“There is beauty in diversity in all areas of life including neurological diversity” (Bella): A mixed method study into how new thoughts on neurodiversity are influencing psychotherapists’ practice

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Abstract The term ‘neurodiversity’ describes the idea that, throughout the human population, different brain developments and structures exist. Neuronal variances, such as autism, are not seen as disorders but as variations, different from the neurotypical brain. Instead of being considered ill and cure-worthy, neurodiverse people should be included and integrated into society. The aim of this study was to explore psychotherapists’ knowledge of current trends in the understanding of autistic people i.e. the Neurodiversity movement. It wanted to identify the sources psychotherapists gained their knowledge of autism and whether terminology impacts on psychotherapists’ approach to therapy. Data was collected using a mixed method online questionnaire and analysed using thematic analysis. The results showed that participants were acutely aware of the potential negative impact of language and terminology on ‘the other’, including shame and judgement. Participants explored the purpose and usefulness of labelling and how using client-preferred terminology was helpful. Most participants felt that further knowledge and training in neurodiversity would benefit their practice. Implications for psychotherapy practice and the profession are discussed, including identifying sources of knowledge and training on neurodiversity. The opportunities, and barriers, needed for psychotherapists to support the autistic community in positive self-understanding and advocating are considered.

Keywords Neurodiversity · Psychotherapy · Autism · Autistic · Asperger’s Syndrome

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1 Introduction

It is estimated that 1% of people are autistic; that's over 77 million people in the world (O'Neill 2020).

Neurodiversity might be the next step of diversity. The term neurodiversity was first established in the online autism community in the 1990's. It describes the idea that throughout human population different brain developments and structures exist. Neuronal variances such as autism should not be seen as disorders, but as variations different from the neurotypical brain. Instead of being considered ill and cure-worthy, neurodiverse people should be included and integrated into society (Lorenz et al. 2017).

The Neurodiversity movement challenges the medical model's interest in causation and cure, celebrating autism as an inseparable aspect of identity (Kapp et al. 2012). Jody O'Neill, an Irish, autistic playwright says "... we've always relied on medical people to define autism, when the real experts, the ones in a position to define it, are the people who are actually autistic." (O'Neill 2020, p. 56). Williams (2002) describes therapy involving verbal language as a grind for autistics, causing information overload. The study aimed to determine awareness of the Neurodiversity movement in the psychotherapy profession, and the impact, if any, on practice with autistic clients. It's important to recognise that autistics may have non-typical communication, behavioural and social style, however, this was not focused upon in this study.

I am a mother of 3 boys who each received an autism diagnosis in childhood. Although there have been challenging times, as with any child, I always found the frequently used expression "suffering from autism" disconcerting. I have described them as "high-functioning" (although I now know to avoid that term) when trying to alleviate the concerns of the 'other', who usually express sympathy when they hear my children are autistic, as if they were dying. I have an autistic niece who has challenging behaviours that make family life difficult, and thus I know there is no blueprint to understanding autism. In my ongoing journey of educating myself on autism to support my children if/as required, I only recently heard of the Neurodiversity movement. Having discovered its existence, I was intrigued as to the implications for the working psychotherapeutically with neurodiverse clients.

Empathy, integral to the therapeutic relationship, is defined as

... our capacity to move away from ourselves as the locus of our reference for understanding emotion and sensation and see these phenomena as they might be experienced by another person, given their context and the information coming to them from their senses and cognition. It involves the capacity to read another's mind and put oneself in his or her shoes. (McCluskey 2005, p. 50)

For autistic clients, part of their human experience will be living in a world where the majority are neurologically different. Awareness of this is crucial for empathy with autistic clients. I have personal experience with autism, but not all psychotherapists are so fortunate. Neurological difference encompasses diagnoses including dyspraxia, dyslexia, and others; for this study I focused on autism.

2 Literature review

The Neurodiversity movement seeks to provide a culture wherein autistic people feel pride in a minority-group identity and provide mutual support in self-advocacy as a community (Jaarsma and Welin 2011). The concept of neurodiversity regards atypical neurological development as normal human difference. The neurodiversity assertion contains at least two different aspects. The first is that autism, among other neurological conditions, is first and foremost a natural variation. The second is about conferring rights and value to the neurodiversity condition, demanding recognition, and acceptance.

