

Book chapter – Embracing the ethical possibilities of researching about autistic individuals’ transition to post school opportunities in South West Queensland, Australia

The following chapter will address the many challenges faced when conducting research with the autistic community. In particular, the considerations, challenges and wicked problems that were encountered as the researcher worked towards obtaining ethical clearance for the research study ‘Self-determination for the rest of my life: Young autistic adults’ insights into the interaction between Queensland secondary school transition practices and post-school quality of life’. The question of why and how autistic people came to be marginalised within education and educational research, and the impact that this has for the people themselves and for research outcomes will be addressed. The specific and evolving strategies employed to address some of the challenges and wicked problems within this research project are shared, while considering the processes needed for developing effective, and at times innovative, strategies to effectively include this marginalised group. Throughout the chapter, concepts and approaches for further engaging the autistic community in *communicating their experiences and articulating their voices* are woven into the discussion, with the aim of supporting researchers, autistic people and the wider community to engage in reflective dialogues about effective educational research with the autistic community.

Autism spectrum disorder (ASD) is a condition in which individuals display differences in how they engage in social communication. Rigid and repetitive interests and behaviours are also exhibited (Diagnostic and Statistical Manual 5th edition [DSM 5], 2013). Contemporary understandings recognise one condition, autism spectrum disorder, with a strong emphasis on acknowledging the wide spectrum and levels of differences each individual experiences, and the supports required by each (DSM 5, 2013: Vaccaro, Kimball, Wells & Ostiguy, 2015). Thus, the use of the umbrella term ‘autism’ throughout the chapter is utilised, whilst acknowledging the significant variation that exists between individuals with the same diagnosis.

The researcher has both a personal and professional interest in this topic, as both the parent of a young autistic adult, and as an educator who has worked for many years supporting autistic people within the Queensland education system in Australia. Both experiences have shown that education can, and often does, function as an agent of marginalisation for people with autism. Research supports this experience, finding that the majority of individuals with autism experience poor academic and social outcomes throughout school and poor post

school outcomes as they transition from school to adult life (Hume, Boyd, Hamm & Kurcharczyk, 2014). Conversely, the researcher posits that education and educational research can act as a means of empowerment for the autistic individual, their family and their community. However, to achieve this outcome, research must avoid replicating the marginalisation that currently exists within education and educational research. Rather it must identify and challenge inequities, and offer innovative methods for conducting inclusive research.

Situating the research project within a bio-psycho-social model of disability, (Convention on the rights of the Person with Disability [CRPD], 2006) reinforces the importance of educational research as an avenue for empowerment for people with autism. On the other hand, it also leads to the primary underlying wicked problem faced in obtaining ethics approval for the research project. The bio-psycho-social model of disability acknowledges that disability results from the impairments that are experienced by persons with disability, and the attitudinal and environmental barriers that hinder their full and effective participation in society (Anastasiou & Kauffman, 2013). Paradoxically, this acceptance of impairment and difference, in and of itself propagates marginalisation (Vaccaro et al., 2015). Marginalisation exists when an individual or group are not considered a part of dominant mainstream society. Thus, this recognition of the differences in the way autistic individuals experience the world, communicate and behave, automatically positions the autistic individual 'outside' of the mainstream.

Many people in the autistic community contest this ideological basis of their marginalisation and positioning by denying that their difference implies impairment. By moving away from a deficit-based neurobiological discourse about autism to emphasise the concept of neurodiversity, the autistic community suggest that their experiences are seen as just one of the many variations of the ways in which human beings experience life (O'Dell, Bertisdotter Rosqvist, Ortega, Brownlow & Orsini, 2016). Within this understanding, how the person experiences the world, communicates and behaves is valuable to the individual, and the fact that others may struggle to interpret this does not detract from this value (O'Dell et al., 2016). While in principal this conceptual shift appears to challenge the marginalisation experienced by the autistic community, and therefore should be supported within educational research, the process of obtaining ethical clearance for research with autistic individuals does not easily conform to this conceptual understanding (Short, Barton, Cooper, Woolven, Loos & Devos, 2017; Souto-Manning & Winn, 2017)

