



Here to Help

Project mid-way impact report

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Executive Summary

In 2023 The Department of Health and Social Care (DHSC) established a £10 Million Suicide Prevention Grant Fund, launched in August 2023, to run from 2023 to March 2025. The fund was designed to support voluntary, community and social enterprise (VCSE) organisations to develop diverse and innovative approaches to preventing suicide in identified priority groups. This fund coincided with the publication of a new strategy aimed at reducing the rates of suicide across in England and Wales.

The Department of Health and Social Care Suicide prevention in England: 5-year cross-sector strategy (2023) identified autistic people as a priority group. A 'priority group' is described in the strategy as being *"a group that could particularly benefit from more bespoke support"*.

In 2023, SJOG were successfully awarded a portion of the Suicide Prevention Grant Fund and embarked on developing a targeted approach to suicide prevention for autistic people across the 5 localities within the Tees Valley area. The project design was supported by subject matter experts including autistic people and their families, and essential practitioners from health and social care to ensure alignment with demographical need and local strategy.

Since the official launch of the Here to Help Project in June 2024 the project team have engaged with over 300 professionals to share a common goal of reducing the risk of suicide for autistic people and the project has been widely publicised through various routes on social media and information sharing platforms.

Key partnerships have progressed in which the project team have developed training and guidance for people working directly with autistic individuals to inform autism capable communication strategies for those who respond to crisis calls.

Engagement and interest in the project has been extensive and evidences the magnitude of projects like this as essential in supporting the aims of the Department of Health and Social Care Suicide prevention in England: 5-year cross-sector strategy (2023).

Introduction

In the general population, data from the Office of National Statistics in 2022 indicated the North East had the highest registered suicide rate, (ONS, 2022) with 12.8 people in 100,000 dying by suicide in the years between 2020 and 2022. Two hundred and sixty eight deaths by suicide were recorded across the Tees Valley in this timeframe.

The most recent figures published in The Guardian on 29th August 2024 suggest that the national rate last year was at its highest since 1999 and although the North East is no longer the highest region for suicidality, the rate has still increased by 15.1%. (ONS, 2024).

Research in 2018 found that 66% of autistic adults have thought about taking their own life, while 35% have attempted suicide, Cassidy, S and Rodgers, J (2017). Further research undertaken by the National Autistic Society highlighted that 82% of autistic adults surveyed stated that getting support from mental health services took too long (APPGA, 2019) and only 11% of local areas have mental health crisis services that support autistic people without learning disabilities, Public Health England (2019).

The Here to Help Project focuses on increasing awareness of suicidality in autistic people and provides training and guidance to families and professionals on potential support strategies. We are working with local ICBs, Local Authority representatives and other entities across the Tees Valley to increase knowledge and awareness and work in partnership towards reducing suicidality.

Here to Help also facilitates access to non-clinical advice and signposting for autistic people and offers opportunities for autistic people to influence change in how they are supported by services through steering groups. The steering groups provide validity to the information produced by the project and offers a safe space for people to discuss their experiences.

The project delivers support and guidance in three of the five common risk factors listed in the Department of Health and Social Care Suicide prevention in England: 5-year cross-sector strategy (2023),

- Physical Illness
- Financial and Economic Adversity
- Isolation

Whilst harmful gambling and substance misuse are also listed as common risk factors, this is outside the scope of the Here to Help project.

Autism and Suicidality – How Here to Help Helps

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. More than one in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK. (National Autistic Society, 2024). As articulated in an article by Cassidy et al in 2020, *"autistic people are at significantly higher risk of suicidal thoughts and behaviours compared with non-autistic people"*, and lifetime prevalence of suicidal ideation in autistic adults ranges between 19.7% and 66%, (Cassidy et al, 2020).

When exploring why the prevalence of suicidal ideation is high in autistic individuals it is suggested in research a number of factors can be considered, Here to Help has explored the below factors in the first 6 months of the project.

Camouflaging

Autistic people report camouflaging their autistic behaviours in order to 'fit into' social situations (Hull, et al 2019), this can lead to thwarted belongingness and not feeling accepted as the persons 'true self'. Camouflaging can impose many difficulties on autistic individuals, including depression, anxiety, and burnout and may also lead to delayed diagnosis, which prevents the person from getting appropriate care. (Alaghband-Rad et al, 2023).

The Here to Help Project has developed information and training to provide families, professionals and autistic people to identify how to support an autistic person who may be camouflaging (also known as masking and fawning).

