

Counselling, autism and the problem of empathy

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Counselling, Autism and the Problem of Empathy

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Abstract

The experiences of disabled people suggest that Ableism insidiously and invasively impacts upon the practice of counselling and related therapies. This paper critiques a particular account of psychotherapy with a child with the label of autism to illustrate how Ableism can disrupt the process of empathy and negate the therapeutic experience. In so doing the paper highlights the inherent difficulties in traversing different epistemic positions to make sufficiently informed readings of counternormative expressions of being. General principles

of counselling practice are then proposed to support practitioners with providing effective therapy for all clients.

Keywords: autism, disability, Ableism, counselling, empathy, psychotherapy

Introduction

The focus of this paper is on using the experiences of people described as being on the autism spectrum to illustrate the extent to which Ableism (defined below) has infiltrated even the counselling room. I say 'even' because the counselling room might be anticipated as an enlightened space where disabled people are understood, appreciated and empowered. Instead, it appears that the act of disability is practised here also (Lago & Smith, 2010; Reeve, 2000). Good counselling practice is predicated upon the need for counsellors to have a heightened awareness of themselves and the client within the process (Rhode, 2004; Williams, 2003). Prouty (2001, p. 35) argues that this requires therapists to really '*look and see* the phenomenology of behavior (sic)' that the client is presenting. Titchkosky (2007) also warns of a need for a careful watching of our watching and reading of our readings so that we remain alert to what is informing our perceptions, understandings and performance of disability. Natalie Rogers (2010), recognising that counselling and psychotherapy can also be domains of discrimination and inequality (Lago & Smith, 2010), encourages therapists to 'dig deep into our own blinkered spots of discriminatory practices' (p. xv) in order to challenge any of their beliefs and assumptions that might limit access to the world as the client experiences it.

This paper seeks to identify what might support counsellors, and other therapists, with appreciating what being in the world might mean for a client who 'is' on the autism spectrum.

Failure to look and see, to watch our watching and read our reading can lead us to misplace the 'problem' in the individual rather than in the environments that clients inhabit and the ableist practices that they encounter. In turn counsellors might then try to restore a 'normal self' within a client who is not necessarily biologically configured in ways that will allow him or her to ever meet the requirements of being 'normal' as these are currently constituted. The results of such misinformed practices can then be lengthy and expensive engagements that only frustrate and discourage both the counsellor and the client.

Background

The main motivation for me to write this paper was my frustration at not having the resource to support people who identify as being on the autism spectrum when they approach me, as an academic who lectures on the topic of autism, looking for ongoing assistance with understanding and negotiating the social world. I am distressed by how painful and potentially harmful it is for some people without a guide to try and operate in a social world that is 'a mine field in a jungle populated by predators' (Attwood, 1999, as quoted in Stanton, 2000, p. 86).

It seems to me that counselling, as I interpret the activity, could well be an effective mechanism of support. But I cannot find clear and easy funding routes for people through to counselling. Recommending that people access this through their local doctor, without supporting them with making the appointment and making their case is not enough. Even if such appointments were enabled there are not many counsellors who are specifically trained in supporting disabled people (Oliver, 1995). Some of the examples that I will give within this paper will illustrate that qualifications in counselling and psychotherapy do not seem to be sufficient in themselves to enable a bridging of what Mackenzie and Leach Scully (2007)

refer to as different epistemic positions: it is actually a very difficult and challenging process to know and understand ways of inhabiting the world that are very different from one's own.

Initially I expected that empathy and the appreciation of others' experiences would be more developed in counsellors through the value given to supported self-reflection during training and practice (Rhode, 2004; Rogers, 1971) but I now wonder if Ableism puts some sort of ceiling on the development of empathy: even within a reflective context perhaps we can only imagine what it means to be in the world within the boundaries of existences that are already known to us.