Issues around obtaining ethical approval

Obtaining ethical approval for research conducted with human participants is the process of involving other researchers in reviewing and adjusting the proposed research to ensure that the values and principles of respect, research merit and integrity, justice, and beneficence are enacted for those who participate in research (NHMRC, 2007 [updated 2018]). The importance of upholding these values, particularly for marginalised research participants, cannot be denied. Nevertheless, this very protection creates the wicked problem of not conforming to the conceptual understanding of neurodiversity (Midgley, Davies, Oliver & Danaher, 2014). As discussed above, neurodiversity implies that the condition of ASD should not be labelled as medically and functionally inferior to the ‘norm’, and therefore should not be placed under the label of “...cognitive impairment, intellectual disability or mental illness...” as used with the National Statement on Ethical Conduct in Human Research (NHMRC, 2007 [updated 2018], p. 73). Yet, in order to obtain ethical approval to conduct research with autistic participants, the researcher is required to identify the participants as fitting within the bounds of this group. Furthermore, there is little to no recognition within the National Statement of Ethical Conduct in Human Research (2007 [updated 2018]) that ASD as a condition exists separately to the listed conditions, that the implications of the condition can be significantly different, or that the benefits and risks may be different again from other marginalised groups of people with disability. Vaccaro et al. (2015) warns of the inherent difficulty in utilising disability as a singular construct that fails to recognise the significant diversity amongst various conditions, and further yet, fails to recognise the significant diversity and intersectionality among individuals within the same group.

The value of respect for human beings is central to the National Statement on Ethical Conduct in Human Research and is defined as the “...recognition of their intrinsic value” (2007 [updated 2018], p. 11). Underlying principles of respect includes due regard for the welfare, beliefs, perceptions, customs and cultural knowledge of all participants. The use of the terms ‘human beings’ and ‘all’ within this definition implies the inclusion of marginalised groups, including autistic people. As stated by Milton (2014), despite their differences autistic people remain human, and as such, should be afforded the same value as all human beings. The ideological underpinnings of the intrinsic value of people with disability is strongly promoted throughout Australian society through the Convention on the rights of people with disabilities (CRPD) to which Australia is a signatory. Article 17 of the CRPD states that “Every person with disabilities has a right to respect for his or her physical and

mental integrity on an equal basis with others” (2006, p. 13). Thus the value of respect afforded to all human beings, across all areas of life, must be applied to autistic people to the same level as for every other citizen, including as participants within research.

Articulating and communicating the voices of autistic individuals

Despite these key documents supporting educational research with people with disability promoting the value of respect for people with disability, autistic people have had few opportunities to participate in research examining issues related directly to their own experiences or the wider experiences of the community as a whole (Cook-Sather, 2014; DePape & Lindsay, 2016; Tesfaye et al., 2019). Rather, there is a significant amount of research pertaining to the education of individuals with autism, which comes from the perspective of parents, siblings, teachers, health care and support providers, while the voices of individuals with ASD remain largely uncaptured (DePape & Lindsay, 2016; Pellicano, Dinsmore & Charman, 2014). The result of this is that the disability discourse focus remains on those who belong to the collective ‘in’ group, and the inequities and marginalisation of autistic people remain unchallenged (Wollbring & Burke, 2013).

Bringing the value of respect, and therefore inclusion, of people with autism to educational research requires all researchers to recognise the difference and diversity in terms of needs and support of this marginalised group, without taking a deficit-based view of the individual’s capacity. A deficit-based view indicates that the capacity of autistic individuals has been seen, and is still seen by many, as ‘less than’ the capacity of non-autistic, non-disabled individuals. Within this understanding, the capacity to understand information, sequence events, recall experiences and express subjective understandings remains in question, especially for those who have higher support needs (Tozer, Atkin & Wenham, 2013). Including autistic individuals in research challenges these deep seated assumptions about capacity (Cook-Sather, 2014) and supports the view that they can be involved in their own lives, make decisions, influence supports and challenge policy.