Jaarsma and Welin (2011) advise, just as the LGBTQ+ community once had to live in a homophobic society, autistics may be living in an autism-incompatible or even autism-phobic society. They identify a need for discourse about the detrimental effects of this on the well-being of autistics. For high-functioning autistics, society should not stigmatize these people as being disabled, having a disorder or use other deficit-based language. They highlight the use of terms as a moral issue and that group-specific rights for autistic people are needed to ensure autistic culture is treated with genuine equality. They believe it is incorrect to incorporate Asperger’s and high-functioning autistics into the wide diagnostic category of Autism Spectrum Disorder, as the American Psychiatric Association proposes (DSM-V 2013). Some autistics do not benefit from a psychiatric defect-based diagnosis and may be harmed by it, because of the disrespect it displays for their natural way of being.

Jaarsma and Welin (2011) also advise that people with low-functioning autism may be extremely vulnerable, and their condition justifies the qualification “disability”. Thus, it is reasonable to include other categories of autism in the psychiatric diagnostics. They suggest that the narrow conception of the neurodiversity claim should be accepted but the broader claim should not. Furthermore, the degree of social construction of their disability must be considered.

I am interested in how autistics may be disabled by trying to fit into a neurotypical world. This is aligned to the social model of disability that purports that people with any form of accredited impairment are disabled by an unjust and uncaring society (Barnes 2020). Rather than want to change the individual, we should accommodate and support them in ways that enable them to live positively (Lawson 2011). Dainius Puras, the United Nations’ Special Rapporteur, argues that for decades mental health services have been governed by a reductionist biomedical paradigm that has contributed to the exclusion, neglect, coercion, and abuse of people with autism and those who deviate from prevailing cultural, social and political norms (2017, as cited in Kinderman 2019).

Kenny et al. (2015) elicited the views and preferences of UK autism community members—autistic people, parents and their broader support network—as to what terms they use to describe autism. The term ‘autistic’ was endorsed by a large percentage of autistic adults, family members/friends but by considerably fewer professionals. “Person with autism” was endorsed by almost half of professionals but by fewer autistic adults and parents. The findings demonstrate that there is no single way of describing autism that is universally accepted. Use of language is an important variable within the therapeutic relationship (Kearney 2010). Any language

spoken cannot be separated from its cultural context; changes in language reflect the evolution of the people of the culture it belongs to. Language can either mean inclusion or exclusion. It can be the reason why barriers between people are formed (Chikwiri 2019).

AsIAM, Ireland's national autism charity and advocacy organisation, operates as a platform for people affected by autism to share their stories and views; it provides a strong voice for their concerns. AsIAM found many indicated a preference for identity-first language when talking about themselves. That is, they prefer "autistic" instead of "I have" or "I'm living with" autism, because they see autism as an integral part of their personal identities and as difference, rather than disability. They recommend that terms such as "disorder" and "high functioning/low functioning" should be avoided. Terms such as "normal" when referring to non-autistic people implies that those who are on the autism spectrum are somehow abnormal or defective; an alternative is "neurotypical" (AsIAM 2019). Throughout the literature I found the terms 'autists' and 'autistics' used, and I replicated these in this study.

Autistics are more vulnerable to depression because of the mental and emotional exhaustion of socialising, of coping with change and with the organisational aspects of life, and because of a pessimistic outlook. An additional cause of depression can be a diagnosis of Asperger's as a disability and a self-perception of "being irreparably defective and eternally socially stupid" (Attwood 2016, p. 11). Cassidy et al. (2014) noted increased rates of suicidal ideation in adults with Asperger's, and depression as an important potential risk factor for such suicidality. They note that adults with Asperger's often have other risk factors for secondary depression, for example, social isolation or exclusion, and unemployment. Research indicates that identifying positively with an autistic identity mediates the relationship between self-esteem and mental health difficulties; this suggests that personal acceptance of autism as part of one's identity could protect against depression and anxiety (Cooper et al. 2017). Despite this, many autistics frequently report "masking" or "camouflaging", by using strategies to act non-autistic or "neurotypical" to fit into the non-autistic world (Dean et al. 2016; Hull et al. 2017). The effort required by autistics to camouflage may be detrimental to mental health (Cage et al. 2018).

