

Case Study: Improving Outcomes/Experiences at Crisis Point for Autistic Women with a Later-Life Diagnosis

Background

I have been in the mental health system for the last 11 years and spent three years fighting a Borderline Personality Disorder misdiagnosis. No health professional took me seriously. At the age of 24 I received an Asperger's diagnosis by chance (three years into the BPD misdiagnosis I was assessed by an individual who also specialised in Autism Spectrum Conditions and confirmed my belief that I did not have a personality disorder). Over the course of the last 11 years, I have been in and out of A&E, having been at crisis point and attempted suicide many times. My experiences in the mental health system and the harm that many professionals have done means that I now have additional PTSD.

Introduction

This report will be looking at and assessing the ways in which A&E can be improved for Autistic women without a learning disability who received a diagnosis in adulthood (as they present differently to those with childhood diagnoses or have a learning disability), starting at how they should be cared for at the point of initial presentation of distress, then looking at initial presentation in A&E, the experience within A&E, and the way they should be properly cared for after discharge from A&E.

Autism & Distress

Autism & Suicide

When an individual is at the point of crisis, appropriate treatment and support is pivotal. For many people, when they present at A&E, the services and support provided is often harmful, as opposed to helpful. For Autistic people, it can be all the more crucial. Autistic people are thought to experience crises more, as they experience feelings of suicidality more frequently than neurotypical individuals (one study suggests that 7.3-15% of those who are suicidal have Autism (Segers & Rawana, 2014. NICE (2018) also suggests that Autistic people are at a higher risk of suicide than the general population)). Those who received a diagnosis in adulthood are at further risk of suicidality than those who received a diagnosis in childhood or adolescence. One study found that women with Autism without a learning disability were at greater risk of dying by suicide than other Autistic people (Hirvikoski et al., 2016). Another study found that 66% of adults recently diagnosed with Asperger's syndrome had considered suicide (Cassidy et al., 2014).

Sensory Issues

This is partially due to their greater sensitivity to sensory input. Unfortunately, the health service is poorly equipped to deal with people with mental health problems, and it is even less equipped to deal with people who have mental health problems and Autism Spectrum Conditions. Autistic people are more sensitive to sensory input- for example, an Autistic person could find a fluorescent light painful, which could cause high levels of discomfort and headaches. Noises coming from other patients in A&E who are in distress can add to an individual's anxiety: too much sensory input, coupled with the pre-existing feelings of distress (which make the individual more sensitive to this

input) can result in a meltdown, panic attack or autonomic storm.

Services Poorly Equipped

Many people with a diagnosis of Autism but do not have a learning disability can struggle to find a service that can help: services for those with learning disabilities are inappropriate, and Autism services in general are ill-equipped to deal with the co-morbid mental health problems (Maddox, B. & Gaus, V., 2018), but community mental health teams are not trained to deal with the ways of thinking that come with being neurodivergent (Camm-Crosbie et al., 2018). Additionally, most therapies that are offered are not catered to neurodivergent thinking.

The Damage of Gender Biases

In recent years, greater awareness of Autism has resulted in more people receiving an Autism diagnosis. There used to be a stereotyped idea that an Autistic individual had to be male and receive a diagnosis in childhood. Countering this, many people are now receiving diagnoses in adulthood, many of whom are women. Living with undiagnosed autism into maturity can do a lot of damage: many people living with undiagnosed autism experience greater feelings of isolation, burnout, anxiety and depression. This means that by the time an individual receives an autism diagnosis, they are likely to have long-standing mental health problems. It is also likely that they have been unable to receive adequate mental health support as the system is geared towards a neurotypical experience.

Issues with Therapies

Many people spend long periods of time waiting for support such as IAPT (a 2019 BBC News article suggests that 15% of people referred to IAPT had to wait over 90 days for an appointment after the initial assessment) just to be rejected after the initial assessment due to being too severe for the service to help (statistics from NHS digital (2019) suggest that only 53% of people who had an initial session completed treatment). Additionally, conventional CBT is often incompatible for those with neurodivergence as it is based on neurotypical ways of thinking. It is commonplace for Autistic people to receive potentially harmful misdiagnoses before receiving their Autism diagnosis. They can spend years fighting a misdiagnosis, which can result in trauma and years of their life lost due to receiving inadequate and unsuitable support. Borderline Personality Disorder and Bipolar Disorder misdiagnoses are not only common in Autistic women but can also be stigmatising (due to problematic phrasing- imagine being told that there is something inherently wrong with your personality but there is no 'cure'?). It is common for individuals, especially women, to not be taken seriously in the health service, partially due to institutional misogyny (McAuliffe, 2018).