Group sessions have also been designed to provide a safe space for autistic people to share how they may be feeling and to support them in their preferred way. Sessions can be delivered on a 121 basis and can also be delivered remotely via video calling.

Delayed Diagnosis

Delayed or lack of diagnosis is further exposed in an article published for the Journal of Molecular Autism in which it is indicated that 41% of adults with a lifetime history of suicide attempt (s) were found to score above the clinical threshold for autistic traits but had not received a formal diagnosis. The number of patients with an open suspected autism referral in the month of June 2024 for stands at 163, 666 referrals. These referral have been open for at least 13 weeks without receiving a care contact appointment (NHS Digital 2024).

Here to Help provides advice and signposting for those awaiting diagnosis or for individuals who may think they are autistic. We have designed toolkits to support autistic people, families and professionals to help them navigate on line and local information easily. The project website and social media accounts provide information on support groups and services that can help reduce loneliness and isolation and the

project team offer a safe space to meet others who may be experiencing the same process.

Here to Help does not provide crisis management advice but the project is open to all autistic individuals whether they have received a formal diagnosis or are self-diagnosing. We aim to be as inclusive as possible and welcome all calls seeking advice and guidance. SJOG also attend the North East and North Cumbria ICB Suicide Prevention Strategy Programme to support the shaping of formal strategies.

Cognitive Inflexibility

Cognitive inflexibility and the ability to seek and find appropriate resolution to situations may mean that an autistic person can find it harder to see an alternative to suicidality when facing emotional pain and anguish (Jack, C, 2023). Unpredictability or changes in a person's life can cause anxiety to most people, however autistic people may also be unable to effectively process their feelings about the change and then actively work through the process of seeking help in response to how they are feeling.

Around a half of autistic people have difficulties describing and understanding their emotions (Autistica, 2024). Difficulties with processing and describing their feelings to others is known as alexithymia, this can also present with behaviours that may seem outside of the societal norm. For example, when we are happy, we generally smile, laugh and appear cheerful in our demeanour. For a person with alexithymia, they may appear distant within the social arena, humourless or lack the socially responsive action to others cheerfulness even though they are 'happy'.

Alexithymia stifles their emotional vocabulary to be able to communicate their own worries and concerns to others and can lead to feeling socially isolated and at risk of loneliness. Autistic people's increased vulnerability to adverse life events, such as bullying, abuse, exploitation, social exclusion and poverty, also increases their risk of suicidality, Griffiths et al (2019).

Sessions and information provided through Here to Help aim to support autistic people with emotional recognition. The sessions have been specifically designed to involve activities such as Hope Journaling and Mood Thermometers. This means that we can engage with people at a level they understand but without placing an emphasis on low mood or unhappy emotions.

Our sessions also focus on enablement and this is where we support families, professionals and autistic people to understand routines and actions that promote positive wellbeing. We explore good sleep hygiene, the positive effects of a balanced diet and we provide facts sheets and information on deep breathing exercises and relaxation techniques.

(Please request for full list of sessions available from Here to Help.)

Feedback received from a drop in session delivered in August highlights this approach is effective.

"The sessions are proving valuable to different service users in different ways. Some of our service users are opening up about how they are feeling during your sessions and after your sessions and this is good as we are encouraging them to talk. Some of our service users who won't always join in with activities in the main hall delivered by someone they don't know as well have been and this shows how at ease they feel with you. Your sessions are done in a fun way but meaningful way and at the level our service users require to understand. Lots ask after you have gone when they will see you again."

Impact to date

Here to Help launched for professionals on the 10th June 2024 with our project partners, MAIN in North Ormesby. This event was attended by 41 colleagues across the Tees Valley Area and allowed us to share the project aims and objectives with professionals from a range of services including ICB and local charities. The public launch was then held as a drop-in opportunity for families and autistic people to find out more information about the project. We also launched our website on this date.

