Academic/Research Article

‘You are not the person who knows most about this in the room’

An exploration of the experiences of trainee therapists working with autistic adult clients

By Fiona Coyne

Illustration by Ava Kealy

This article had its genesis in psychotherapy training placement, during which the author’s client received a diagnosis of autism. The author, then a third-year counselling and psychotherapy student, had difficulty accessing research and training on what autistic clients need from their therapists

Introduction

Autism makes headlines, and there appears to be an increase in the number of people receiving an autism diagnosis (Zeidan et al., 2022). The World Health Organisation (WHO, 2020) reports that about one in 160 children worldwide are autistic. Most research is viewed through the biomedical model, specifically autism’s aetiology and cure, with men being overrepresented (Botha & Frost, 2020). However, 10%-20% of people may be autistic when those who self-identify are included (Hearst, 2014; ISA, 2021; Wharmby, 2022).

Statistics aside, what do we know about how an autistic person feels? A study by Ireland’s national autism charity found that 92% believed that people do not understand enough about autism (AsIAm, 2022). Is there an epidemic of autism? Do autistic people need therapy for being autistic, or for the pressures of living in a neurotypical world? Are training and education keeping up? This article hopes to address some of those questions.

Literature review

There are many common and incorrect narratives about autism, based on dated, limited research. This informs what the world’s population, including therapists, believe about autistic people (Brook, 2023).

Autism has its roots in psychotic disorders and schizophrenia. Bleuler (1950) identified autism as part of schizophrenia. Kanner (1943) studied white male children and then described autism separately from schizophrenia (Kaplan, 2008). Kanner was cited in Hans Asperger's work, and together with Lorna Wing, they defined Asperger Syndrome (Al-Ghazi, 2018).

From these studies, ways of "treating" autism developed. Devita-Raeburn (2016) explains how Applied Behaviour Analysis (ABA) was recommended to parents of autistic children. Developed by Lovaas, and described as "gold standard" therapy, it was an alternative to institutionalisation (Leaf et al., 2022). ABA is a series of interventions, used on autistic children, based on the principles of respondent and operant conditioning. It seeks to change autistic behaviours to more socially acceptable behaviours (Pierce & Cheney, 2017).

Many programmes recommend ABA sessions of between 15 and 40 hours per week, spanning one to three years (Behavior Nation, 2024). Autism rights movements, neurodiversity advocates, and survivors have concerns about trauma arising from ABA (Fahrenheit, 2020, Leaf et al., 2022; Wilkenfeld & McCarthy, 2020). As a result, therapists could have clients whose children have undergone ABA, or they may see ABA survivors themselves (Sandoval-Norton et al., 2019).

The term autism spectrum disorder (ASD) first appeared in the *Diagnostic and Statistical Manual of Mental Disorders 5* (*DSM-5*) (Maenner et al., 2014). There is little research on autistic adults' experiences and perspectives (Hickey et al., 2018), yet there is much to consider when working with autistic clients. Beardon (2021) highlights that, as each autistic person has unique sensory and social sensitivities, one size does not fit all, psychotherapeutically. The implication for therapists is that there may be many adults unaware, or undiagnosed, due to waiting lists (Kanne & Bishop, 2021) or cost (Coyne, 2022) and many who need support.

It may be helpful to begin by outlining some of the elements important to understanding autism.

Terminology

The Authentistic Research Collective (2021) recommends using identity-first language, that is "autistic person", preferred by many autistic people, rather than person-first language, such as "person with autism". Gernsbacher (2017) explains how this may accentuate stigma. Botha et al. (2021) agree, and caution that to avoid stigmatisation, it is best to ask your client. Bottema-Beutel et al. (2021) further caution against using ableist language. Wharmby (2022) says the previously used "high or low-functioning" descriptors are unacceptable in describing autistic people, and are replaced by "high or low-support needs".

This author will use the terms "autism" and "autistic person" throughout this article, and not "person with autism", or "ASD".