Literature is beginning to support this understanding, with a small number of studies finding people with ASD are able to accurately identify and communicate their ideas, feelings and experiences. Furthermore, this research also indicates that autistic individuals use different perceptions or world views than non-autistic people (Clark et al., 2015; Hong, Bishop-Fitzpatrick, Smith, Greenberg & Mailick, 2016). These findings support the view that knowledge is not universal and needs to be considered within the specific context of the

individual (Couch, Durant & Hill, 2014). As such, specific, distinctive knowledge can be found in the autistic community. Unfortunately, the ability to contribute to the construction of this knowledge is impeded by a ‘disconnect’ in the ways in which autistic people communicate knowledge, and the ways in which researchers collect knowledge (Milton, 2014). However, it would seem that it is less about marginalised research participant’s objective characteristics, and more about the researchers’ distance from that population and inability to adapt to the way in which research is ‘done’ (Couch et al., 2014).

Respect for the autistic community, their value and their ability to construct knowledge in and about themselves necessitates researchers to find effective ways of eliciting and sharing this knowledge (Milton, 2014). The transformation of educational research for marginalised participants requires a rethinking of the role of researchers. The impetus is to revision this role from the position of expert, to the position of learner (Souto-Manning & Winn, 2017). Through this revisioning of roles, the researcher can work alongside the participant, learning about and implementing effective research practices to ensure the voices of autistic people are shared through research (McIntosh & Morse, 2015).

To do this it is suggested that researchers maintain a situated stance of universal design in the construction and implementation of research projects (Vaccaro et al., 2015). Universal design includes, from the outset, flexibility, adaptability and multifaceted approaches that ensure everyone, including people with disability, can access and participate in research (Connell & Sanford, 1999). Routine research design practice that involves the principles of universal design would seem to offer significant opportunity for the inclusion of marginalised participants in research without replicating the dualism of ‘us and them’ that exists within the current retrofitting of research practices to support the inclusion of people with disability (Vaccaro et al., 2015).

Universal design is particularly relevant when considering the goal of giving voice to autistic individuals through research participation. There is significant recognition of the difficulties in eliciting the voice of marginalised populations throughout research, (Cook-Sather, 2014; Midgley et al., 2014; Souto-Manning & Winn, 2017) and in particular eliciting the voice of people with disability, including those with autism (Milton, 2014; O’Dell, 2016; Tesfaye et al., 2019; Vaccaro et al., 2015). Considering voice in relation to autistic people presents both figurative and literal wicked problems for researchers. The voice of autistic people has not been well represented through research as a result of the marginalisation experienced by this

group in relation to participation in research. Additionally, the voice of autistic people, even when they are included as research participants, is difficult to capture because autistic people, as a primary characteristic of the way they function, experience significant differences in the way they interact and communicate with others (DSM 5, 2013; Loyd, 2012). As most research is typically based on verbal or written skills, this prevents individuals who do not communicate in these ways from sharing their voice through research (Tozer et al., 2013). Thus, the question presented by Dervin (2014, p. viii), “In what language are people ‘doing’ voice and what impacts does this have on what they say?” becomes a paramount consideration when researching with people with autism.

People with autism do not speak with one voice, rather presenting with a range of communication styles, experiences and preferences (O’Dell et al., 2016; Tozer et al., 2013). Thus, universal design strategies when considering voice must provide for a diverse range of suitable communication methods. These communication methods should include the possibility for participants to use verbal language, simplified language, written language, pictures/visuals, sign language or a combination of any of these methods. Furthermore, the social expectations of communicating with participants with autism must be considered. The researcher may need to provide additional processing time, re-word questions and use shorter, easier response questions, consider the use of literal language and the tone and volume of language used and ensure non-verbal communication strategies used throughout the research process, such as the use of direct eye contact, are suitable for the participant being interviewed. These strategies relating to both receptive and expressive communication differences can, and should, be woven into all aspects of the research design.

Beneficence, as identified in the National Statement on Ethical Conduct in Human Research (2007 [updated 2018], p. 10) is the concept that “...the likely benefit of the research must justify any risks of harm or discomfort to participants”. Within this concept of beneficence are the two constructs of benefit and risk. Benefit is defined as a “...gain in knowledge, insight and understanding, improved social welfare and individual wellbeing, and gains in skill or expertise for individual researchers, teams or institutions” (NHMRC, 2007 [updated 2018], p. 14). While risk is defined as “...a potential for harm, discomfort or inconvenience” (NHMRC, 2007 [updated 2018], p. 12). Both constructs must be applied to individual research projects to gauge whether the overall concept of beneficence is achieved.