Initial Presentation of Distress

Thanks to greater mental health awareness, we have been taught to reach out when in distress. However, it makes a big difference to wellbeing how this initial presentation is received. An individual may reach out to a loved one. Although they may not have received professional training, they need to be compassionate and understanding. Charities like Mind have guides for loved ones on how to support friends or family members who are feeling suicidal. Suicidal individuals may also reach out to a professional, like a GP or CPN/Care Coordinator, or a mood-logging app. How this is handled is key. Professionals are generally taught that if an individual appears to be at risk, they

should be taken into A&E.

The Importance of Wording

Unfortunately, services use the questions 'are you at risk now?' or a variant of 'do you have plans to kill yourself?' to determine whether someone is in danger. These will be based on neurodivergent understandings. Some people are always at risk because they are always in such distress that they feel suicidal. Answering these questions in a certain way could be the difference between an hours-long experience that causes great amounts of distress and harm, or one where an individual is adequately supported. The best things for loved ones to do for an individual in crisis is to take away the things they can use to harm themselves, listen to them, take them seriously and keep them distracted. Unless an individual needs urgent medical care (such as in the case of severe self-injury or overdose), A&E is not necessarily an optimum or safe environment (which shall be explored further).

Forcibly Transported to A&E

In some situations, an individual is taken to A&E willingly (for instance, by a family member). In these cases, they can somewhat prepare for the encounter (such as by packing reading material, a weighted blanket or something to watch). In other situations, an individual is taken unwillingly, such as by the police or an ambulance. These situations in themselves can cause a lot of distress. The writer has experienced ambulances turning up at various addresses after expressing suicidal feelings. An ambulance arrived, but both paramedics were male, which made the (female) writer feel very distressed. Inevitably, she did not feel safe answering the door to them (as she did not know what they were going to do to her). They then resorted to banging on the window of the room she was in. This resulted in feelings of terror- she had to hide and inevitably had a panic attack. At the time, she was having a video call with her therapist. Fortunately, the therapist was able to call the paramedics to get rid of them, but if the therapist was not present, the paramedics could have triggered a suicide attempt or self-injury to deal with the abnormally high levels of distress. On another occasion, the writer was about to attempt suicide at a train station. The British Transport Police turned up (which in itself, caused very high levels of distress). Eventually, the situation calmed down and the writer willingly went to A&E, under the guise that they would be seen right away, be offered food and provided with transport home (in the end, only the offer of food came into fruition). Mental health staff and nurses should know that it is incredibly harmful to make promises to patients that they can't keep. The writer would not have attended A&E if the promises had not been made, knowing due to many experiences what going to A&E involves.

Upon Entry to A&E

A & E is a harmful environment for Autistic people in distress. Simply signing in at the reception can cause distress- it could be that it is within the waiting area and people sat within the waiting area stare (which can trigger panic attacks, meltdowns or induce feelings of paranoia). An individual in distress may also be unable to speak or process information, meaning that they cannot answer any questions asked by the receptionist. After this initial interaction, they are usually then asked to wait in a waiting area to be seen by the triage nurse. This can take an indefinite amount of time, and after it occurs, the individual may feel that the support is moving forwards. However, this is usually not the case. Between an assessment from the triage nurse and then further assessment from mental health professionals, it can usually take hours (the government target is that everyone spends less

than 4 hours in A&E), with patients rarely given any indication of how long they will be waiting (CQC, 2019).

The Waiting Environment

Sensory Considerations

The environment that the individual waits in can cause distress. An Autistic person has sensory needs and requirements that are unique to them, but these can also vary by situation and mood. For example, lighting could cause a great deal of distress. Autistic people can struggle with harsh lighting or lighting of particular colours (NAS, 2021). Some Autistic people also struggle with some colours, meaning that the décor of the waiting area could cause distress. Additionally, they may struggle with certain noises or particular smells. Waiting areas are generally designed in a way that causes stress to those with anxiety- it is often a large, open area full of people. The writer has severe social anxiety and is unable to wait in a large waiting room due to the presence of people and being unable to prevent them from staring. On top of this, individuals often feel unsafe in waiting areas- drunk people can be taken to A&E, and they are partial to 'kicking off'. The shouts and screams not only cause distress but can trigger an autonomic storm or panic attack.

Ensuring the Space is Appropriate

Sometimes, staff in A&E often decide to place an individual in distress in a side room, out of the way, however these are essentially glorified cells (which are sometimes referred to as a 'safe room' in literature). Understandably, some elements are removed to prevent the individual from additional suicide attempts, but the setting causes a great deal of distress. Especially if an individual has been escorted to A&E (such as by the police or an ambulance), they have minimal items with them. The room also may not have internet connection or phone signal, meaning that they are unable to get in touch with loved ones and have nothing to keep them entertained and distracted. Being left in a room alone, with just thoughts for company, is incredibly harmful for a suicidal person. It is normal to be left in the cell-like room, or unsettling waiting room for hours, with distress generally compounding. If an Autistic person has been taken to A&E involuntarily, they have not been able to take with them items which they would usually use to lessen distress (such as glasses with tinted lenses to reduce the glare of the lights, weighted blankets, books, stimming toys and noise-cancelling headphones). It would be worthwhile for A&E staff to have at their disposal items such as these which can be used to lessen the distress of an Autistic individual, in the same way that they can offer somebody in pain with pain relief. There needs to be a room which is safe but also comfortable. This may involve having a television or reading materials. Lightbulbs are now available whose brightness and colour can be adjusted using an app on a smartphone. It may be worth installing one of these in a safe room for an Autistic individual. It would also benefit to have access to phone charging cables and a USB socket in the wall (which would be safer than a plug socket). The room should also be temperature controlled. (For an additional first-hand account of the negative impact of A&E safe rooms on an individual without Autism, see

