



Listening to the Voices of Students with Autism Spectrum Disorder – “When you are at school, you have to behave in a certain way”

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ABSTRACT

Models of special education that are diagnosis-orientated mean that individuals with ASD are seen as ‘different’ from their non-disabled peers. These views reproduce school practices in which those labelled disabled are likely to be treated as problematic rather than ‘coming from a different place’. This article explores the narrative of one Year 9 student with ASD and his understanding of his identity as a learner and his sense of belonging and friendships at school through a double hermeneutic approach. In it, the observations of the researcher and the professional relationship they both have, as well as the collaboration and engagement with the student at the time, are intertwined. The narrative reveals something of the continuous amounts of resilience and determination that students with ASD must draw on so to participate successfully in school life. The article suggests that mindfulness on the part of teachers is needed in daily interactions to fully-support agency and well-being in this student group.

Research paper

Keywords:

autism, student voice

INTRODUCTION

Historically, much of the research surrounding autism/ASD has focused on identifying aetiologies and generating therapeutic interventions (Nadesan, 2005). These characterisation often locate ASD in deficit-based perspectives, mostly situated within a medical model view (Broderick and Ne’eman, 2008). In these views, the locus of the disability lies within the person. The definition of ASD below is a typical example of this manifesting-within-an-individual idea.

... [ASD is] a clinically defined behavioural syndrome that initially manifests in early childhood and is thought to reflect underlying neurodevelopmental abnormalities. Core symptoms of autism include abnormal or unreciprocated interpersonal and emotional

interactions, disordered language and communication, and repetitive and stereotypic behaviour... (Sparks et al., 2002, p.184)

The difficulty with this view is that diagnostic processes used in clinical settings rely on practices of behavioural interpretation based on a qualified specialist’s clinical judgement. The kind of language used in this process - such as abnormality, disease, disorder - reinforces the view that the individual is to be considered deficient in some significant way/s. Such descriptions serve as gateways to social stigmatising and marginalisation, while also posing significant issues around identity construction for the person concerned (Bagatell, 2007).

Medicalised views of ASD are now being challenged by a growing number of different opinions about the meaning and function of ASD-related behaviours. Members of the autistic community themselves argue that ASD is not necessarily a disability, and that there are both advantages and disadvantages to the condition and the differences current ASD prognoses identify (Lalvani & Broderick, 2013). For Connors and Stalker (2007), the ASD identity should be grounded in the notion of surplus/excess in certain areas rather than characterised by inferences of deficiency/lesser. Some ASD advocates prefer that ASD be regarded as a unique culture through which underlying standards of normality, deviance and other particularities that require understanding, acceptance and advocacy become salient (Silverman & Hinshaw, 2008). Such alternative views are important as they build on the idea of ASD as essentially ontologically ‘different’. Whether any of these descriptions of ASD fully capture the essence of this way of being in the world, the fundamental issue remains: when an individual is attached to a label, diagnosis or disability, some kind of ‘master narrative’ of the individual is often developed (Syed & McLean, 2016). This storyline supersedes the individual, thus constraining individual agency in the production of identity, often by limiting individuals to a certain range of socially – sanctioned and deficit implicit stories.

Inclusive education policies have now been advocated for almost 30 years and there is a global trend of placing students with special educational needs (SEN) in mainstream, inclusive educational settings (Woolfson & Brady, 2009). In education, models of special education that rely on processes of identifying and then smoothing out the barriers to inclusion that a diagnosis of ASD presents (Dillon, Underwood & Freemantle, 2016), ensure that individuals with ASD will not enter educational spaces under the same auspices as their non-disabled peers. As an example, after a five month observation period in one primary school in the UK, Wood (2018) concluded that many teaching staff showed an allegiance to an 'impairment narrative of ASD' when teaching students with ASD. This researcher suggested that this perception diminished possibilities for full acceptance by the teachers of what the ASD students themselves could offer. Similar challenges for ASD children in regard to inclusion in New Zealand have also been highlighted by Kearney and Kane (2006). In an earlier piece of research, these authors suggest that dominant attitudes held by teachers towards inclusion mainly stemmed from traditional ideas of special needs. They found that children who were viewed as disabled were more likely to be described as challenging or presenting with problem-orientated dispositions. As Fisher and Goodley (2007) propose, it is important to reflect on how the meanings of a label/disability are constructed as these impact on the provision of support that the student will receive.