Definitions

The word "autism" derives from the Greek word *autos*, meaning "self", and was coined by Swiss psychiatrist Bleuler in 1911 (Rowland, 2020). The Irish Society for Autism (2021) outlines how the *DSM-5* "is one of the most widely used diagnostic guides for autism by healthcare professionals across the world". The *DSM-5* defines autism in terms of deficits in social-emotional reciprocity, relationships, and restricted, repetitive patterns of behaviour.

This deficits-narrative focuses on obvious or extreme presentations and adds to myths and misconceptions. Rowland (2020, p.1) says autism is "neither neurodevelopmental nor a disorder. It is simply an inherent neurophysiological difference in how the brain processes information". Therapists may encounter deficits-based information, potentially creating harm to autistic people (Kenny et al., 2016).

Autism and counselling and psychotherapy

Limited research into specific therapies for autistic adults exists (Vahabzadeh, n.d.). Rutten (2014) argues that therapy can be helpful for autistic people who face challenges with communication, stigma, and understanding. Lipinski et al. (2022) highlight co-occurring mental health conditions creating demand for mental health services, yet autistic people experience barriers such as therapists' lack of knowledge, unwillingness to work with them, outdated beliefs, and little training. A study by Cooper et al. (2018) identified how adaptations to cognitive behavioural therapy (CBT) for autistic people would also require changes to therapist training and supervision. In terms of useful modalities, Hawkins (2017) and Stephens (2021) value person-centred therapy. Research by Mills (2023) identified pluralism as helpful.

Gaus (2019) and Spain et al. (2015) present CBT as effective for autistic people, while Ramsay et al. (2005) and Proctor and Cahill (2021) say the therapeutic relationship is key. Outcome measures for autistic people, for example, can present problems. No two autistic people have the same sensory and processing profiles, making clinical decisions more complex (Hearst, 2014). In terms of how autistic people view

therapy, a study by Benevides et al. (2020) found that 31.4% favoured participating in psychotherapy, while 43% expressed interest in art therapy, and 49% in animal-assisted therapy.

Laws and training

In the UK, the 2009 Autism Act and NICE guidelines make autism training mandatory for staff in health and social care (DHSC, 2019; NICE, 2021). No similar law exists in Ireland, where counselling and psychotherapy remain unregulated (Germaine, 2022).

The WHO (2023) finds "a common barrier is created by healthcare providers' inadequate knowledge and understanding of autism". A German study of 498 psychotherapists found many had "little knowledge and outdated beliefs" about autism, as well as little training (Lipinski et al., 2022, p1509). However, many therapists expressed interest in training.

The Authentistic Research Collective's *Psychological Therapy for Autistic Adults* guide (2021) recommends that therapists be informed on intersectionality, double-empathy, camouflaging, sensitivities, culture, race, and identity; and that they practice demonstrating emotions, showing positive regard, and explicitly stating hopefulness. The Collective (2021, p.47) acknowledges that "it would be helpful for counselling, therapy, or psychology boards to develop a competency framework for working in disability". Donahue (2023, p.18) also asserts that "the practitioner must be culturally competent in the autism world" as late-diagnosed women may need extra skills and competencies from their therapist.

Figure 1: *Neurodiversity affirming practice: Core principles*

Note: This infographic of the core principles of neurodiversity-affirming practice was developed by S. J. Wise, 2023. From *Lived Experience Educator,* by Wise, 2023.

Disorder, difference, or culture?

Autism is framed as a disorder in mainstream media and by the pharmaceutical industry, where Stevenson (2015) suggests a disease model of autism-for-profit is perpetuated. This creates problems for how autistic people are viewed and treated by society, medical professionals, and therapists. Porter-Brooks (2019) suggests autism can be viewed as a distinct culture and a disability, while Wharmby (2022) also views autism as a disability. The dominance of the medical model may create difficulty for therapists in accessing neurodiversity-affirming resources.