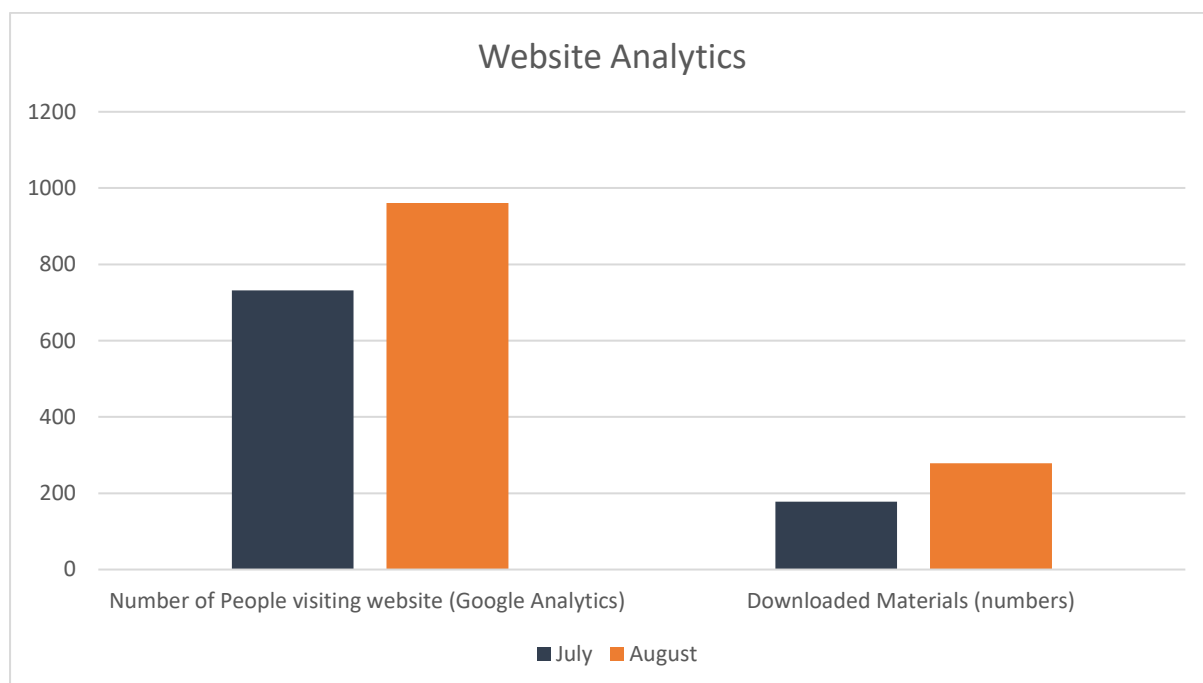
We predominantly measure our impact through analytical data provided through our website and social media platforms. This provides us with quantitative data that is analysed monthly.

Qualitative data is analysed through feedback provided to us. We do this in a number of ways such as digital and written feedback forms, face to face conversations and via email/telephone. We do not hold any personal data for people we meet but we do request consent to publish key words from feedback. Here is a snapshot of our feedback.

I wish I knew about this earlier
The team are friendly
Supportive
I like the passion from the
people who run the session
Keep Making a Difference!
Thankyou for listening to me
Much needed project
Non-judgemental
Informative
The project sounds great!
Very good event
This is too important to cease at all
Such a fantastic resource

Project Outputs:

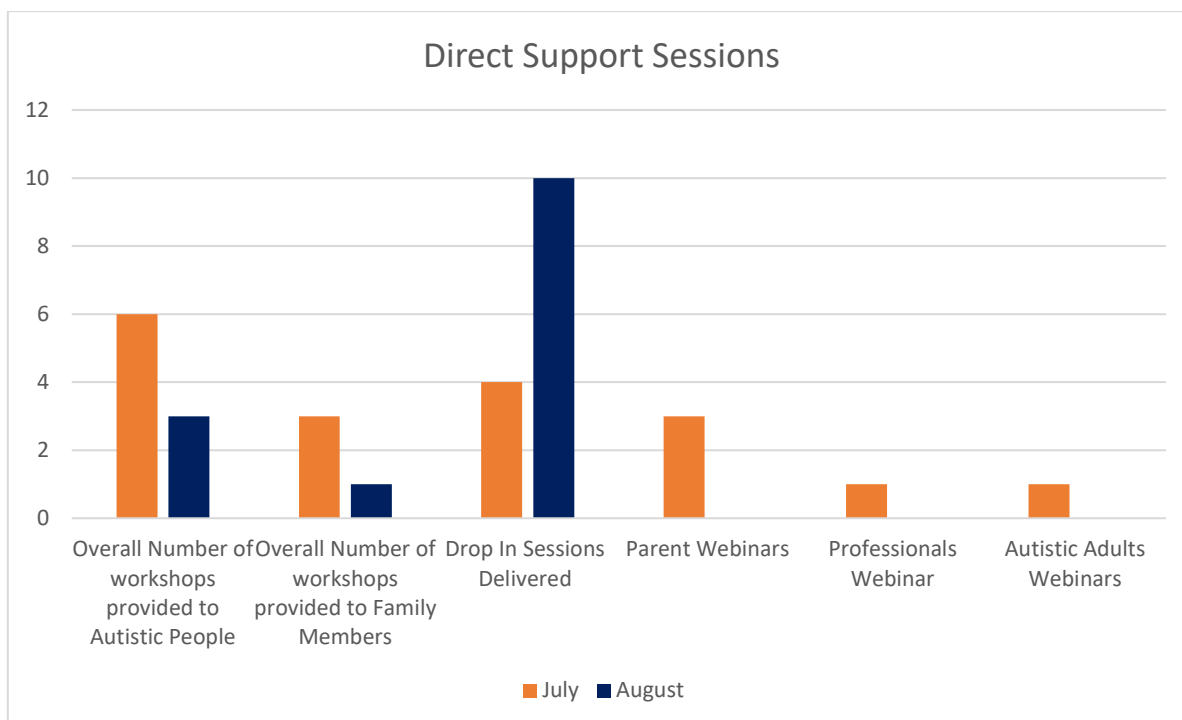
Here to Help Toolkit and Web platform. Including co-design participant workshops to create content tailored to needs, specifically regarding accessibility and relevant information.