Research conducted with human participants must be justifiable by its potential benefit. That is, the likely benefit of the research must justify the risks of harm or discomfort to participants and may include benefits to the participant, to the wider community, or both (NHMRC, 2007 [updated 2018], p.73). Implicit in the consideration of benefit is the understanding that participating in research will provide the participant, and the wider community, with increased levels of knowledge, improved practice, skill and awareness (Short, Barton, Cooper, Woolven, Loos & Devos, 2017). These benefits have been widely recognised for the community who live and work with people with ASD, however, there has been a lack of recognition of the benefits for autistic people themselves with the underlying characteristics of autistic individuals seen as incompatible with improved outcomes through research participation (Milton, 2014). This understanding is being redressed with contemporary findings of research supporting the benefits for marginalised people, including those with autism (DePape & Lindsay, 2016; Loyd, 2012; Tesfaye et al., 2019; Tozer et al., 2013).

When the construct of risk is applied to autistic individuals, there needs to be a recognition that these individuals are "...more than usually vulnerable to various forms of discomfort and stress" (National Statement on Ethical Conduct in Human Research, 2007 [updated 2018], p.73). Research conducted by van Steensel, Bogel & Perrin (2011) reveal substantial comorbidity for anxiety in youth with ASD, with approximately 40% of all individuals with ASD experiencing either clinically elevated levels of anxiety or at least one anxiety disorder. Moreover, these findings are consistent with previous reviews of ASD literature with regards to ASD and the experience of anxiety (van Steensel et al., 2011). This increased risk of anxiety for autistic individuals results in the identified increased risk of discomfort and/or stress for autistic individuals when participating in research, particularly if this research requires them to take part in interviews where they need to respond directly to questions (Danker, Strnadova & Cumming, 2019; Tozer, 2014). As suggested by Midgley et al. (2014), it can be this increased risk of harm experienced by marginalised groups and the focus of ethics committees on the construct of non-maleficence, or 'do no harm', that may actually discourage researchers from engaging in research with these groups. In the case of research with autistic participants, this is a significant difficulty (Milton, 2014; O'Dell et al., 2016).

When considering the risk of participation in research, it is important to acknowledge different forms of risk and the implication of harm across time and contexts. Thus, researchers need to consider the short-term harm of increased levels of anxiety for the

individual, versus the long-term harm of not allowing the person with autism to have a say and influence their own, and others, future. This construct of risk for people with disability must also consider the human dignity of risk (Perske, 1972). Dignity of risk is the awareness that self-determination and the right to take reasonable risks are essential for human dignity and self-esteem. This right to human dignity should not be impeded by excessively cautious or overprotective policies or practices. Dignity of risk is further implied in the Convention on the Rights of Persons with Disability (2006) where the rights of people with disability to make their own choices and be actively involved in decision-making processes for and about themselves is expected. Thus, the consideration of risk for autistic people participating in research again presents the wicked problem of recognising the potential for elevated risk, while at the same time not allowing this elevated risk to prevent the individual from choosing to participate in research and face the possibility of experiencing anxiety.

To address this, it is recommended that researchers employ universal design throughout the research design to both minimise this risk of increased anxiety, and manage this risk effectively throughout the research process (NHMRC, 2007 [updated 2018]). Universal design strategies for research provide a sliding scale of support, as required by the individual, along with participant choice regarding their involvement (Danker et al., 2019). Strategies suggested for the current research project included participant choice on the number and length of interviews, as well as a choice of place and time of interviews. Choice will also be provided on how interviews are to be conducted, either face to face, online, or via phone or written interviews. Additionally, participants will be offered a choice of communication methods; verbal, written, photographic, pictorial, or a mix of communication options so that preferred communication styles of the individual can be used during interviews (Loyd, 2012; Tesfaye et al., 2019; Tozer et al., 2013). Participants will also be invited to spend time getting to know the researcher prior to engaging in the interviews with the hope of developing a positive relationship between the participant and researcher before the research is started. This opportunity to develop a positive relationship is suggested to support effective communication during the research process (Couch et al., 2014; Loyd, 2012; Tesfaye et al., 2019).