The neurodiversity movement

Neurodiversity, a term attributed to Singer (2017, as cited in Baumer, 2021), "describes the idea that people experience and interact with the world around them in many different ways; there is no one 'right' way of thinking, learning, and behaving, and differences are not viewed as deficits". Chapman and Botha (2022) explain how the neurodiversity movement emerged as a social movement among autistic self-advocates. Now encompassing many with diagnoses of bipolar, dyslexia, and dyspraxia, for example, it reconceptualises neurodiversity as part of biodiversity and calls on society to support neurological minorities rather than proposing treatment or cure. They posit all are deserving of dignity, and recommend therapists take a neurodiversity perspective, proposing the concept of Neurodivergence-Informed Therapy (NIT).

Stephens (2021) conceptualises NIT as therapy that views

neurodivergence positively rather than problematically and adapts settings, approaches, and goals to the particular ways autistic people process the world. He recommends it be person-centred, trauma-informed, and strengths- and motivation-focused.

A search of the word 'autism' in the *DSM-5* returns 149 results, highlighting the number of complex co-occurring conditions and labels. Intersectionality describes the different influences that make up a person's experiences, which Wise (n.d.) claims is a core principle of neurodiversity-affirming practice (see Figure 1). Examples of intersectionality are gender, sex, ethnicity, race, and disability. Awareness of intersectionality helps therapists understand the many overlapping ways that autistic people are marginalised, judged, shamed, and excluded (Cascio et al., 2021).

Challenges and complexity

Emad et al. (2019, p. 48) posit autism is "one of the most confusing disorders for which not only no exact cause has been identified, but also no definitive cure has been found yet". Autistic people and neurodiversity advocates would disagree, refuting the idea that autism is a disorder and rejecting a myopic cure focus (Beardon, 2021). Therapists may face challenges working with autistic people, due to the complex and unique nature of autism; difficulties in finding suitable research, training, and supervision; and the complexity of autistic lives (Hallett & Crompton, 2018; Hallett & Kerr, 2020). Masking (behaving neurotypically to fit in), interoception (not knowing how one feels in their body), and alexithymia (difficulty recognising emotions) create challenges (Hull et al., 2017; Kinnaird et al., 2018; Shah et al., 2016).

Autistic women may present differently to men (Askham, 2021; Baldwin & Costley, 2016; Bargiela, 2019; Bargiela et al., 2016, Dean et al., 2016). Myths and misconceptions add to challenges. One such misconception is that autistic people are not empathic. Another is that non-speaking autistic people are presumed to have intellectual difficulties, yet some autistic people are therapists (Gollwitzer et al., 2019), authors (Higashida, 2013 & 2017), software developers, and competitive sailors (Mannion, 2023).

Mental health

Research by the National Autistic Society (NAS, 2020) found that 96% of autistic respondents experienced anxiety, and 83% depression, while 76% reported reaching out for mental health support in the last five years. Another study by the NAS showed 70% of autistic children had a mental health problem. Similarly, a systematic review confirmed that autistic people experience substantially higher rates of anxiety, depression, bipolar disorder, psychotic disorders, obsessive-compulsive disorder (OCD), sleep disorders, and conduct problems than allistic people (or non-autistic people) (Lai et al., 2020). Consequences include lower quality of life, unemployment, suicidality, and premature mortality (Cassidy & Rodgers, 2017; Hirvikoski et al., 2018; Newell et al., 2023).

Controversy surrounds autism research expenditure, with spending focusing on finding cures, not on providing support (Camm-Crosbie et al., 2019; Pellicano et al., 2014; Stenson, 2019).

Author research

This research paper aimed to explore trainee therapists' experiences when working with autistic adults. It will answer a need, and a demand, by autistic people to have research co-produced by and for them. As an insider researcher, the author is conscious of both bracketing personal bias and a social justice element to prevent harm to autistic people (Braun & Clarke, 2022; McLeod, 2014).

Methodological approach

To best meet the aims and objectives, basic qualitative research (BQR), reflexive thematic analysis (RTA), and semi-structured interviews were chosen to ask participants about their experiences, and to allow a rich perspective to develop in their answers (Braun & Clarke, 2022; McLeod, 2014). This approach has proven particularly informative in this area of autism (van Schalkwyk & Dewinter, 2020). It allowed for researcher reflexivity (McLeod, 2014) and co-production, as autistic people call for research to be by and for autistic people, rather than "on" them (Stark et al., 2021).