Walker's (2014) web-article, on the benefits of building a neurodiversity-positive society, is inspiring and captures the value of inclusion:

Neurodiversity is an invaluable creative resource, a problem-solving resource. The greater the diversity of the pool of available minds, the greater the diversity of perspectives, talents, and ways of thinking—and thus, the greater the probability of generating an original insight, solution, or creative contribution. And in any given sphere of society, we only get the benefit of the contributions of those individuals who are empowered to participate ... without being forced to suppress their differences.

The core of minority-group claims is often that there is something special to be protected, such as a certain culture in risk of being swallowed by the majority culture (Jaarsma and Welin 2011). The authors suggest if autists have a vulnerable status as a group, that confers obligation on the majority of neurotypicals. This study aimed to understand if we, as psychotherapists, have the capacity to fulfil that obligation.

3 Aim and objectives

The research aim was to explore how the Neurodiversity Movement has impacted upon the practice of psychotherapy.

The objectives sought to establish

- Where psychotherapists gained their knowledge related autistic people
- What psychotherapists’ understanding is of the landscape of terminology concerned with autism
- How terminology impacts on psychotherapists’ approach to therapy
- Psychotherapists’ levels of knowledge of current trends in understanding autistic people i.e. the Neurodiversity movement
- How knowledge of the Neurodiversity movement will impact on their psychotherapy practice

4 Methodology

I used a mixed-method study using an online questionnaire. The advantage of mixed methods studies is they recognize the value of iterating between that which can be counted and that which cannot to generate richer insights about the phenomena of interest (Kaplan 2016). The use of an online questionnaire permitted ease of participation for psychotherapists across Ireland and, although not by design, allowed the research to continue during the COVID-19 lockdown.

The questionnaire was semi-structured to:

- a) allow for the identification of patterns amongst the psychotherapy profession in Ireland via quantitative responses
- b) use qualitative open-ended questions and/or comments boxes to allow respondents to discuss the topic in their own words, free of limitations. This provided opportunity to uncover the respondents’ meanings and avoid the researcher imposing her own structures and meanings.

As the research was focused on the use of terminology, no consistent terminology was used in the invitation to participate or in the questionnaire itself; this was to avoid leading the participants. Thus “autism”, “autistic” and “neurodiverse” were used as alternatives in the questionnaire, and in the write-up of the findings. The invitation and the questionnaire itself were designed to introduce participants to the broad concept of Neurodiversity, and considerations of neurodiverse differences not as disorders but as a minority group that need to be included and integrated into society.

4.1 Participants

The inclusion criteria were psychotherapists in general practice. There were 15 participants, who self-selected by responding to an invitation in the IACP (Irish Association for Counselling & Psychotherapy) E-news online publication, which is

distributed to the entire IACP membership, from Student to Supervisor status. The exclusion criteria were psychotherapists who identified as working in specialist autism services, on the basis that they are required and/or are likely to be informed on latest trends as part of on the job experience and/or continuous professional development (CPD). No respondents met the exclusion criteria.

Participants were asked to categorise their experience to determine if this influenced their knowledge of neurodiversity. The level of experience is outlined in Fig. 1.

4.2 Procedure

To promote confidentiality, questionnaires were completed through the specialist survey website 'SurveyMonkey'. Quantitative data was analysed using Excel to examine correlation between the variables e.g. years in practice and identified need for additional training in autism.

Qualitative data was analysed using thematic analysis approaches to promote the identification of semantic patterns in the text. Thematic analysis allows for the emergence of key themes that most appropriately inform the research question, whilst still allowing for the richness of respondents' experiences to be heard (Braun and Clarke 2006).

4.3 Reflexivity

I was aware that my own values and experiences, especially as a mother of three autistic persons, could bias the selection of literature and influence the interpretation

Fig. 1 Participants experience in Psychotherapy

of data (McLeod 2015). A pilot group was used to identify, evaluate, and eliminate, bias in the design of the questionnaire. Thematic analysis by taking a quasi-phenomenological/hermeneutic approach was used to give a voice to respondents’ experiences and meanings, rather than my own interpretation of the data.