A final and critical strategy in addressing risk is the option for the participant to nominate an advocate who will work with the researcher to impart knowledge about the participant and how they can best be supported to reduce risk and engage effectively throughout the research process. The advocate will be a person who is over 18 and able to give consent. The advocate

is someone who knows the person with ASD well and is willing and able to advocate for the participant throughout the research process to ensure the participant's choices are implemented, and the risk of increased anxiety or distress is reduced. The role of the advocate will be to liaise with the researcher from the beginning of the research process to share their knowledge about the autistic individual's preferred communication methods and to ensure the researcher is aware of, and monitors for, signs that the participant may be experiencing elevated levels of stress during an interview. The use of support people who are familiar with the autistic individual is strongly recommended throughout literature on researching with the autistic community (Loyd, 2012; Milton, 2014; Tesfaye et al., 2019; Tozer et al., 2013).

Universal design strategies to support communication differences also provide significant benefits in meeting the requirement of consent necessary to obtain ethics approval. In the National Statement on Ethical Conduct in Human Research (NHMRC, 2007 [updated 2018]), the requirement of consent implies that participants will exercise the right of voluntary choice with regards to participating in a research project, and that this choice will be based on sufficient information, and an adequate understanding of the research and the implications of participation. The deficit-based model of disability reinforces underlying assumptions that the autistic individual would not understand the information provided, nor what will be expected of them during the research or the possible implications of this. As a result, it was deemed by many that a person with autism was not capable of providing informed consent to participate in research. Alternatively, a strengths-based approach that sits within the bio-psycho-social model of disability recognises the potential difficulties associated with the effective communication of information, while at the same time, acknowledging that the provision of the information in a format that is relevant, easily accessible and well supported, ensures the individual is able to provide informed consent (Loyd, 2012).

Strategies specific to the provision of informed consent again provide a range of options to address the diverse capacity of autistic individuals. These options range from written consent forms for young adults over the age of 18 who are able to provide consent, to verbal assent that will be re-negotiated with the participant after consent is obtained from the young adult's legal guardian or carer (Loyd, 2012; NHMRC, 2007 [updated 2018]). All documents related to informed consent, including consent forms, assent forms and participant information sheets are made available in a range of formats including audio recordings, written documents and documents using visual or pictorial information. Consent, or assent, depending on the context

can be provided through either written, verbal or non-verbal agreement (NHMRC, 2007 [updated 2018]).

A key strategy employed in the stated research project was the co-construction of the participant information sheet involving the researcher, the participant, and their advocate. The participant information sheet is the means by which the researcher provides information about the research project, and the ways in which the participant will be involved, including the benefits and risks of participation (NHMRC, 2007 [updated 2018]). Given the underlying basis of working with each participant to adopt strategies to support their participation, the provision of a single information sheet was not appropriate. Rather, an outline of the research project that allowed for the inclusion of strategies specific to the individual was deemed as more appropriate, and more likely to meet the principles of universal design. Thus, prior to collecting data the researcher and advocate would spend time with the autistic individual, learn about their preferences, and design an information sheet based on this information which will then be provided to the participant. In particular, information relating to the number, time and place of interviews, the preferred communication styles, and the support services that could be accessed if the participant experiences distress throughout the research process, were included on the information sheet during the process of obtaining consent.

Conclusion

Throughout this chapter it has been demonstrated that disability, and in particular autism, cannot be reduced to either the experience of impairment or the experience of social and environmental barriers. Rather there is a need to acknowledge the role that both play in the discourse of disability, and the impact this has on working with autistic people in educational research (Gallagher, Connor & Ferri, 2014). The use of universal design principles throughout the research design process have been suggested as an effective technique for developing research that supports the participation of autistic individuals. More specifically, universal design strategies that have been used to address the ethical concepts of benefit, risk and consent have been shared with the hope that more researchers will be confident in obtaining ethical approval for research conducted with individuals from the autistic community. Furthermore, researchers who work with all people who experience disability, can modify, build upon and improve such strategies to further empower those marginalised through disability and generate productive and transformative outcomes for these educational fringe dwellers.

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