Inclusion in New Zealand

Due to the interpersonal areas in which ASD is salient, many teachers continue to be challenged in the classroom by the presence of students with ASD-related responses. Able et al., (2015) note that many teachers feel untrained or ill-equipped to manage when ASD-related behaviours manifest. However, Dillon, Underwood and Freemantle (2016) believe teaching styles having a vital impact on ASD student's success at school. The importance of the nature of the relationship forged between any student and their teachers is paramount, with teachers who are trustworthy and interested in student-earning experiencing the greatest degrees of success (Hughes, Bullock & Coplan, 2014). In this regard, practices of inclusion of students with ASD also appear to be influenced by more traditional special education paradigms which define individuals with disability/difference and impairments as negative or undesirable. Thus, while contemporary policies and practices continue to locate the 'problem' of disability within an individual who must be assisted to 'fit in' to educational settings pre-designed by able-bodied others, these difficulties will continue (Oliver,

1996). It is vital for teaching staff to recognise how an inclusive ethos in schools that goes beyond the idea of mitigating the problem can significantly improve the experience of all students (Dillon, Underwood & Freemantle, 2016).

THE STUDY

Ethical permission was gained from the Faculty of Education Ethics Committee (FEDU 021/18) to interview four Year 9 students who have a formal diagnosis of ASD. The study was guided by three key areas of interest:

- The possibility of working from an 'alternative view'/perspective. How might listening to the stories from someone identified with 'difference as ontology' become a valuable source of information to learn about the educational lives of young men with ASD? Could this way of thinking support teachers to forge relationships that lie *beyond the diagnosis* with students with labels of difference/disability?
- Identifying aetiologies and generating therapeutic interventions often position individuals with ASD in deficit-based perspectives (Nadesan, 2005). How have attempts to include students with labels that can create marginalisation/stigma impacted on students enrolled in the New Zealand High School system?
- What possibilities might surface from a project that prioritised listening to the voices of young men with ASD?

Motivation for the study came from the first authors own personal and professional experience with ASD.

1. Personal Experience

"In 2005, approximately 14 months after the birth of my first son, I had my first encounter with ASD. At the time I was not conscious of this, instead I thought I was a bad Mother with a child who was not developing in the right way. As I recall, I was faced with the dilemma that my son did not respond when you called his name, yet I was aware he could hear perfectly well. After an initial consultation with my general practitioner, who advised me to think of 'normal development' as something that needs to be placed on a very long continuum, I was told to go home and to try not to concern myself too much. I left the office with my son thinking of nothing else. Things though, were simply not falling into place ... In 2007, I entered the world of psychologists and clinical assessments. This phase of 'discovery' carried, like a double

edge sword, both hopes and fears. The hope, a diagnosis to provide clarity and understanding of the 'wrongness' or 'deviation from the norm'. The fear, permanent life-changing news and an unknown story of what was to come. It was a story of a life as a mother I had not expected and it was a place I was totally unprepared for. As I take myself back to the diagnosis, this was my first experience of accepting and understanding ASD in a way that was personally affecting for me rather than 'other' from me. I end my personal story, letting the reader know the little family of two grew to four. Three boys and one girl. Two of my sons carry labels of difference (first and third) in the diagnosis of Autistic Spectrum Disorder..." (Basel, 2018). [1]

