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Missed and Misdiagnosis -Mental Health Issues for Autistic girls and women

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Aim

- * To provide a brief explanation the the assessment and diagnostic process for Autism and how females can often be missed
- * To explore the issue of misdiagnosis
- * To discuss the mental health issues which can result as a result
- * To examine the impact upon families and siblings

Diagnostic issues

- * Mental health difficulties can be experienced by girls, boys and those who do not identify with either gender who are on the Autism Spectrum
- * However, my particular interest in the mental health challenges of girls and young women with Autism began when I worked in an Adolescent Tier 4 inpatient services and was shocked by the high number of teenage girls with Autism who were experiencing significant levels of distress.

Diagnostic issues

- * Many of these young women had either not been assessed for Autism prior to their hospital admission or had only recently been diagnosed.
- * A large number had been diagnosed as having an 'Emerging Borderline Emotionally Unstable Personality Disorder'.
- * Some of the difficulties in accessing and securing an appropriate diagnosis lie in the lack of understanding in some areas of how Autism presents in females
- * However, it has become clear that many females 'mask' their difficulties and attempt to hide their true selves in an attempt to fit in with, and be accepted by, their peers.

Diagnostic issues

- * Many clinicians using a more 'male' model of Autism to diagnose (which often includes restricted interests and more obvious social communication difficulties), miss girls who are often better at making eye contact, using gesture and who often watch, observe and imitate their peers.
- * Some tools, such as the DISCO (developed by the team at the Lorna Wing Centre) are better at picking up the female presentation of Autism.

Diagnostic Issues

- * Whilst this talk is predominantly focused upon the issues of girls and young women on the spectrum, it is important to acknowledge that a number of boys and young men also present with a more ‘female’ presentation of Autism. They too are often missed in a diagnostic assessment.

Misdiagnosis

- * Many young women with Autism when they present with mental health difficulties or behaviour challenges are given a diagnosis of Emerging Borderline/Emotionally Unstable Personality Disorder
- * This diagnosis has a number of negative connotations, particularly with regard to treatment options and is actually a description of behaviour that individuals in distress may adopt as a coping strategy

Misdiagnosis

- * It might be more appropriate to consider these young women as having experienced trauma as a result of many years of struggling to manage social and academic pressures
- * Many will have experienced 'burnout'
- * However, their coping strategies can be misconstrued and without a clear understanding of why this has happened, it can be hard to offer appropriate support

Risk Factors for Mental Health Difficulties

- * Girls with Autism are often hyper-sensitive to the emotions of others but frequently misinterpret intent and subtle nuances
- * They may struggle to maintain friendships (often these difficulties emerge in the final two years of primary school and become progressively worse through high school)

Risk Factors for Mental Health Difficulties

- * Some girls experience bullying and rejection which can be deeply confusing, upsetting and damaging to self-esteem, as many strongly desire friendships and relationships
- * A number begin to struggle academically, despite being fundamentally cognitively able.
- * Most will experience some level of sensory overload or sensory processing difficulty.

Social Difficulties

- * At times, high levels of anxiety can lead to a need to control the environment in order to maintain predictability. This can often lead to accusations of 'bossiness'
- * Some young women become fixated upon one particular friend and even copy their mannerisms and way of dressing. This is not always well received and can lead to bullying and rejection
- * Other girls on the Autism spectrum try hard to 'fit in' but get it slightly wrong and are called 'odd' or 'weird'

Social Difficulties

- * Some young women become extremely vulnerable sexually as they are not always able to 'read' the intentions of others and can be led into situations they are not ready for.

Anxiety and Depression

- * A conservative estimate suggests that 70 – 80% of individuals with Autism will experience high levels of anxiety at some point in their lives
- * Depressive episodes are also common
- * Many young people struggle to access support for anxiety until they reach crisis point.

Anxiety and Depression

- * When anxiety reaches an extreme level, it is not unusual for the young person to experience brief psychotic episodes
- * Dissociative disorders are also quite common and extreme cases can lead to the young person appearing almost catatonic
- * Therapeutic programmes which help to improve emotional literacy and manage the 'critical voice' (See McGillivray and Evert, 2014) can be helpful.