Practising disability in the counselling room

One expectation that I held when first I started to explore disabled people's experiences of counselling was that the process would lend itself naturally to understanding difference, that counsellors would be practised in identifying, responding to and enabling individual ways of being. I was surprised therefore to come across Donna Reeve's (2000) account of how the disabling processes that operate within society are also reflected in the counselling room. Reeve identifies that there are barriers for disabled people to even get as far as the counselling room in the first place. The cost can be prohibitive, for example, for disabled people who often have fewer financial resources. Tantam (2003), thinking about Asperger Syndrome in particular, identifies additional barriers. These include a lack of awareness in people on the autism spectrum of the facility of counselling, and how it might help them; some people with autism may focus only on the need for the world to change and not perceive themselves as having also to do some things differently; there might be a fear of revealing oneself as autistic; or practical issues such as actually locating a counsellor, finding the venue and arriving to a set time. Counsellors themselves might set up further barriers. If a

potential client discloses a label, some counsellors may feel that this needs specialist support that is outside their expertise (Raffensperger, 2009). I encountered further illustrations of practice in counselling and other forms of therapy that concerned me and I began to lose confidence that counselling would always be a positive and empowering experience for disabled people.

The potential of counselling

I am not trained in counselling. However, I do believe that counselling has value in that it can help significantly in supporting us with understanding our performative selves (Butler, 1997), the self that carries out consciously and unconsciously the expectations placed upon us in relation to our gender, class, race, sexuality and, most significantly here, our bodily, cognitive and emotional configurations. Counselling can at the very least help us to recognise that we are to a significant extent the product of others' making and so the responsibility for when we find ourselves being 'out of place' (Kitchin, 1998) is not necessarily ours. Counselling can then support us with appreciating the relationship between the internal and the external and enable accommodations that might help to repair some of the injury of chronic experience of 'misfit': the incongruity between mind and/or body and environment (Garland-Thomson, 2011). Counselling may then be able to help a client to settle upon a performative self that is less problematic for him/her.

Autism: essential or constructed

As this paper relies upon the example of autism to elucidate how Ableism operates in the counselling room, before defining Ableism I will make explicit my current position in relation to the concept of autism itself, as to whether I see it as something essential, a

condition that can be 'had', or as a social construct (Timimi, Gardner & McCabe, 2010). I stand here with Ian Hacking who in 2009 stated,

I take for granted that underneath the spectrum is a family of definite biological conditions, be they neurological or genetic or whatever, but that in an important sense the spectrum itself is a 'moving target' that has evolved dramatically (p.1467).

My interpretation of Hacking's view here is that human beings are physically constructed in differing ways. For some this will mean that they are more interested in objects than people, the system for decoding social messages might not be so accessible to them and aspects of the social world, as it is currently constructed, might appear too nebulous to keep track of without imposing some sort of personal system of order and control. The observance of these ways of being in people can lead to a label of autism. And of course, as with all labels, 'autism' also carries with it a whole range of assumptions, expectations and limitations that others may well apply to people with the label regardless of whether these may or may not be relevant to them as individuals (Gillman, Heyman & Swain, 2000).

Ableism

Campbell (2009) describes the project of Ableism as 'the compulsion to emulate ableist regulatory norms' (p.3) resulting in '[a] network of beliefs, processes and practices' that casts disability 'as a diminished state of being human' (Campbell, 2001, as cited in Campbell, 2009, p. 5). Campbell is interested in trying to identify and then expose the processes through which a standard of 'normal' is created, agreed and maintained. Campbell is arguing for the gaze not to be on disabled people, their perceived needs and limitations but rather on why and how society establishes, and maintains, a hierarchy of physical forms. Some ways of being become privileged over others. For example, the capability for walking is valued above

rolling, speaking above signing, and reading print above braille (Hehir 2002). In establishing this hierarchy society through a seemingly unconscious but necessarily agreed process moves some of its members to the sidelines. It positions them as deviant, dependent and sometimes dangerous and constitutes them as a sub-human species that requires identification and controlling. This act of marginalisation, of 'othering, and the ways in which it is achieved is Ableism. Davis (2002), by the grafting of an analogy from Michael Bérubé, tries to explain Ableism by defining it as 'the psychological distance most people put between themselves and disability' (p. 35). Garland-Thomson (1997) employs the term 'normates' to refer to those people who 'can represent themselves as definitive human beings' (p. 8), who are accepted as 'normal'. Ableism is then the mechanism through which 'normates' try to suppress a terror of infirmity. Ableist processes and practices might then be said to be all those things that 'normates' do that enable them to pretend that impairment does not exist. In this way normates can manage their own fear of the temporality and fragility of being by moving disabled people to the margins of society, to deny bodily configurations (Garland-Thomson, 1997) that do not permit the myth of eternal life and continual beauty. In doing so Ableism through the processes of categorisation and regulation creates groups who are defined and understood by labels rather than all people being recognised as individual and unique. One effect of this is for therapy to often focus on seeking to make the client 'normal' rather than on the full development of the client's currently constituted self.