https://www.cqc.org.uk/sites/default/files/20201016b_AMSAT_report.pdf.)

Assessment by Professionals

By the time an individual is seen by someone, they are exhausted and not in a fit state to converse and answer questions. In the writer's last experience of being in A&E due to high suicidality, the noise from the waiting room and the feelings of isolation led to a meltdown, which resulted in the

fight/flight/freeze stress response kicking in. Often, there will be more than one member of staff brought in. This is under the guise of safety, however, to an Autistic person, this could feel confrontational and also make them feel very unsafe. It can cause a great deal of distress and anxiety. Staff working in A&E are unlikely to have adequate training in dealing with people in crisis.

The Importance of Professionals Receiving Adequate Training

As there are no teams within a hospital for those with neurodivergence, this means that there would be no staff in an A&E department who would be trained in how to properly deal with and care for those with Autism Spectrum Conditions. They would understand that crowding someone is going to worsen distress. They would also understand that asking an individual in distress questions is ineffective- Autistic individuals have issues with executive functioning, and with that comes issues with memory recollection. During a distressing time, the body is in fight/flight/freeze mode, which minimises any bodily and brain functions which are inessential to survival (as it has evolved from our early ancestors who had to survive in wild environments full of threats)- this means that an Autistic individual could be unable to answer questions and may also be unable to speak. Some Autistic individuals usually present as non-verbal, whereas others are only non-verbal when under stress or high levels of anxiety. Members of staff who work in A&E or regularly deal with people in crisis all need to receive sufficient training in the appropriate ways of dealing with and caring for Autistic people.

Utilising Those With Lived Experience

Hospitals need to engage with lived experience advisors who can steer them in ways of improving the services and hospital environments to make them less distressing and more Autism-friendly. Lived experience advisors are key because they can give input on what the Autistic sensory experience is like, which a neurotypical person cannot truly understand. Another way in which neurodiverse people can be taught about minimising distress, could be through the use of VR, which puts them inside the head of an Autistic person. The needs of Autistic people need to be taken seriously. Autistic people all have different needs, and it would additionally help these members of staff for hospitals to use Autism Passports, which explain what an individual's needs and requirements are (such as how to speak to them, any allergies they might have, what triggers distress, what calms them down). At the point of crisis, it would be difficult to thoroughly go through this, as the Autistic individual will not be in a sufficient mindspace to recall information (this could be due to a variety of factors, such as being non-verbal or experiencing the side effects from an attempted overdose).

Treatment Post-Admission

As hospitals do not have sufficient facilities for Autistic people, it is unlikely that an individual would be sectioned in an environment that is suitable for them. Usually, after spending hours in an entirely unsuitable environment, an individual is discharged from A&E feeling as bad, if not worse, than when they were sent in. Spending time (prolonged or otherwise) in an environment which is not comfortable or familiar, along with having to answer questions, is exhausting. A day or two later, they may receive a visit from the Home Treatment Team who are usually unable to help (as people are generally suicidal for certain reasons, such as a poor home environment, relationship breakup or redundancy). Alternatively, less than 24 hours after admission to A&E they may receive a call from a GP. Conversations and calls within this time frame should not be recommended. An Autistic person will be exhausted from such a distressing, high-anxiety experience the day before. It is best to not

force an Autistic person to engage in anything socially (such as a conversation from a GP) as they need a lot of time to recover and ensure that their cortisol drops back to their 'normal' levels, and that they have had a chance to 'recharge' their energy. In terms of treatment, unless the causes of the distress and suicidality are sorted out, the Autistic individual will continue to be suicidal and in distress.

Looking at the Long-Term

In terms of long-term aftercare, professionals need to look at exactly why the individual is suicidal. If an individual is struggling because their home environment is entirely unsuitable for them, then housing options need to be considered and arranged. If they are struggling because they feel isolated from the community, then they need to be offered ways in which they can engage with the local community- such as support groups and voluntary positions. Unfortunately, services for Autistic people without a learning disability are few and far between. Autistic people without a learning disability often fall through the cracks- they have minimal access to social care services, and community mental health teams are unable to help because the mental health services aren't designed with consideration of neurodiverse ways of thinking (and they often struggle to deal with people who are persistently suicidal and in distress).

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