Dissociation

- * Dissociation and depersonalisation in Autistic individuals are often the result of stress and part of the fight, flight or freeze response
- * It is not unusual for the person to appear completely 'shut down' and to be unresponsive to external stimuli

Psychotic episodes

- * There is some evidence to suggest there is a shared genetic link between Autism and Schizophrenia
- * The two co-occur at a higher level than would be expected by chance
- * Depression is common – up to 20% of young autistic people will have experienced a significant depressive episode by the age of 18

Psychotic episodes

- * The prevalence of suicidal behaviour in Autistic individuals is between 11 – 50% (Zahid and Upthegrove, 2017)
- * Recent evidence suggests (Milne et al, 2017) experiences such as visual and auditory hallucinations are common in Autistic persons
- * This has been referred to as an ‘Autistic pathway’ to psychosis – mediated by how well the young person is able to manage their emotions.

Autistic Burnout

- * Autistic burnout is described as:
- * ‘ Having all of your internal resources exhausted beyond measure and being left with no clean up crew’
- * (Raymaker, et al, 2020)

Autistic burnout

- * Autistic adults described the primary characteristics of burnout as:

- * Chronic exhaustion
- * Loss of skills
- * Reduced tolerance to stimulus

This can be caused by the cumulative burden of life stressors (for young people this is often school) or the strain of trying to 'mask' or 'camouflage' difficulties

Appears to be a distinct clinical phenomenon from clinical depression.

Self-harm

- * Self-harm in Autism is relatively common and is often associated with frustration and poor communication ability.
- * There can also be a sensory element to some types of self-harm
- * However, a number of individuals with Autism also self-harm due to high levels of anxiety

Self-harm

- * One feature I noted during my in-patient work was the level of self-harm displayed by some young girls
- * High pain thresholds are often reported by individuals on the Autism spectrum
- * However, there is little research evidence about the prevalence of severe, and potentially damaging, self-harm in young people with Autism and mental health difficulties.

Self-harm

- * It is possible that it may be linked to poor emotional literacy, hyper-emotional reactions and emotion processing.
- * An intervention programme such as Dialectical Behavioural therapy (DBT) which teaches emotional literacy skills may prove helpful.

Eating Disorders

- * Eating difficulties or selective eating are very common in young people on the Autism Spectrum
- * One study reported that up to 60% will display selective eating patterns (will only eat certain types of food)
- * Some children are diagnosed with ARFID (Avoidant and Restrictive Food Intake Disorder) which is now in the DSM 5.
- * These difficulties are often linked to sensory issues

The link between Eating Disorders and Autism

- * There has been much speculation regarding the link between Autism and Eating Disorders
- * Research has largely focused on the presence of similar cognitive processing styles
- * A study by Mandy and Tchanturia in 2015 using the ADOS-2 found that out of a sample of ten women with an Eating Disorder 50% of them met criteria for an Autism Spectrum Disorder.

Treating Eating Disorders in girls and women with Autism

A number of factors make treating girls and women with Autism a particular challenge:

- * Rigid thinking style and a need for control
- * Reduced sensation of hunger in some young people with Autism
- * Sensory issues around certain food types and texture

Treating Eating Disorders in girls and women with Autism

- * Family therapy (which is a traditional treatment for Eating Disorders) can be a challenge – if deficits in theory of mind are present, understanding their own feelings and comprehending the impact of their eating disorder on others is likely to be difficult
- * Cognitive Behavioural Therapy (which aims to modify unhealthy thought patterns) can also be a challenge for individuals with poor social imagination.

Treating Eating Disorders in Girls and Women with Autism

- * It may be that techniques that are used to support young people with ARFID (Avoidant and Restrictive Food Intake Disorder) which include a graded exposure approach may be helpful for young women on the Autism Spectrum with Eating Disorders.

The impact of Mental Health Issues on Families

- * The impact upon any parent of having a child or loved one with mental health challenges is enormous
- * Having a child with Autism and mental health difficulties – particularly if parents have had to fight to get an appropriate diagnosis, appropriate educational provision and support for their mental health - is doubly so.

The Impact of Mental Health Issues on Families

- * Very often appropriate mental health support is hard to access and if the young person needs a hospital admission, they can often be placed many hundreds of miles from home
- * Vohra et al (2014) discuss the multiple and varied challenges faced by parents who have a child with Autism and mental health difficulties. These include challenges in terms of time and financial difficulties, particularly if the ability to work is impacted upon.

Siblings

- * Lovell and Weatherall (2016) report on the emotional, social and physical challenges that can be associated with having a sibling with Autism
- * They are more likely to hide any difficulties they themselves have in order to avoid placing further worries on their parents.

Concluding thoughts

- * It may be that heightened levels of anxiety are part of life for many individuals on the Autism Spectrum
- * This does not mean that associated mental health difficulties are necessarily inevitable
- * Early intervention and good support for both individuals with Autism and their families is essential

Any Questions