4.4 Ethical considerations

The dignity, rights and welfare of the research participants were considered to ensure protection from harm. This included ongoing research supervision as part of this process. I followed McLeod’s (2001) ethical framework, giving attention to his question (p. 176) “What are the broader moral implications of the study, in terms of the ways that results will be used?”. My concern was of a negative impact to the relationship between the autistic community and the psychotherapy profession, for example, via any implication that psychotherapists are not sufficiently informed to work effectively with autistic clients and/or cannot empathise with the needs and preferences of the neuro-diverse community.

5 Findings and discussion

I will present the results firstly by describing at some of the relevant results of the quantitative data and secondly the results of the qualitative text, using the words of the participants *in italics* for the key themes that emerged from the analysis.

5.1 Quantitative analysis

Eight participants (53%) had experience of working with autistic clients (Fig. 2). There was a correlation between experience of working with autistic clients and level of experience in Psychotherapy. This is not surprising given the potential for depression and suicidality amongst autistics (Cassidy et al. 2014; Attwood 2016) and that may contribute to autistics seeking therapy.

Only two participants (13%) indicated they gained knowledge of autism through formal college or Continuing Professional Development (CPD), and both participants were at Supervisor level. This indicates extensive experience in psychotherapy practice is gained before formal training on autism occurs. Twelve participants (80%) indicated their knowledge of autism was through media sources and/or personal and professional relationships rather than formal channels.

Regarding the Neurodiversity movement, 53% of participants had never heard of it (Fig. 3). There was no correlation between knowledge of the Neurodiversity movement and level of experience in psychotherapy. Three participants, who had never heard of the Neurodiversity movement, had experience with autistic clients, with one of those having significant experience with autistic clients.

87% of participants believed that further knowledge and training on autism would benefit their practice and this was not differentiated by level of experience. As a result of participating in this study, 33% of participants felt they would investigate the Neurodiversity movement. When asked where they would access such additional

Fig. 2 Participant experience of working with autistic clients

Fig. 3 Psychotherapists' awareness of the Neurodiversity Movement

Please review the following terms and check the box if you feel any of these terms are inappropriate

Answered: 15 Skipped: 0

Fig. 4 Inappropriate terminology

knowledge and training, the participants would look at autism organisations, online, CPD training courses and colleagues. One participant felt it should form part of core training in counselling or psychotherapy. Three participants (20%) looked to the IACP specifically to provide such resources.

To warm participants up to a discussion on terminology, they were asked to complete an exercise on the appropriateness of different terms (Fig. 4). Twelve participants (80%) selected “Autism as a developmental disability” as an inappropriate term, consistent with the aims of the Neurodiversity movement. Thirteen participants (87%) selected “Autistic person”, the term preferred by the autistic community (Kenny et al. 2015; AsIAm 2019), as an inappropriate term, which evidences a disconnection between psychotherapists and the autistic community.

5.2 Qualitative analysis

From the analysis of the qualitative text, five main themes emerged:

1. *Language can equally throw up barriers between humans* (MB)
2. *It's a minefield that needs to be walked through carefully* (Samantha)
3. *Terminology has a purpose* (Jennifer)
4. *Look at a client's issues in surviving and being as happy as possible in this world* (John)
5. *Consider diversity of how people are ... including neurologically* (Bella)

These five themes are used to collate the participants' words and understanding. The participants chose their name/identifier for this research, which may or may not be their own.

5.2.1 *Language can equally throw up barriers between humans (MB)*

Participants were acutely aware of the potential negative impact of language on another, consistent with Chikwiri (2019), and themes of shame and judgement arose; *... language can be loaded with judgement—real or perceived—and language can be emotionally triggering* (Bella). The importance of language in the therapeutic relationship was recognised, consistent with Kearney (2010). Bella states the importance of communicating *respect, positive regard, empathy and understanding* via language and checking with clients *what is ok and not ok*. MB felt that using *normalising language* with clients would be *HELPFUL TO THEM*. Some participants were aligned with preferences of the autism community in terms of identity-first language and avoidance of terms such as “normal” (AsIAm 2019). Bella felt it wasn't *helpful or fair to label people as 'normal' or having a 'disorder' /... being abnormal*.