2. Professional Experience

I have been a teacher since 1997. Initially, I trained in physical education and psychology. Throughout my practice, I have attempted to build a repertoire of skills to enable me to reach all children. Especially those who learn differently. Currently, my role is Head of Learning Support in a private school. My professional work as a teacher with students with ASD has taken many directions over the last 5 years. With interests in psychology, my attention [initially] concentrated on the processes of diagnosis and early identification. More recently, I have trained as an applied behaviour analysis (ABA) therapist with the view to supporting individuals to learn and participate in routines and regular classroom expectations. As I began to see some of the limitations with ABA in the classroom, I began to pay attention to the use of individual education plans (IEPs) as a way of supporting individuals to access inclusive education experiences. It is through this work that I have come to know the power of developing relationships. This process enables unique understandings of the individual, better supporting them to be agents of their own learning. This is, however, in opposition to (some) IEP processes I have witnessed in other schools. There are times when discussions and decisions about an individual may be carried out with their support team (parents) and their teachers in the absence of the student. It is through a combination of my work with IEP's and teaching that I have come to realise relational practices with students and their families will enhance levels of engagement and provide greater, superior levels of curriculum achievement for the individual... . A further, significant learning in my role has been in relation to labelling and identifying ASD has

taken place. I now have a broader insight into the concept of stigma, the practices of stigma and its effects throughout our communities What I have found is that the benefit labels can bring regarding the development of shared understandings, though sometimes useful, can also bring about unwelcomed and unthoughtful responses that include oppression, distancing and disabling practices" (Basel, 2018).

THE METHODOLOGY

The research project this article reports on was sited within an inclusive standpoint perspective so to ensure that the fieldwork environment would allow participants to feel recognised as students, and their contribution valued. Thus, while students were asked to participate because of their ASD affiliation, at no time were questions about this factor put to students during interview sessions. A repeat interview method was employed to explore various aspects of participants' school experiences from their point of view, and designed so that the young men concerned could take up a position of expert, with insider knowledge of their own experiences of learning as a student in a high school setting. Participants were asked to comment on their engagement in school in terms of their learning, how they identified themselves within the school body, and their sense of belonging within the school environment and their friendships (MacArthur & Rutherford, 2016). Guided by the first author's personal and professional knowledge of students with ASD experiences at high school, three avenues for inquiry were developed for each interview. These included: the process of transition (How did these students experience this change?), classroom learning experiences (How do the students experience their learning?) and developing peer relationships (How are their friendships established and maintained?).

Research decisions made regarding how best to interpret the experiences offered by participants involved reflecting on the idea of using a double hermeneutics – an approach where the researcher 'strives to operate in an already interpreted world' (Cohen et al., 2007, p. 26). As Presser (2005) observes, within a double hermeneutic, "the researcher's goal is not to emancipate the authentic story of the narrator – none exists – but rather to expose as much as she can of the relations that influence the construction of the story that is told" (p. 2087). Thus in the stories that emerged from the interview data, the observation of the researcher and the professional relationship she had with them, as well as the collaboration and engagement with the students that took place in the interview moment, are intertwined. The second half of the article includes

the narratives that emerged from the three interviews undertaken with Student A, a Year 9 student in his first three months of high school.

INTRODUCING STUDENT A

A is first generation New Zealander, with both parents coming from different parts of the world. He is the oldest of four children, with one sibling also carrying a diagnosis of ASD. My work with A is usually in the role of advocacy, supporting his teachers to look beyond the label and to find ways for A to be able to develop his abilities. Demonstrating abilities is not always easy as A also has dysgraphia. At school he is in the accelerant class, an achievement he proudly shares with me on our first meeting. In addition, he reported to me that his maths and reasoning scores rank in the top 10 percent in his cohort. During the interview process there were no outward signs of being over-stimulated by the questions and we were comfortably able to stay with the main interview script.

