

UNDERSTANDING AUTISM North West

Therapeutic Services for Individuals and Families with Autistic Spectrum Conditions

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Mental Health Support for People with Autism

Introduction

Autism is a very complex condition; the cognitive and sensory processing of individuals with autism is very different to that of neuro-typical individuals.

Adults diagnosed with autism spectrum conditions (ASCs) are at high risk of co-occurring mental health conditions, non-suicidal self-injury and suicidality. Autistic adults without intellectual disability (ID) are at highest risk of contemplating suicide (66%) and dying by suicide.

Lack of mental health support for autistic adults has been associated with increased risk of depression and suicidality. Autistic adults also report a significantly higher number of unmet support needs than the general population; autistic adults and children struggle to obtain appropriate emotional/therapeutic support post diagnosis. Young autistic adults (16–25 years) also face challenges in accessing appropriate treatment for mental health problems. Hence, despite autistic people being at significantly increased risk of mental health problems and suicidality than the general population, **they appear to be less likely to be able to access support and therapy** for these difficulties. The impact of this on family members can be equally debilitating.

Issues faced by individuals requesting therapeutic support

1. There is a shortage of professionals trained in both autism, mental health and therapeutic intervention.

- GPs and psychiatrists are generally not trained in recognising and understanding ASCs.
- There is a lack of appropriate adapted psychological therapies for autistic people. (or -Therapists who are unaware of autistic communication styles and autistic ways of being are not able to adapt psychological therapies effectively)
- A therapist unaware of the neuro-developmental differences can cause distress and harm to an autistic person (who is left feeling even more marginalised and believing that no-one can help). The outcome for the therapist is to feel de-skilled.
- Many autism related issues can threaten therapeutic engagement, which can be unknowingly sabotaged by a therapist who is unaware of the sensory processing differences, delayed processing and different pace of communicating.

2. Mental health, self-injury and suicidality in autism are poorly understood and under-researched.

3. There is a lack of appropriate evaluation and outcome measures and therapies for this group.
4. There is a lack of appropriate validated assessments to effectively identify mental health problems such as depression and suicidality in autistic adults.
5. Being misunderstood due to difficulties in expressing emotions or black-and-white thinking being seen as “coping” and therefore discharged from mainstream mental health services without support

These challenges are greater for autistic adults without intellectual disability (ID), such as Asperger’s syndrome, who experience:

- Greater delay in diagnosis and accessing treatment
- Increased risk of being initially misdiagnosed (schizophrenia, bi-polar disorder, borderline personality disorder).
- Increased risk of other conditions ‘masking’ the underlying condition of autism (Epilepsy, OCD, ADHD, Eating Disorder, Pathological Demand Avoidance, Ehlers Danlos Syndrome) leaving autism unrecognised and undiagnosed.
- Lack of post-diagnostic support.

Specialist Autism Mental Health Support

A therapeutic service with specialised knowledge to support the mental health and well-being of those with autism plays a vital role in reducing anxiety and depression related illness, reducing suicidality, improving self awareness, self understanding and self-esteem, which would in turn increase integration and promote economic and social opportunity.

People with autism need their therapeutic service to be:

- Person-centred.
- Delivered from an autistic frame of reference.
- Available at the time of need.
- Delivered by therapists who are “autism aware” and have a more in depth understanding of the intricacies of autism and how to work with the issues these present. For example, therapists may be expected to have personal and professional experience of living and working with autistic individuals and to be qualified to postgraduate level in autism.
- Delivered in an autism friendly environment with an easy and flexible way of making appointments. The processes for booking appointments and the physical environment need to be ASC friendly (e.g. sensory difficulties to be acknowledged and addressed, flexible procedures made available for the booking process with no need for clients to speak on the telephone)
- Appropriate in the number of sessions offered for the needs of the individual, rather than dictated by arbitrary limits.
- Flexible in approach to the frequency of sessions (weekly, fortnightly, 3 weekly, monthly) to suit the client.

- Consistent in continuity of care and considerate of the development of a therapeutic relationship between therapist and client.
- Able to recognise common co-morbid conditions - (Ehlers-Danlos syndrome, Epilepsy, ADHD, OCD, hypermobility, Alexithymia, Prosopagnosia, Dyslexia, Dyspraxia, Cyclothymia, Avoidant Restrictive Food Intake Disorder, Complex PTSD, Addictions, Hearing Voices, Interoceptive deficits, Dysbiosis)
- Understanding of specific issues which are relevant to autistic people, for example:
 - Understanding of delayed processing and how anxiety affects concentration
 - Understanding and acceptance of the different pace of processing
 - Understanding of different communication style (rigid thinking, literal, honest, no 'small talk').
 - Understanding of how anxiety is experienced differently in autism
 - Understanding of sensory processing differences
 - Understanding the complex nature of empathy, the double empathy problem and the Theory of Mind and have the ability to explain and discuss such concepts with a client.
 - Able to recognise and work with the different female presentations of autism
 - Understanding, and being able to explain, the autism spectrum and its different presentations (a spectrum for each of the diagnostic criteria)
- Educational with advisory elements relating to the disability incorporated into therapy
- Able to establish direct links with other appropriate support services
- Able to view autism from a social rather than medical model perspective – allowing the therapist to work with the client to understand their difficulties and strengths in a context that is meaningful to them

As a service providing therapeutic support to autistic clients we have found that the most common feedback given, when asked “what has been useful in therapy”, is that the client has felt accepted for who they are and the way they are, and they have not had to spend their precious therapy time explaining autism and educating their therapist. For others, those who have little or no understanding of their autistic way of being (and therefore cannot explain it to others) their feedback relates to how much they've learnt about how autism affects their lives and has had an impact on their own personal histories. For both outcomes it is necessary for the therapist to have a thorough understanding of what it means to be autistic, and the wide variations that this can involve.

Social Return on Investment

Many autistic people struggle to access mental health support and many refuse to engage with statutory services as a result of previous negative experiences, which have caused extreme distress and for some, increased suicidal ideation. This is caused in most part by the lack of knowledge, experience and understanding of the autistic condition amongst the staff of statutory services.

Statutory services are in turn discharging many individuals, children and adults, from their care, citing refusal to engage with therapy.

Outcomes from specialist autism support clearly demonstrate that autism specific therapeutic intervention for people on the autism spectrum improves mental health and wellbeing, which in turn encourages engagement and reduces reliance on statutory services such as GPs, A&E and Community Mental Health Services. This results in some people finding or returning to work, no longer needing or less dependent on medication, reducing their contact with or no longer needing medical services. These outcomes represent a significant social return on investment.

References

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