Making up kinds of people

Ian Hacking (2007) talks about the way in which diagnosis and labelling supports this process of distancing by 'making up kinds of people' that normates can then legitimately see as being far removed from their own experience and anticipated futures. Of course I reject both Ableism and its tool of making up kinds of people but I find that this then presents me with a dilemma. Within this paper I am arguing that people on the autism spectrum do require

counsellors to enter into different modes of thinking and being in order to provide them with effective support. I worry that by doing so I am encouraging counsellors to see people who are on the autism spectrum as a different kind of people with the risk that they are then interpreted as being of a lesser, inferior and diminished kind who can only benefit from specialised and segregated services. Such a position might be described as representing a medical or individual model of disability that positions the 'problem' in the individual rather than in social, political, economic and cultural environments (Oliver, 1990). The danger of such a view is that people on the autism spectrum may then be seen as the victims of their own neuro-biological construction, for whom counselling has nothing to offer, rather than as people who are suffering from the challenge of managing hostile and exclusionary ableist environments. This is certainly not what I intend: I am not asking counsellors to engage with different kinds of people; rather I am urging them to reflect on whether their own perceptions of how people experience the world might be unduly limited, to consider whether they may be trapped within their own particular narrative (Porter Abbott, 2002) and thus prevented from imagining ways of being that may, as yet, be unknown to them. Counsellors may find themselves restricted perhaps, through a loyalty to particular creeds of counselling that proselytise normative understandings of what it means to be human. Rather than counsellors colluding with making up kinds of people I want them to recognise that people can exist in the world in many different kinds of ways, some of which may be beyond the counsellor's current knowledge and understanding.

Ableism in the counselling room

To illustrate how Ableism might impact upon the counselling process, I would now like to reflect on an example of ableist assumptions disrupting the psychoanalytic process that is

described in an article by a psychoanalyst, Vera Regina Fonseca (2009). This is a piece of writing that seems to speak with great authority about autistic ways of being in the world and yet I can find no reference within it to how people on the autism spectrum, themselves, define and speak of their experiences. Instead, the article seems mainly to be based on outdated theories of autism from thirty years previously and the author's own prior academic outputs. The article is entitled, 'The autistic dialogic style; a case of Asperger's syndrome' and it recalls the history of nine years of psychoanalysis experienced by a boy whom Fonseca names as Arthur. At the time of Fonseca writing the article Arthur was twelve and he had been given three therapy sessions a week since he was three years old, from which, according to Fonseca's account he seems to have received very little benefit. For the initial five years Arthur had a different analyst until that therapist died and so Fonseca took over Arthur's 'therapy'. The issue of drowsiness in therapy is well recognised (Williams, Polster, Grizzard, Rockenbaugh, & Judge, 2003) and a significant part of this case study report centres upon Fonseca's problems with staying awake during her sessions with Arthur. 'Since the beginning, the sessions with Arthur have had the effect of making me very drowsy' (p. 253) writes Fonseca. Later from her therapy notes, she recalls, 'It is very hot and the mere sight of Arthur in the waiting room is enough to make me drowsy' (p. 256). However, in spite of its prominence as an issue, the reasons for Fonseca's boredom, and the ways in which this might have undermined the therapeutic value of the sessions is not fully explored. Fonseca does not seem to reflect on her own contribution to the dull nature of the therapeutic relationship. Instead, perhaps freed to do so by ableist presumptions of deficit, a word that Fonseca uses a lot in reference to Arthur, Fonseca appears to place all the responsibility and blame for the tedious nature of their relationship on him alone. For example, she states 'As far as affect is concerned, he drained every emotion from the relationship...' (p. 250). Fonseca does not appear to reflect on the cultural context in which she is operating. For example, it may be that

her boredom arose partly through frustration at what seemed to be a repetitive therapy process with little change. Fonseca's work, like all western therapy, is embedded within a culture of conversion narratives, such as the seminal account of Dibs and play therapy (Axline, 1971) in which children with autism, through therapeutic intervention, make 'miraculous' breakthroughs into social and emotional 'normality' (Fisher, 2007). Fonseca clearly did not experience such dramatic changes for Arthur remained, fundamentally, the same and perhaps this made the sessions somewhat disappointing and less engaging for Fonseca.