Interview 1

A and I settle ourselves into the classroom and the interview environment; we are able to get straight to the main question. *"Is it okay to talk about your experiences of transitioning to high school?"* I ask. *"They have been successful,"* he says, but admits that initially things were much more touch and go. *"I felt like I wasn't gonna make it really Yeah, I didn't really think I'd be here now [...] I've needed to adapt [...]".* A's account of transitioning was heavily influenced by learning how to manage the regimentation of the school day. At first it seemed very strange to him. *"We have this house period [...] then after that we just then kinda just get stuck into the periods [...]".* Routines and structures were a significant feature throughout our discussion, however he also spoke of the need to adapt to the speed of the changes and knowing where he was to go next as areas of initial difficulty. *"You have to rush [...] I've needed to quickly check what period it is [...]".*

A's conversation highlights the challenges of the educational institution and how traditional practices and spaces (e.g. structured timetables, roll call, interval, etc), direct students to a 'one-size-fits-all' approach, providing little opportunity for those with differences to develop alternative practices. However, A did his best to come up with ways of navigating the challenges presented by tradition. *"You have to rush [...] I've needed to quickly check what period it is [...]".* Fortunately, A quickly found a way to learn the rhythm of the school day and he developed a method of keeping up. The solution he describes is typically twenty-first century adolescent, *"So to adapt, I put the timetable on my phone. I just look at my phone".*

Initially, when A was asked about friendships, he inferred they happened 'outside of school'. A mostly chose to speak about old friendships made prior to high school. Interestingly, he mentioned the behavioural requirements of school life as a constraining factor to his ability to making new friends. This suggests that trying to make friends in-school might have been (more) difficult for him, *"... because when you are at school you have to behave a certain way but when you are not at school then you do not have to behave a certain way".*

A and I stay on the topic of friendships for a little while. He reveals a number of interesting insights as well as key suggestions for the institution to assist, and how the school might go about removing some of the constraints he found. A suggests a possible alternative approach to developing friendships could involve meeting earlier outside the school grounds *"in a different environment, maybe [...] like [name of park]- that's always a good place to start [...]".* In this environment, he suggests, *"You just behave how you want to ... In their natural way... you know, the green grass and all that stuff. It's nice to have nice surroundings".*

A and I finish our discussions about peers and we move to settling into the classroom, and what it has been like to be in the accelerant class. A explains to me that each teacher is different and how the teacher expectations of the accelerant class has created some unease around his learning. A comments on the need to stay away from *"off topic questions"*, that friendships in the classroom environment are not easily sought. *"Yeah, I kind of focused on the good band but now I realise it is the good class ...".*

From my work outside of the research with A, I was aware of some of the challenges he had been facing in the accelerant class. There were a number of issues we had spoken about, however A chose to share with me how he had been paying attention and contemplating how to plan and manage what it was he needed to do with 'the work'. *"Yeah, I manage my homework at lunch times ... that's kind of not so hard since Week 7 ... it's not a good effect really because I don't like being pulled away from my friends ... but I get it done".*

In response to the use of lunchtime for homework, A reveals he has thought of a little plan (friendships are an important part of school life. A admits he has been struggling with them). He has been finding time and space for this outside of class time during morning tea *"... I sit and talk to my friends where every Year 9 has to sit ... near the door".* A and I concluded our first interview at this point.

Reflection

The issue of adapting to a new high school was raised in several ways throughout the conversations with all students. Clearly, transition is a complex process in which the determination of the student to be successful is paramount. As I listened to Student A's story, I could hear him express an overwhelming desire for friendship at the new school. However, he realises the challenges faced in making new friendships for everyone and is able to insightfully suggest a new way to support individuals to 'behave in their natural way', suggesting this as a better opportunity for everyone to get to know one another.

Interview 2

Keen to find out if A would be willing to share some of his experiences in the classroom, we begin the second interview with a discussion of subjects on the timetable. At A's school there are eight different subjects, with six subjects on the daily timetable to attend as well as a chapel service, house period, assembly or a mentor group. A decides to talk about three key subjects: science, physical education and French. They presented vastly different experiences for him. We begin with science.