Drop-in sessions hosted at MAIN charity in Middlesbrough for families and carers to drop in and get information and training on using the toolkit, accessing advice and information, as well as making connections.

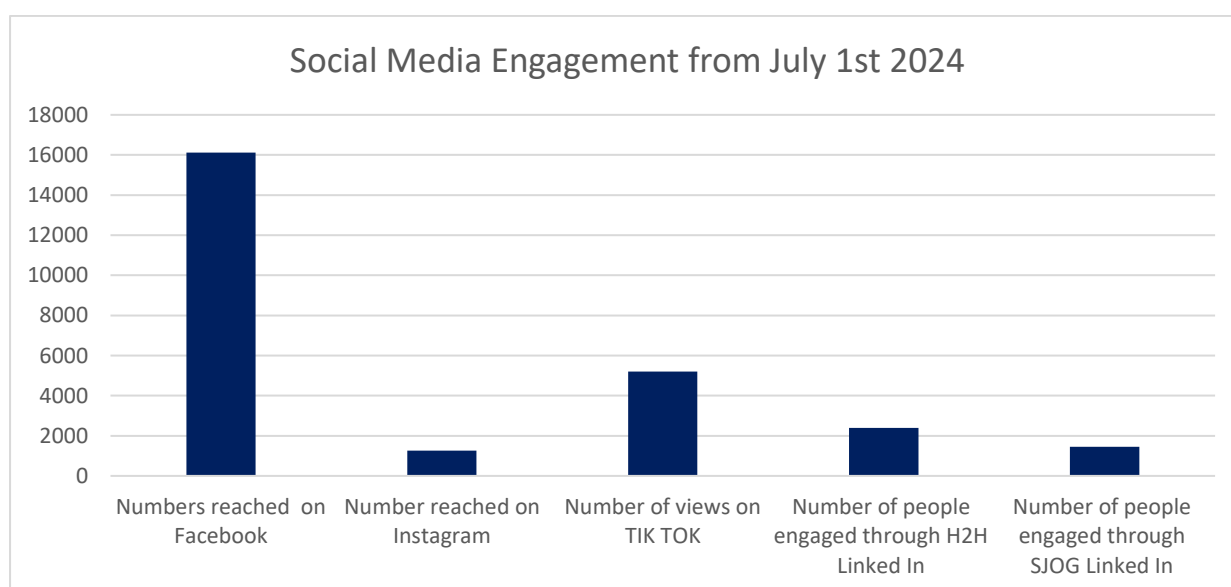
Since our launch we have secured regular drop in sessions in Darlington, Redcar and Hartlepool and have communicated to 5207 people through newsletters, leaflets and sharing information with other providers on how they can access support.

Recent partnership working with Samaritans has also provided an opportunity for SJOG to develop an online training event for Samaritans colleagues. This training will elaborate upon their current support techniques when taking crisis calls from autistic people and will help them to shape their language and communication to be more autism able.



We have currently supported over 100 autistic people and 44 family members through our direct workshops and drop in sessions. We have held 2 Parent and Families Steering Committee meetings and work consistently with autistic people, their families and professionals to develop our resources.

Awareness Raising Campaign - SJOG's mobile sensory unit "Magic Space" will visit communities across the Tees Valley, to raise awareness. Our extensive awareness campaign is promoted via social media and throughout our professional's networks that include Autism support organisations, commissioners, public health and social care practitioners and organisations.



Since our launches in June and July our total number of people engaged in the project stands at 34,922 people. Our website analytics also provide us with a geographical overview of the previous 2 months, this indicates the reach of platform has also had international interest.