The reason Fonseca gives for the lack of connection between her and Arthur seems only to be the impairment effects of autism. Other potential contributors to drowsiness are not explored, such as Fonseca having indulged in a heavy lunch before sessions, which she reports in the text, or her not appearing to know how to stimulate and engage with Arthur beyond the same psychoanalytic tools of talking and drawing that Fonseca perhaps uses with all clients.

Ableist assumptions abound within this short text. Fonseca is surprised by what she finds to be Arthur's flat vocal expression and gaze as, 'he has the look of a healthy and normal boy' (p. 252). For Fonseca, Arthur's modus operandi would seem therefore to be an illness rather than a legitimate expression of simply being. Arthur likes trees and he usually draws them. On one occasion he drew some that were bent by a tornado and this seemed to excite him. To Fonseca, who seems only to operate in a world of feelings, social connections and human bonding, the reason for this is clear: 'It seemed', she says, 'that this was his way of depicting the annihilation anxiety (Tustin, 1981) triggered by his analyst's death' (p. 253). Now I am not insisting that this interpretation is wrong: I recognise that it has been suggested that the motivation behind some of the special interests of people with autism might be attempts to master a source of anxiety (Volkmar, 2011) but this remains a contested position (Mintz, 2008).

This is, therefore, but one interpretation and one that applies normative expectations of human development. Fonseca offers no substantial reason for this explanation and I feel it says more about the limitations of her own world view than about Arthur's for Fonseca appears not to conceive of the possibility of a life world in which trees are more interesting than people. Nor is there any logic to her claim. Fonseca's whole argument is based on the concept, 'that the central problem in autistic disorders is the acceptance and tolerance of otherness' (p. 251). So at the same time as claiming an autistic rejection of the other, Fonseca asks us to accept that Arthur is so traumatised by the loss of another that he needs to play this out in therapy, that only in the form of drawing can these feelings be managed. It simply makes no sense.

It appears that Fonseca is blinkered by Ableism and embedded within the beliefs and practices of a form of psychoanalysis that does not account for neuro-biological difference (Shuttleworth, 1999). Fonseca seems unable to accept that for some people other people do not do anything for them, that they might be of very little interest and do not capture the attention. Prouty (2001, p. 35) argues that '[M]any therapists do not respond to the literal experiencing. They respond through schemas about experience'. Fonseca demonstrates an awareness of autism theory but she does not use it in any meaningful way to facilitate the therapeutic process. This is somewhat surprising as in an earlier report (Fonseca & Bussab, 2006) the authors seem to use autism theory much more effectively in reflecting on, and responding to, the behaviour of their client, Gabriel. The value of really coming to know and understand difference is illustrated by Jacobsen (2003), using examples from her clinical work with people on the autism spectrum. Jacobsen demonstrates the positive impacts for therapy of reframing the psychotherapeutic process so that it takes account of the client's developmental history, experience and system of being.