"In science [...] you do need to do a bit of listening [...] they create a slide and you copy it [...]". As such, perhaps stereotypically, this appeared to me a compatible style of teaching and learning for a student with ASD. However, this particular style did not appeal to A *"Um, you can't ask off-topic questions [...]"*, he replies. A is not the only one who may be struggling with 'off-topic questions'. *"People do it (off-topic questions) like once every seven weeks [...]. The teacher just shuts the question down sort of thing. [...] The teacher said, 'No, I'm not going to talk about it, no'.* Student A's dialogue indicates there is perhaps limited opportunity for him and the others to explore, practise and perfect their skills of inquiry.

A then moves to a subject he does not enjoy. *"In PE... [...] I don't enjoy the learning [...]. Like if someone yells out, 'No, I don't like that' [...] I feel like walking away from the subject [...].* I enquire as to why he does not like physical education *"Oh, I don't know, sometimes they get a bit competitive and sometimes I say what, that's not possible, Play fair [...]"*. He mentions his understanding of how he sees his position and how to transform this less-preferred 'neuro-typically dominant' environment into a counter-narrative of resilience. *"I'm like no athlete but I think I'm alright. I just think you have to join in anyway so you just do it."* A then refers to practices that are necessary for him to be involved in the skills and knowledge required for learning this

subject. He reveals a dual consciousness in his ability to express a dislike for traditional physical education yet persistence in attempting to adhere to the school rules and norms, stating: *"I don't enjoy the learning ... Like when someone yells out, 'I don't like that' ... I feel like walking away from the subject"* on the one hand. Yet, on the other, *"I just think you have to join in anyway so you just do it"*, he tells me.

A leaves his favourite subject until the very end. It is a language – French. When asked why, he responds, *"When I went into French not so much rules really [...]".* Initially, I was taken aback by his response, however he quickly identifies this as a safe space for learning. ... *"If something happens, I like to try and learn it and if I get wrong - and yeah ... I prefer language perfect ... it is competitive ... you get a certain thing right three times you get a rank up".* These remarks suggest that this is an environment where competitive teaching and learning practices take place and that this is a kind of ASD-related culturally-responsive teaching and learning environment. I am unsure if other students with ASD would agree, but this environment seemed to be offering A the opportunity to engage in preferable ways. A lets me know he likes French, *"Um I'm not sure (why) ... I like to try and learn it [...] and yeah ... [...] I prefer language perfect [...] I'm trying to compete with the guys in my class. Yeah I prefer learning that way".*

I ask A if he thinks of himself as a good learner in French and whether he felt he was able to make the most of the learning opportunities in that class? *"I don't know [...]"*, is his first reply. I wondered if this was too difficult a question, however A managed to respond a little more. *"To know that I am a good learner means that I will be learning more [...]"*. I quickly reply with another question ... *"Do you think good learning is happening in French?" "Good learning [is happening when] the teacher isn't prejudiced [...]. I don't think Mr ... (French Teacher) is prejudiced. Yeah I don't think he's... . Is sexist the word I am looking for? I'm not sure [...]."*

It would appear A can quite clearly identify when he can learn well and when he is being presented with (other) challenges, and that he is working hard in his own way in all of his lessons.

Reflection

The conversation between A and I explored three very different subjects. He was able to clearly identify when he is provided with what he considers an appropriate space for learning, and that in these spaces he is able to be very successful as a learner. Unfortunately, some of the experiences he describes

suggest he is not always able to access the most effective and worthwhile educational experiences for him. Admiringly, in the physical education class, A has developed a steely resolve and an ability to 'just do it' and, as such, the similarity between himself and at least some others in his class is established.

Interview 3

A begins our conversation by reflecting on his peers - *"I don't think it is helpful to my learning when there are other kids around"* he said. I ask him, "What has led you to think about working with your peers in this way?" His initial comments cohere around how negotiation of emerging identities and behaviours are handled amongst his peers. *"You get quite a bit of kids who like to get attention [...]"* he remarks. He cites a particular example: *"One of the kids tried to be funny and then make a noise or something [...] Or say they drop their rubber - distracts you [...]"*. Sometimes the challenging behaviour is directed at him. A really does not like this. *"One time the kid had knocked my paper [...]"*. He admits, *"I get annoyed. I say don't do that [...]"*. However he is conscious of how far he can go in voicing his objections in this environment. *"I don't want to cause any fights"*. I can see how unsettling this is for A but we stay with the story a little longer. I ask, "In what ways is this behaviour most challenging?" *"Everyone else falls off-task [...] it means you are wasting time when you could be learning [...]"*. A and I did not get to elaborate further on what 'wasting time' meant, however I found this story an intriguing account of social engagement with the institution, yet not necessarily with his peers and with the dominant school-boy culture of his particular high school.