5.2.2 *It's a minefield that needs to be walked through carefully (Samantha)*

In terms of the terminology that may feature in working with autistic clients, Samantha described it as a *minefield*. Participants felt terminology was important *to avoid possible shaming of clients and to avoid judgement* (Miranda). Six participants used the term ‘label’ in some form. Pdraigin stated *teenagers, in particular with high functioning Autism, find being labeled [sic] very humiliating*.

Participants were keenly aware of the role terminology and language can play in stigmatizing a minority group. Aidan said *some terminology is stigmatising, offensive and demoralising to others* and particularly in relation to the autism community. Furthermore, MB felt *the word autism ... still carries a lot of stigma in common language*. Participants recognised how the Neurodiversity movement was striving to address stigma, though with certain drawbacks, as MB describes, *'Neurodiverse' seems to be a new word that attempts to overcome existing prejudice, however in my eyes risks simply adding more exclusive, unnecessary jargon to professional's vocabulary (MB)*.

I believe this demonstrates that, within the psychotherapy profession in Ireland, there is no universally accepted single way of describing autism. This is consistent with the findings of Kenny et al. (2015) from the broader autism community in the UK, including professionals and the broader support network. Three participants believed that they would be more thoughtful in the language they use in terms of sensitivity, labels, and awareness, because of participating in the study.

The term “developmental disability” was offered in the inappropriate terms exercise, yet only one participant referenced disability in their open text response. Jennifer felt the Neurodiversity movement *acknowledges the uniqueness of the individual and their particular ways instead of making it into a disability ... or something that needs fixing*.

5.2.3 Terminology has a purpose (Jennifer)

Participants spoke of using terminology that the client preferred, such as asking them to explain their choice, to *get an insight into their terminology and relate to them in their language* (Smyth), and *to be respectful* (Stanford). This is consistent with the preferences of the autistic community (Kenny et al. 2015; AsIAm 2019). Terminology can help clients *feel understood and accepted by their therapist* (PMC) and *feel that they are not alone* and can help in understanding *their own behaviours and feelings* (Jennifer). Terminology can help them *understand themselves* (MB) and for their therapist to understand *them better, faster*. (MB). MB supports Jaarsma and Welin’s (2011) argument that, while lower-functioning autism is also part of natural variation, categorization as a disability maybe necessary for autistics to get access to necessary supports and resources *such as specific information, services, support groups*.

5.2.4 Look at a client’s issues in surviving and being as happy as possible in this world (John)

Although some participants had not heard of the Neurodiversity movement, their view of their role as therapists was to help autistic clients live positive lives (Jennifer, John), aligned with Lawson (2011), and to assist with overcoming the degree of social construction of the disability of being autistic (Jaarsma and Welin 2011). Jennifer described work with autistic clients as *to help them to find ways of living the life that feels right for them rather than trying to get them to conform to societal norms*. My overall sense was that participants were instinctively neurodiversity-positive. Anthony identified that for autistic clients, autism is only part of their human experience, and that labelling someone as autistic *neglects all the other characteristics of that person*. He was concerned that the label would create *stuckness* for the client (and possibly the therapist) in what they can achieve *and what we can do to help that client in a way that works for them*. My interpretation of this strong belief is that a greater understanding of neurodiversity, including the challenges of being neuro-diverse in a neuro-typical world, would be helpful to both psychotherapists and their clients.

5.2.5 Consider diversity of how people are ... including neurologically (Bella)

Participants seemed generally aligned with the Neurodiversity movement. MB agreed with the intention of the movement *to avoid stigmatising, medicalising, ‘othering’ of individuals not fitting societal pre-conceived notions of ‘normal’*. Bella stated *there is beauty in diversity in all areas of life including neurological diversity*, which I experienced as an impassioned statement.

Jennifer was excited by the movement but stated as a humanistic psychotherapist *I continue to be led by the client*. This leaves me with a concern that clients and counsellors may not be aware that the client may be disabled by society by trying to fit into a neuro-typical world under the social model of disability (Barnes 2020).

I think this may implicitly inhibit the client in determining, and communicating, how they need to lead.

