suicidal thoughts and behaviours in autistic people in research studies, (it is not validated for use in clinical settings).

They have also produced a guide for GPs on mental health and autism and a safety plan.

Autistica

Autistica is an autism research and campaigning charity. They provide some information and resources in relation to suicide, including supporting mental health and coping with uncertainty. They have produced a helpful guide on: Supporting autistic children and young people through crisis.

National Autistic Society

The National Autistic Society have provided some advice and guidance on a range of topics, including suicide.

Papyrus

Papyrus is a charity dedicated to suicide prevention and mental health promotion for young people. They have a free and confidential helpline available to young people, concerned others and professionals. They also offer a number of useful resources and training opportunities.

Useful Resources Cont.:

STAK.Life

STAK.Life delivers training, consultancy advice and workshops on autism, autism and mental health, sensory processing disorder and autism and intersectionality for organisations, professionals, and parents.

Kent
Autistic
Trust

Kent Autistic Trust offers individual, tailor made, person centred, solutions of support for adults through living and day vocational and life skill services.

Mind

Mind have worked in conjunction with the National Autistic Society to create a Good Practice Guide for professionals delivering talking therapies to autistic adults and children.

The
Autism
Apprentice

The Autism Apprentice CIC provides support and advice for families that care for a young autistic person.

Zero
Suicide
Alliance

The Zero Suicide Alliance have produced a free, online 'Autism and Suicide Awareness' training session co-produced with the autistic community. It can be accessed here:
<https://www.zerosuicidealliance.com/autism-suicide-training>.

Resources aimed at promoting self-care within the workforce:

Everyday Mental Health Training

This free, one hour training session from mid-Kent Mind aims to help people better understand their own mental health and wellbeing, and learn how to apply that improved knowledge to the steps they can take to support others.

Self-Care Psychology

The Self-Care Psychology website contains a number of free tools aimed at supporting frontline practitioners with their own self-care, including a self-care planner and self-care cards.

EasyHealth. org.uk

EasyHealth.org.uk contains a range of easy read health information about common conditions, including autism and how to look after your mental health. Resources are free to download, but you must sign up as a member to be able to access them.

Other Support Available Locally:

Amparo

Free emotional and practical support for anyone bereaved by suicide in Kent & Medway:

- Call - 0330 088 9255
- Visit - amparo.org.uk/refer



Release the Pressure

For free 24hr help and support you can:

- Call - 0800 107 0160
- Text - 'Shout' to 85258
- Visit releasethepressure.uk



Suicide Prevention Training

For free 3hr training provided by Mid-Kent MIND, visit:

tinyurl.com/ypctrwdy



Stay Alive app

Pocket-sized suicide prevention resource full of useful information and tools to keep you safe in crisis.

For more information, visit tinyurl.com/3js5tf8c