A shares with me that he has a plan, a counter-narrative of survival. The identity he claims is a safe, smart learner and the plan is, *"You ... be quiet, stay low, don't say anything. If no one notices you they won't annoy you"*. A has a clear sense there are injustices and power relations operating within the classroom. Clearly, too, he rejects dominant 'neuro-typical' behaviours from his peers. I found this plan both remarkable, yet also sad. Without wanting to probe too far, I ask A what happens when he finds peer behaviour challenging. He says:

A: Just talking to a family member that I trust [...].

Researcher: Do they offer good advice?

A: Nah, they are just people I feel comfortable talking to.

Comforted, A has an outlet; we both acknowledged the importance of reaching out and sharing with others. We conclude our conversation with a

question drawing on insider knowledge and hopes that would offer a position of agency regarding his experiences as a student with ASD. "After talking about your experiences with me, do you think you would ever be able to give advice to others students with ASD?" I ask. *"I guess,"* he replies. "What would it be?" He responds, *"Best advice not to speak [...] Yeah lay low until when you know what others attitudes are like [...] then you do not lay low, then you can stop hiding and start being social [...]. If no one notices you they won't annoy you [...]"*.

A has identified a plan to get around the challenges of school life and a way to convert obstacles into opportunities so that he can become a good learner. I wonder what it must be like for him to refuse the invitation to join in the normalised practice(s) expectations of his school: to try and negotiate how 'to play fair' while others 'fall off-task' while also negotiating his ASD label. What might it be like to display yourself as a student in a different kind of way, an ASD way, that could help others to also be social in ways that are different?

Reflection

A's hopes to establish himself as a learner in the classroom have been shaped by the way he employs his stay-safe plan. This suggests A has spent time having to respond to comments and actions of non-disabled others. This strategy suggests this kind of discrimination can occur for a variety of reasons, including negative stereotypes about disabled children or children classified as 'other' (Ellman, 2012). Yet there is a cleverness in how he knows to draw less attention to himself to limit opportunities of being bothered/affected by others. Thus, he can focus on the things that are important to him, he can keep safe, and he can continue to be the good student that he wants to be.

CONCLUDING DISCUSSION

The narrative this article contains provides the reader with a window of insight into how students with ASD engage with the structures, relationships and practices that shape their school day in a Year 9 high school. All were able to reflect on, and respond to, current practices in regard to both teachers and peers, and how these practices affected them. For all participants in this study, teaching styles were reported as a significant area that affected their engagement with what was required of them. As the narratives showed, when teaching practices adopt a relational manner, with consideration given to the students and their individual interests and needs, students with ASD are able to share in enjoyable school experiences in a manner that is very similar to the experiences

of their non-ASD peer group. Findings from the narratives also revealed that students in this group are being asked to draw upon continuous amounts of resilience and determination to participate well in school life. Carefulness is needed in day-to-day interactions so to support agency, well-being and successful practices of inclusion for the students concerned. In saying this, it is also recognised that the high school experience contains complexities for all Year 9 students and adapting to the new environment is something that ontologically 'similar' students also have to contend with. How difficult this might be for at least some Year 9 students whose (non-disabled) 'master narrative' is secure is hinted at in Student A's descriptions of aspects of daily life in his class. At these times, should the additional support and care offered to students with ASD be available so they too can become the good students that they want to be? Further research to explore this question is needed.

Notes

1. A full copy of the dissertation is available from the first author on request.

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