It seems to me that for Fonseca, Arthur is, to use Buber's term an, 'It' (Buber, 1957, as cited in Hess, 2009), rather than a Thou. Fonseca does not demonstrate that she has truly worked to create an 'I-Thou' relationship where 'two retain their individuality, delight in how they meet, yet respect that there are fundamental differences between the two' (Hess, 2009, p. 27). In an 'I-Thou' relationship Fonseca would be actively seeking to understand who Arthur is and what being Arthur means for him. Instead Fonseca appears to be placing all the responsibility for their relationship on Arthur alone, and is using autism to excuse her from watching her watching, reading her reading and really getting to know the life behind the label (Goodley, 1996). Sadly in doing so Fonseca is missing the opportunity to develop as a therapist and a person (Rhode, 2004; Volkmar, 2011), to 'learn more about (her) own tastes, preferences and limitations' (Hess, 2009, p. 27). Shuttleworth (1999) in an account of psychotherapy with a child, whom she refers to as having Asperger Syndrome, reports on the changes to her own understandings about being human and the practice of psychotherapy that result from the sessions. Had Fonseca taken a broader reflective stance on her engagement with Arthur then she might have been able to act as a bridge between two very different epistemic positions (Polmear, 2004). If therapy is to be a truly inclusive practice then it may well be that the therapist needs to change as much as the client (Lago & Smith, 2010), although Oliver (1995) suggests that this often only requires a shift in emphasis for counsellors rather than any dramatic rejection of the methods in which they are trained.

Autism and the value of psychoanalysis

Some might argue that the problem here is not Fonseca but the tools that she is trying to work with, that psychoanalysis is an interpersonal approach that is dependent upon a client having a developed 'sense-of-the other' (Hess, 2009). Many people on the autism spectrum also

dismiss psychotherapy as an intervention, rejecting the notion that their present difficulties might be rooted in the psyche rather than neuro-biological differences (Singer, 1999).

Koenig and Levine (2011), however, argue that psychotherapy does have something to offer people on the autism spectrum so long as therapists are prepared to alter their 'previously established processes and rules for therapeutic engagement' (p. 34). Volkmar (2011) also argues that therapists will need to modify their practices when working with people on the autism spectrum. If they manage to do so then Volkmar claims that there is value in psychoanalysis as it can help people on the autism spectrum to represent their inner self more effectively and enable more developed understandings of the relationship between this and the external world. Tantam (2000) suggests that for this to happen with people with Asperger Syndrome counselling will need to be based 'around the client's subjective experience of Asperger syndrome' (p. 61). In fact I would apply this principle more widely by arguing that effective counselling needs to be based around any client's subjective experience of being, that this is always essential for the creation of an I-Thou relationship.

Polmear (2004) suggests that for some clients, like Arthur, counsellors will need to 'go beyond what is usually required in understanding and responding to the experience of another' (p. 88). In doing so counsellors may find useful Prouty's (2001) principles of pre-therapy. This is a development of client-centered therapy, the focus of which is clients who are labelled as being 'low-functioning' (p. 31) and who are not yet considered able to access therapy. The principles of pre-therapy are designed to provide a structure for nurturing psychological contact between the counsellor and the client in order to move the client to a position where person-centered therapy is meaningful. Although excellent in its attempts to include people with intellectual and social/emotional impairment in the counselling process unless person-centered therapy remains adaptable to different modes of being then it will always exclude from therapy those whose neuro-biological configurations might mean that a

language based therapy never becomes accessible to them (Shuttleworth, 1999). It might be better, therefore, to think of pre-therapy simply as principles for developing psychological contact that can be therapy in itself for clients who have little experience of interpersonal connection. In achieving this the inclusive counsellor will also be helped by engaging with different theories of being (Jacobsen, 2003), developing understanding of which might involve the counsellor in working alongside other professionals (Rhode, 2004).

As part of the process of coming to know another counsellors will therefore benefit from using what Donna Williams' (1996), a writer who identifies as being on the autism spectrum, termed 'the inside-out approach'. Williams calls for professionals to balance textbook theory about how life should be for particular impairment groups with a focus on how life really is for the individual in front of them. It seems to me that Fonseca's example is an illustration of what happens when an outside-in approach is applied, when what Arthur is labelled as comes to dominate who he is. Although, Fonseca did feel that Arthur made some progress in his engagements with her, the developments identified came, it seems to me, at far too high and unnecessary a cost for Arthur and his family.

Fonseca, de Barros and de Almeida (2001) report on another case study example of a little girl, Ida, who seems to have begun therapy sessions twice a week with Fonseca when she was just one year old. After sixty seven sessions when Ida was still only two years old, the parents decided to end psychoanalysis with Fonseca in favour of speech and language therapy.