Aims and objectives

This study aimed to explore and gain an understanding of trainee therapists' experiences of working psychotherapeutically with autistic clients. Its objectives were to gain insight into training and working psychotherapeutically with this cohort, to identify trainees' needs in doing this work, to add to existing research, and to address a gap in this research area.

Participants

Purposive sampling was used to identify and recruit participants, and a sample size of three was agreed upon (Denscombe, 2021). Criteria for participation were approved by the IICP Ethics Committee. Participants were fourth-year students on the BSc (Hons) Counselling and Psychotherapy

course at IICP College, working psychotherapeutically with autistic adults without intellectual disability. Participants received an interview schedule in advance, to allow for sensitive interviewing (Dempsey et al., 2016; Moore et al., 2020) and facilitate all neurotypes (Cascio et al., 2021). Participant names are anonymised.

Key findings

For this article, findings are summarised into differences and similarities in participant experiences.

Differences

Two different experiences became evident throughout interviews, and when reviewing data. This first theme was identified as "expectations of working with autistic clients". Subthemes of "training" and "being in trouble" were then explored.

Expectations

Two therapists, Mary and Emma, resident in the Republic of Ireland (ROI) talked about not expecting to do this work. Jak, resident in Northern Ireland (NI), described being prepared in university and, therefore, expecting to work with autistic clients.

> "All this happened by chance. I work in a service that provides family support. It's not that the service specifically provides a service designed for people with autism." (Emma)

> "We were advised very strongly [in university] that we would definitely come across counselling someone neurodivergent … we were given the statistics about how many in the UK, and Northern Ireland, have the diagnosis and how many males and females." (Jak)

Training

A subtheme of training developed from this theme of expectations, and Jak describes a depth of training, including several courses, as well as an ambassador as a resource.

> "Autism was something I was always interested in, intrigued in … for personal and professional reasons. I've done loads of training over the years. We have a National Counselling Society Neurodiversity Ambassador too." (Jak)

The ROI therapists did not have training. Both expressed a wish to have autism training in college.

> "Wouldn't it be nice to have a module on this and CPD? I'm doing my dissertation around suicide ideation, which you know, there's one module in college and there's also postvention [a second suicide module]." (Emma)

Two perspectives appeared: one where training was provided by the participant's university; and another where neither training nor continuous professional development (CPD) were provided. The importance of training was expressed.

> "You will definitely have someone come in and sit in your chair who is neurodivergent. And to do them a service and yourself a service, you would need to have more than one day's training." (Jak)

Being in trouble

Another subtheme that emerged from being trained was the idea of "being in trouble". This was only evident in interviews with ROI participants.

> "I was flying by the seat of my pants. And there's probably a bit of imposter syndrome because I'm not confident about [it]. Have I got all of what I need to have to be doing this?" (Mary)

Similarities

One research objective was to explore potential differences between working with allistic versus autistic clients. All participants agreed that there were differences between working with allistic versus autistic clients. However, there were also similarities in how participants worked with autistic clients. Some examples are being flexible, and allowing autistic clients to take the lead (in taking breaks, for example).

Different ways of working and being

Mary and Jak both give examples of different ways they worked with autistic clients.

> "I do a lot more checking in … 'Have I got that right?'. Just being really sensitive, I suppose, to the sensory things that you wouldn't be keeping in mind for somebody not on the spectrum. They can be more tired, and we might need to take more of a break." (Mary)

> "I would be quite upfront … I asked him straight away 'What sort of stuff would bother you … set you off?' and he said 'You know, that clock's doing my head in' and I'm like 'I'm so glad I asked, let's throw the clock out!'" (Jak)

Trying something different

Another subtheme emerged of participants trying something they would not usually do. Emma described her client doing preparation work for her job during her therapy session. Jak talks about "going off on a tangent".