Participants did not identify any role that the psychotherapists could play in promoting a culture wherein autistics feel pride in a minority group identity (Jaarsma and Welin 2011). I see a role for psychotherapists in helping clients with identifying positively with an autistic identity. This could combat the mental health difficulties caused by an autistic diagnosis (Attwood 2016) and discourage the “camouflaging” and lack of self-acceptance that that hinders autistics from “coming out” (Dean et al. 2016; Hull et al. 2017). Carrie noted that clients often are parents of autistic children, who struggle with worries about their children. Thus, psychotherapists can contribute to a society that embraces neurodiversity, beyond the autistic clients themselves. Anthony summed up the overall sentiment of participants by stating

Every human is unique regardless of labels applied onto them.

6 Conclusion

The findings reveal that, aligned to wider society, there are opportunities for psychotherapists to enhance their knowledge of current trends in the autistic community, to promote individual self-acceptance with their autistic clients, and to advocate for autistics as a minority group. This may help combat the mental health difficulties that brought autistic clients to therapy. Further knowledge and training on autism would benefit psychotherapists’ practice, and a clear source should be established. Accredited psychotherapy organisations could provide such training in the form of online CPD courses. Given the implications of language and terminology, a glossary of terms could be developed to guide psychotherapists at all levels of experience.

6.1 Limitations

This study purposefully took a broad approach to Neurodiversity and the awareness and views of psychotherapists on the Neurodiversity movement. This does not consider the complexities of autism and the challenges this may bring to the therapeutic relationship.

6.2 Recommendations for further research

Further research on the use of neurodiversity-positive terminology, and its impact on the therapeutic relationship, from the client’s perspective would be worthwhile. Using the principles of the Neurodiversity movement in psycho-educating autistic clients and impact to therapy outcomes could be researched, particularly where the client had no prior knowledge of the movement. Other recommendations include an examination of the neuro-compatibility of therapist and client and how that influences therapeutic outcomes.

7 Reflexive statement

My introduction to the world of autism, over eleven years ago, with the first autism diagnosis of one of my children, left me shocked, bereft and immediately shamed. I felt I had borne children that had something wrong with them and this was corroborated by society. A new door had opened in my life into routes peppered with struggle and stigma. While I had the resilience to navigate these routes successfully, the positive outcomes always felt like a “get out of jail free” card rather than a winning lottery ticket. I sensed my role was to bolster my children in navigating the world that was available to them and to champion their needs with schools, organisations, and family. It is a surprise and disappointment to me, as a mother and aunt of autistic children, and now as a psychotherapist, that I have only recently heard of the Neurodiversity movement. I recognise that it is slowly gaining momentum. I believe that we are on the precipice of change for the neuro-diverse community, as the LGBTQ+ community were 40 years ago, and I take comfort in that.

Nevertheless, I am still surprised when I see this neurological difference in my children manifest itself in crippling anxiety, particularly in those life experiences that are considered a “normal” part of growing up. This is largely because of trying to operate in a neurotypical world or, at a minimum, trying not to stand out as “different”. For me, this confirms the need for recognition of support and resource needs for autistics, that are not required by neurotypicals, simply because of their way of being. Thus, the debate between acceptance of normal human difference and the need to categorize those who cannot function adequately in society so that they can receive adequate support, is unresolved.

For Psychotherapy, perhaps the goal is to be knowledgeable on both considerations in order to integrate both, depending on the needs of the client. Yalom (1989, p. 185) tells us that

Even the most liberal system of psychiatric nomenclature does violence to the being of another. If we relate to people believing that we can categorize them, we will neither identify nor nurture the parts, the vital parts, of the other than transcends category. The enabling relationship always assumes that the other is never fully knowable.

Thus, along with my humanistic integrative colleagues, I continue to be led by my client.

With knowledge of the Neurodiversity movement, I feel I could have, and still can, advocate better for my children by a positive embracement of their neurological difference, rather than focus on their impairment. This is my wish for my fellow psychotherapists and the autistic clients with whom they will most likely work.

As a helping profession, I believe we have a role to play with this special minority-group by advocating for pride in their natural way of being and accelerating the momentum of the Neurodiversity movement. To do this, and to strive for true empathy, we must try to inform ourselves and not expect the other to explain to us, using our terminology, what it is like to be

born on the wrong planet. (Hammerschmidt 2008)

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