

How to support neurodivergent children and young people at risk of suicide and self harm.

"Rarely can a response make something better... what makes something better is connection..." Dr Brene Brown 2010

Findings from a Positive Practice Audit
conducted by the Kent and Medway CYP
Suicide Prevention Network.

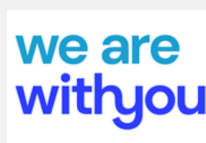
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Introduction

This briefing is based on the results of the second Positive Practice Audit (PPA) conducted during 2022 by the Kent and Medway Children and Young People (CYP) Suicide Prevention Network.[1]

The aim is to help front line practitioners to improve the support they give to neurodivergent[2] children and young people who are at risk of suicide or self-harm. This group was chosen by the Network given the perceived increased risk of suicide and self-harm they face, especially during and since the pandemic.

The Audit was conducted by individuals from the following organisations:



1 The Network's first PPA, Supporting Suicidal Care Leavers, was published in 2021, and is available [here](#)

2 For a definition of what is meant neurodivergent please see Appendix A

What we did

This audit takes a positive approach to identifying and sharing best practice when things go well. It celebrates best practice and demonstrates the effectiveness of the support available to children and young people.

The young people at the heart of this audit have a history of suicide attempts, significant self-harm and many other adverse life experiences. However, when professionals followed the principles identified in this report, the risk of future self-harm incidents or suicide attempts were reduced.

Professionals from a wide range of agencies, services and charities volunteered to answer questions in relation to 18 neurodivergent young people who shared experiences at the heart of this audit. Professionals were asked to identify the key features of the support they felt were most important in leading to positive outcomes.[3]

Five factors to improve practice

The Positive Practice audit highlights the factors identified as being key to providing effective support.

For each of the factors, we provide an introduction and quotes from individual workers with experience of working with the 18 young people whose experiences are at the heart of this audit. In addition, some quotes were also taken from professionals who discussed the submissions as part of a multi-agency forum.

1 Support according to need rather than diagnosis status

The neurodivergent aspect of an individual's identity (and issues such as assessment, diagnosis and waiting lists) should not be allowed to get in the way of their right to expect appropriate, effective and timely support. The audit responses highlighted the best outcomes were achieved as a result of the young person's relationships with practitioners who focused on the young person's pace and understanding of their needs rather than the need for diagnosis.

While medical treatments to support concentration maybe of value for some people, the audit responses highlighted that relationship-based practice, rather than diagnosis-based treatment, was often the key underlying factor in achieving positive outcomes.

"Young people will know themselves better than anyone else, and yet we're expecting them to wait for someone to diagnose them before they can get support that is effective."

"We should be responding to the uniqueness of the individual rather than waiting for a diagnosis."

"We need to think about systemic support - social prescribing, strategies, intervention, provision and also medication if needed."

2 Recognise diagnosis does matter to many but it shouldn't drive practice

Having a diagnosis is important to many parents and professionals. In many circumstances access to financial support, specialist services and other forms of help is felt to be dependent on a diagnosis; therefore, it is understandable why many parents place such an emphasis on it. Professional accountability, particularly emphasised by local and national safeguarding children practice reviews, also drives many professionals to do what they can to support accessing a diagnosis.

However, this combined parental and professional desire for a diagnosis is often not shared by the young person and can develop a toxic atmosphere for them, creating feelings of rejection, isolation and being labelled as being “broken” with a diagnosis required to “fix” the individual.

Diagnosis of neurodivergence should be led by the young person, with professionals and parents supporting them on their journey of self-validation.

“The problem {with the concentration on diagnosis} is that it makes young people think that they are broken or there is something wrong with them. It shouldn't be like that at all. It should be about ensuring support to access the correct methods for that young person, because they process things differently, not wrongly.”

“There may be a lot of stress on people because certain avenues of support may be blocked for people until they've got that diagnosis. But whether you get a formal diagnosis or not, it's about responding to needs in that moment and about action.”

“The diagnosis acted as a barrier and a label for the young person. It did not actually provide a route way for engagement. This was achieved through professional and personal relationships.”

3 Listen to young people as individuals and support at their pace

The importance of supporting young people at their own pace, and in ways they value, does not change just because they happen to be neurodivergent. Many of the audit responses highlighted consistent and stable relationships between the young person and the professionals were often the key feature which reduced risk of harm.

“The support from trusted individuals (IRO and social worker) have been a strong protective factors, being there and recognizing her own agency, pace of engagement and decision making, even in the face of crisis, has supported resilience.”

“Her wishes and feelings directly inform the plans and interventions which is to support her relationship with Y whilst maintaining her rights and entitlements.”

“Open honest conversations that works with the child at their pace and build on relationships they feel safe and secure in.”

“Case notes are written clearly with X's voice - her wishes and feelings are well documented. The records show that professionals listen to X's distress and felt able to talk about what is happening to her. The professional provided opportunities for X to talk about her emotions, what is making her angry and distressed, before pressure builds.”

“The young person was at the centre of the discussion. They were well supported by family and professionals, but the aspirations of the young person were always the focus.”