Steering group for local relevance. A project steering group made up of members of local authority, ICB, people with autism and families will meet 5 times over the 13-month project to review delivery and ensure that it is focused on meeting local priorities and groups.

We have held 3 project steering groups in 2024 and have co-produced our material with support from 18 autistic individuals. SJOG have been invited to the North East and North Cumbria Suicide Prevention Strategy Programme and continue to explore local opportunities to drive our awareness campaign. We include the voices, perspectives and insights of people with personal experience and believe this should inform the planning, design and decisions at all levels of suicide prevention activity. This includes people with experience of feeling suicidal, those who have made previous suicide attempts, and people who are bereaved by suicide. (DHSC, 2023)

Challenges and Adjustments

One of our biggest challenges has undoubtedly been linked to the scale of the project. When embarking on this project the team had not considered the amount of interest Here to Help would generate and indicative of this interest is the need for projects of this kind. We have been asked on several occasions whether the project can be extended beyond the Tees Valley area. At present our online pages are available to all however our delivery of sessions can be limited by geographical area. If we are able to extend the project beyond the current funding period we would look to increase our support further across the North of England.

Nobody should be left out of suicide prevention efforts. This includes being responsive to the needs of marginalised communities, addressing inequalities in access to effective interventions to prevent suicides, (DHSC, 2023).

What we are beginning to see through our data collection and meeting people is that which autistic people often feel unsupported due to being excluded from what is deemed as a societal norm for people presenting with suicidality. This echoes a statement made by Julie Bentley, Chief Executive of Samaritans in an article in September 2023. It was discussed in an interview for The Guardian that whilst a 'no wrong door' approach has been endorsed in the Suicide Prevention Strategy for England, *"people have told us they can find it difficult or impossible to access support. This may be because they have been actively excluded from certain services as a result of self-harming or using alcohol, or because they simply aren't taken seriously"*.

Recent feedback from our engagement sessions highlights this remains a significant area for future development.

"I was discharged from Mental Health Services as they couldn't meet my need due to my autism."

"I feel that people dismiss my struggles, specifically as I am described as 'high-functioning'- there is not much understanding of autism being a dynamic disability so telling me I am 'faking it' if I can't do something I have previously done"

"Staff not being aware of how their comments are construed by someone autistic. One lady described how a MH nurse described her suicide attempt as 'half hearted' and the lady described how this 'spurred her on' to try harder"

Here to Help is also not a crisis response service and we have seen increasing numbers of requests for direct support. As a non-clinical provider we are finding that our support pages on our website are being accessed frequently and we continue to signpost to services. To respond to the challenges around support for autistic people when accessing Mental Health Services, we have approached local authorities and ICB with offers of training. In August we delivered training to 32 colleagues in the ICB and as a project team this is an area that we will remain focused on supporting.

Next Steps

Here to Help is moving into the final 6 months of the project and we will complete a full impact evaluation in partnership with autistic people, academics from universities, and our steering groups to provide a full report on the project.

We will seek additional funding to continue with Here to Help throughout 2025 and have developed a provisional budget for this. Strong collaboration, with clarity of roles, is essential. Suicide prevention is the responsibility of multiple government

departments, as well as wider public, private and VCSE sector organisations and we will begin approaching potential funders in October 2024.

We are currently exploring wider areas of practice with regards to autism and suicidality and our project research has led us to examining the correlation of socio-economic disadvantages and how this impacts on the autistic person.

Our project team are looking at resources that can support autistic people currently in the Criminal Justice System and those experiencing rural poverty. Here to Help will also meet with NECA in late September to offer advice on how to support autistic people who may access their charity for advice on gambling. Whilst direct support for harmful gambling is outside of the scope of the project, we continue to look for ways to be of more help to more people.

Conclusion

The inclusion of data for autistic people during 2022 as a separate group for the first time was a step towards improving information and data collection on the causes of death for autistic people in England (Kings College London, 2023). The LeDeR Report for 2022 highlighted that data involving a review of 36 autistic people without a learning disability, 30% of those deaths were linked to death by suicide, misadventure or accidental deaths. After heart disease, suicide is now the leading cause of early death in adults with autism and no learning disability: this group are over nine times more likely to take their own lives than the typical population (Autistica, 2019).

As this impact report has highlighted it is imperative that more support is made available to autistic people and their families around the risks of suicidality and suicide prevention.

Through the Here to Help Project we aimed to reach 2000 autistic people and their families. At a mid-way point in the project we have a current reach of over 34,000 individuals.

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