> "Another lady … she'd be cutting up little spelling words for school, and that would be wild because

she couldn't sit still. She was listening, but doing art at the same time."(Emma)

"As long as you check in and say 'Now, I'm gonna go off on a tangent here … stay with me, and at the end let me know, if you know what I'm talking about, if you think I've lost the plot'. And they love that." (Jak)

Sensing the client is autistic
All participants described sensing that clients were autistic, even without diagnoses, or when clients came for reasons not related to autism.

"She came [to therapy] because [her] dad was in recovery from alcohol. I wasn't naming it because it wasn't mine to name. But if I'm honest, I knew straight away." (Emma)

Autistic client as teacher
All participants described how autistic clients taught them to be autism-informed therapists.

"This particular client, I would say, has been as good as any course. You are not the person who knows most about this in the room." (Mary)

Am I autistic?
From this subtheme of client as teacher, participants converged on wondering if they or their family members are autistic. As Mary asks, "You wonder yourself if you're on the spectrum".

Time
All participants similarly reported that time was more difficult to manage with autistic clients.

"I've found it way more difficult to manage the boundary of time. They definitely want to stay longer. Like, I might say, 'OK, we're wrapping up in five'. Or maybe they don't know what five minutes feels like? It's more of an issue." (Mary)

Being the first
All participants reported clients saying that they were the first to work well with them.

"He said, 'This is the first time I can kind of understand myself where I'm sitting with somebody who's understanding or wanting to understand me'." (Mary)

"For you to take the time to view them holistically, and non-judgementally, that may be one of the first times they have ever experienced that in their lives." (Jak)

Tiredness
Of note was that both Mary and Emma reported working with autistic people as more tiring, whereas Jak described levels of intensity, which was no more difficult with autistic or allistic clients.

"I'm more engaged. I'm definitely 'on'. I'm also very tired. It's physically impactful because I'm so hyper-alert." (Mary)

"Sometimes there could be a level of intensity, but no more than what you'd have with someone else who was intense." (Jak)

Satisfaction
All participants had positive things to say about working with autistic clients. Jak described it as "a joy". Emma mentioned feeling pride as she described the biopsychosocial changes in her client's life.

"That girl wouldn't leave the house. She'd disconnected from friends. She'd left school at the age of 12. That girl is now back out socialising and is starting the CE [Community Employment] Programme and an art course." (Emma)

Discussion

Three student therapists were asked about their experiences of working psychotherapeutically with autistic adult clients. Following reflexive thematic analysis of the data, two themes of differences and similarities emerged, with 12 subthemes of their different ways of working with autistic compared to allistic clients.

Two participants expressed being surprised when autistic clients presented, as neither had the training to work with this cohort, nor the expectation of doing so. One participant was prepared, following training at college. A study by Mack (2019) validates this theme of feeling unprepared.

Findings from this study – that participants wanted training, and felt it was needed – are supported by research by Lipinski et al. (2022) and Mandy (2022). These researchers concur with Emma's belief that training for therapists is provided for other areas of mental health, such as depression and suicidality, and should be provided for autism. The importance of training is extolled by Hearst (2014, p.30) who writes "By committing to learn about autism, therapists can be in the vanguard of the cultural change needed to enable people with autism to live meaningful and fulfilling lives".

Implications and recommendations

It would be a positive step to introduce autism training for therapists as a core module, along with CPD, and to consider passing laws similar to those in the UK for those working with

autistic people to be adequately trained. There is also a need for such training programmes to be designed and delivered by autistic people, to ensure that they take a neuro-affirmative approach and that they accurately reflect the lived experience of the autistic community.

Furthermore, the findings from this research may assure trainee therapists that small things with autistic clients make a difference. Where a therapist knows or suspects autism is present, and comes from a non-judgemental and curious perspective, autistic clients can feel as though this is the first time that they have felt seen and understood.

Conclusion

This study builds on the current literature on working with autistic clients. Importantly, as much of the autism literature has focused on medical, deficit, or disease models, this small study found that trainee therapists are working well with autistic adult clients.

As autistic people experience mental health issues more often, and in greater numbers than the neurotypical population, it behoves therapists to explore NIT and to challenge educators to provide training.

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Please visit www.thethatchtherapycentre.ie for more information.

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