4 Make reasonable adjustments to your practice

The audit responses highlighted being able to be flexible and adapt service provision to accommodate the individual's needs and experiences will increase the chances of developing the effective relationships needed to trigger and sustain positive change. Person centred and co-designed plans led to the best outcomes often before crisis points were reached.

"The young person didn't like the location of our office due to past trauma and anxiety. So, we would work around that and meet in different locations."

"Where she has received a consistently high level of attention and support from staff, she has shown she does not need to resort to self-harm."

The illustration on the following page was produced by autistic people from Aucademy.co.uk (supported by NHS Kent and Medway) and highlights adjustments professionals can make when working with autistic people.

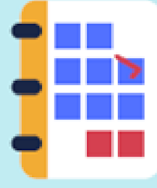
How to Make Reasonable Adjustments

For Autistic and/or people with Learning Disabilities

Created by Autistic people from Aucademy.co.uk & supported by NHS Kent and Medway

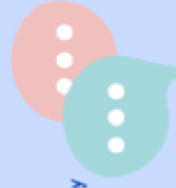
Plan Your Appointment

Research the person's history and their physical, sensory, and communication needs in advance • Consider the appointment location: would a home visit be less stressful? • Consider offering a longer appointment and/or offering it at a quieter time • Let the person know who will be attending the appointment and why • Don't assume people will read an appointment letter or email, find out their preferred method of communication • Presume competence (i.e., don't underestimate).



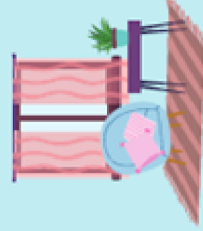
Clear Signs And Communication

Use good signage & directions. • Talk directly to the person using their chosen name, even if they are unable to answer (do not infantilise), & involve family/carers for clarification if needed. • Ask if the person has communication or visual needs, e.g., tools that would help them understand & participate (AAC/Makaton/pictograms). • Have stim tools available. • Use short sentences, avoid jargon. • Allow time for the person to process what has been said.



Have A Quiet/Calm Space Available

Have a room that is quiet/calm for people to go to in case they get overstimulated, tired or need a space to be alone • It is helpful to have this clearly signposted, let people know that it is available and have pictures of the inside of the room available on posters/website.



Pastel Colours

This can help to prevent the sensory overload that Autistic and/or people with learning disabilities may get from colours which are very bright and overwhelming.



Easy To Read Information

Have all information available in easy read formats • Consider the use of Comic Sans, dyslexia font or pictograms with a pastel background. Some patients will find that helpful



Reduce Sensory Over-stimulation

Lighting can be overwhelming • Use natural or dimmable light to reduce glare and intensity • Use comfort setting/filters on computers • Use soft close doors and drawers to reduce the loudness and shock that can startle and overwhelm • Remove unnecessary equipment and limit interruption.



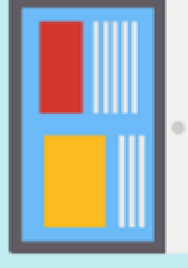
Be Willing To Adapt Your Assessment

Include tasks which are interesting and relevant to their needs • Explain what you are doing and why • Show the person what you want them to do • Let them interact with the equipment where appropriate • Be flexible and relaxed in your approach • Autistic and/or people with learning disabilities can experience and process physical symptoms atypically, e.g., pain scales and asking for descriptions of how they feel may not be effective • Some patients may only present behavioural changes when experiencing a significant medical issue.



Website Content

Make your website and social media pages accessible too. This includes having a font and a visual display that is uncluttered, and you can use an accessibility widget like UserWay.



Patient Won't Engage/Can't Engage

If patient can't engage — it's an issue with the environment (accessibility), communication (the way or speed at which it's presented), a need of the patient not being met • Try to understand the Autistic sensory experiences: light/sound/smell/interoception/proprioception/alexithymia/aphantasia/pain etc.



5 Don't forget the basics of strong multi agency assessment and communication

When supporting suicidal neurodivergent children and young people many of the responses highlighted strong multi-agency support was critical in producing positive outcomes. The best examples of multi-agency work included the assessment phase and the support phases, with regular communication and input from all relevant stakeholders.

"Improvements in the health/welfare of young person only emerged when the MDT came together."

"A robust Multi-Disciplinary Team (MDT) which had the young person at the centre and also took into account the family's views. They were able to talk about X and respond to her individual needs. Supervision, professionals' meetings, and placement planning meetings provided opportunities for sharing information across the network."

"Maintaining daily contact with the young person and/or their placement was a clear way to ensure risk was managed as appropriately as possible and also ensure that professionals in the network were "sharing the load", supporting each other as well as the young person."

Wider recommendations to the system

The original aim of this report was to provide support and advice to front line professionals to help them support neurodivergent young people who are self-harming or suicidal. We hope the sections above do that successfully by highlighting the features of positive practice which were critical in securing positive outcomes in the 18 recent cases we used as a basis of the audit.

However, during the analysis and discussion of the audit responses by the multi-agency professionals drafting this report it became clear there are many systemic and structural barriers which often get in the way of supporting the young person in the best and most effective way.