Fonseca's report does not contain evidence of the type of developmental progress that I might have expected from an intervention of this frequency. However, when the parents decide to try something else for Ida, because they feel that her challenges stem from neuro-biological difference rather than psychological disturbance, Fonseca does not reflect on the value of psychotherapy in this instance. Instead she frames the parents' rejection of psychoanalysis as '[p]erhaps they are following the easiest path: if this is a pure neurological problem Ida is

their burden, not their fault' (p. 151). Fonseca illustrates here that she is working to an individual model of disability that sees disability necessarily as a personal tragedy (Runswick-Cole, 2008). Certainly Fonseca and the therapists writing with her do not appear to give any serious consideration to the potential limitations of their practice. Ableism appears to permit Fonseca to place all the responsibility for any 'failure' in therapy on the 'impaired' child and her 'damaged' family. Ableism is clearly at work in this counselling room.

Practice guidelines

It might be frustrating for some therapists that this paper does not present a more definite set of practices that can be said to constitute effective counselling for people on the autism spectrum. Trying to provide this, however, would be an act of Ableism in itself as this requires the positioning of a group of people as inherently distinct. Nor would the establishment of particular guidelines for different impairment groups help those who have not yet acquired the label. Rather, I encourage therapists to reject such categorisations and to reflect instead on general principles that might enable a quality counselling experience for all clients. How and when these are applied will be an organic process within each therapeutic relationship but I suggest that the principles of practice might include:

- Being curious and enjoying learning about new or less familiar ways of being in the world.
- Remaining mindful, reflective and open to challenge about one's own beliefs and values.
- Coming to knowing the client rather than the label.

- Acknowledging the client's difficult experiences and helping her/him to recognise why these might have occurred. Helping to repair the damage to self of living in a world that can seem alien to the client or in which the client appears alien to others.
- Remaining open to new ways of working e.g. embracing technology, flexible sites of practice and working with others around the client.
- Adapting customary practice to take account of the client's mode of being. Focusing on more directed strategies for change, for example, where the client is demonstrating limited capacity for self-reflection and analysis.
- Evaluating whether there is the potential for progress within this therapeutic relationship and not assuming that a label always makes a client the domain of experts.

Conclusion

It can be seen therefore that the experiences of people on the autism spectrum suggest that the counselling room does not evade the rule of Ableism. In spite of a focus, within the majority of counselling approaches, on understanding the world view of the client, appreciating the ways of being in the world of some disabled people can provide counsellors with significant challenges. These might then lead some counsellors to neglect the watching of their watching and the reading of their readings, thereby failing to recognise counternormative expressions of being. Counsellors and other therapists need to remind themselves of Goodley's (2011) warning to 'always view psychoanalysis with healthy scepticism rather than deluded affiliation' (p.123), to avoid becoming wedded to ontologies that position the 'problem' within the client and not the social world. Goodley (2011) argues that '[p]sychoanalysis might be at its most powerful when employed to make sense of organisational prejudice and

discrimination against disabled people' (p.135) and this may then help clients with healing some of the injuries inflicted by the violence of Ableism (Campbell, 2008). But even this may not be enough in itself to improve the quality of everyday lives that include struggles with an absence of meaningful occupation, lack of money and exploitation by others (Feltham & Horton, 2000). Even approaches such as cognitive behavioural therapy and solution focused therapy that have been reported as having some benefit for people with ways of being framed as 'autism' (Tantam & Girgis, 2009), can only go so far in supporting clients if the focus is solely on developing personal strategies for trying to manage an overwhelmingly incomprehensible and uncomprehending, hostile and socially focused world. In order to understand, empathise with and support fully some disabled clients, counsellors will need to recognise that their client is a guide into a different way of being that the counsellor may not yet be able to imagine. If, through an inside-out approach counsellors can traverse different epistemic positions in the successful development of emotionally resonant I-Thou relationships (Hess, 2009) then they will achieve some understanding of the impact of living 'out of place' on the client. Effective counsellors will be those who are curious; who really look and see; watch their watching and read their readings; are flexible in their ways of working; informed about different ways of being and who are prepared, at times, to work with other professionals and advocates. Such counsellors will then be able to recognise and challenge Ableism within their practice. The quest to achieve empathy with their clients will then become a stimulating challenge and journey of change for counsellors, with no time for boredom.

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