With this context in mind, we felt it necessary to add a section on recommendations to colleagues across the system who may be in commissioning, service design or senior decision making positions of authority. Please note these recommendations are from individuals involved with the Audit and should not be taken as organisational views.

Many of these systemic and structural barriers revolve around the perceived need and benefit from securing a diagnosis for the neurodivergent young person. Throughout the preparation and research for this audit, we heard a number of specific examples where access to financial support, specialist services and other forms of help is felt to be dependent on having a diagnosis. Therefore, it is understandable why some parents and professionals place such an emphasis on it.

However, this understandable desire for a diagnosis can lead to a toxic culture of parents and professionals who develop the belief a diagnosis and treatment plan will support individuals when more emphasis could be made on nurturing and developing the relationships at earlier opportunities to prevent difficulties from escalating.

In addition to the material benefits that can be accessed after diagnosis, there was also a feeling amongst the panel drafting this report that some of the statutory and legal frameworks have inadvertently placed emotional weight and responsibility on professionals to at times advocate for an individual's needs beyond the pace the individual wishes, or, likely controversially, does not require.

“There are likely many young people who don't need the diagnosis but who deserve the support sooner. If we can support these individuals effectively we maybe able to remove those individuals from the waiting lists for assessments, and therefore those that do need the assessment will get it quicker.”

Wider recommendations to the system

The current system adapted to learning from previous serious incidents by creating hierarchy and thresholds to be met. This portrays an image that medical diagnosis and treatment is critical to addressing needs whilst systemically ignoring the real success drivers which make a difference to best outcomes, making those factors essentially invisible to parents and professionals.

“If delays in assessment had been decreased the MDT engagement would have been quicker.”

Collaboration between parents and professionals is therefore required to reinvigorate the understanding of the local offers of what is available to provide support at earlier stages whilst identifying gaps and creating opportunities for co-design of earlier interventions and support within education, health, family and social settings.

Recommendations to commissioners and senior decision makers

- Although this Audit was completed by professionals with many decades of experience between them, the number of young people's experiences considered was only 18 individuals. Therefore we recommend commissioning additional research into the unintended consequences of using a neuro-diverse diagnosis status as an access threshold to services and support
- Review any thresholds where diagnosis of neurodivergent condition is the access requirement to services, financial support or other types of help
- Consider commissioning an advocacy service to support the voice of neurodivergent young people be heard and impact decision making
- Consider the importance of supporting parents and professionals to recentre the young person at the front and centre of practice by responding to their individual needs

Summary of positive outcomes

The following quotes illustrate successful outcomes are possible even in the most challenging of circumstances.

The professional network has been able to deliver a robust and planned support package and she has been able to significantly reduce her self-harming behaviour."

"She has been able to develop positive and meaningful relationships with others and recognize the type of relationships that she wants with her family. This has led to a reduction in harmful behaviours."

From time to time the young person still experiences challenges with their mental health, however the young person finds it easier to ask for help when they are struggling, there is more support for them and a clearer support plan."

Thank you

We would like to express our thanks to the professionals and support workers who completed the Audit Tool and provided such high-quality information to prepare this report. A particular thank you to Jason Hickson from the Kent Analytics team within Kent County Council for the design of the audit survey and the collation and analysis of the submissions.

But our greatest thanks are reserved for the young people whose experiences form the basis of this work. Each of them was selected as an example of how individuals can transform their lives with the right support to become independent in keeping themselves safe.

For more information on this report please contact suicideprevention@kent.gov.uk

Appendix

A – Definition of “neurodiversity”

For the purposes of this report the Autistic UK definition of neurodiversity was adopted. They explain that neurodiversity is a broad term, used to describe the many and varying ways in which human brains are wired and the term neuro divergent includes people who are autistic, ADHD, ADD, Dyslexic, Dyspraxic, Dysphasic, Dymorphic, Dyscalculic
<https://www.autisticuk.org/neurodiversity>

B – More detail on methodology and the 18 young people at the heart of the audit

The report includes the experiences of 18 young people who come from a range of backgrounds. They are a cohort of male, female and transgender young people. Most had a confirmed diagnosis of a neuro-divergent condition, while the others were either on a waiting list for assessment or were suspected in having such a condition at the time of the research.

The majority also had other adverse life experiences which may have impacted on their wellbeing. For example, most of the young people involved were misusing drugs or alcohol, approximately half had a mental illness and around a third had experienced domestic abuse within their family or home environment.

No audit responses were received in relation to children and young people from minority ethnic or religious communities. Although it is difficult to draw definite conclusions from such a small sample size, this maybe evidence to support the 2014 National Autistic Society research which found “BAME autistic people faced;

- additional challenges getting a diagnosis
- barriers to access support
- communication problems with professionals”[4]

Although the methodology of this Positive Practice Audit allowed for the young people to give their views as part of the response process, this was not used in any submission. This is likely to be either because the service is not in contact with them anymore, or a concern not to risk re-traumatising the young person.

There are no case studies or pen portraits of individual stories, in order to preserve the anonymity of the individual young people who are at the heart of this report.