

An Ethnography on the Experience of Autistic Children and their Families in Scotland

By Molly Paechter

Introduction

I am the older sister to an autistic brother. My brother has just turned 18, has a job in outdoor education, and is one of the most insightful, caring, and intelligent people I know—I have no idea how we got here. Well, maybe I do; on the back of some hideous discrimination and abuse my brother encountered in his early education. His life was saved by people who may not even realise how much they changed things for us.

Thus, this ethnography explores the experiences of autistic children in Scotland's educational system by exploring the attitudes and approaches of the professionals who represent the institution of education and the real experience of families with autistic children. The importance of social validation in the ownership of discrimination experience will be further explored as a central theme.

My brother was profoundly let down by the educational system in Scotland. This as well as my experience working as a Pupil Support Assistant in a special education school and later as a playworker in an integrated environment, comprises my personal motivation for this ethnography. Supporting children and young people with extremely complex behaviour and

emotional differences led me to question the gap between words and action in relation to children with disabilities.

Methods and Ethics

I'd like to preface by saying if I had been working with a longer timeframe for my research, participant observation would have been a better suited methodology. However, given my circumstances, I determined that interviews would be the most appropriate way forward. This decision was informed by my previous work in educational and play work settings that highlighted not only the different approaches between the various institutions, but also the daily nuances within the institutions. With this in mind, I conducted interviews with professionals who work with children of all abilities, parents of autistic children, and autistic people.

Most interviews began with me presenting two scenarios (see appendix A and B). These were fictionalised scenarios, although they were based on real situations. These scenarios give an idea of the tone of the interviews, but also show the reader examples of more subtle forms of discrimination.

Everything presented here is anonymous; names have been changed and I have not interviewed any children.

My Turning Point

A turning point in this research came after interviewing some of my professional informants. I had intended to analyse the gap between training, policy, and practice. However, I found that when a professional is presented with these scenarios, they answer with seemingly inclusive answers. It was clear that they were mindful to not answer in a way that could be classified

as discriminatory. Noticing this, I tried asking when they had seen examples of bad practice but again received elusive answers with little substance.

Nevertheless, I got a much clearer idea of what happens every day in play work and educational settings when I interviewed parents. Parents, having experienced multiple institutions, such as schools and out of school care, provide a good overview of how inclusive these spaces really are. Additionally, parents have a vested interest in real inclusion, whereas professionals appear to first and foremost care more about the appearance of inclusion.

I have purposefully not included ethnographic data of the professionals because of this; however, I would like the reader to keep in mind their partial responses. This is important as the first two parts of this ethnographic report show the difference between people who believe they are acting in inclusive ways and the reality that families experience.

All of the experiences discussed here are those of parents and autistic adults as I felt their responses were more representative of real practice. It must be noted that each experience discussed is not unique – each form of discrimination was repeatedly discussed in interviews. I have chosen to only focus on a select few interviews in this piece, to give each experience the justice it deserves.

Defining Discrimination

Discrimination is defined in various ways in anthropological discourse and most definitions go further than what the UK government describes as discrimination (Reid-Cunningham 2009: 101). For the purposes of this report I am choosing to use the legal definition of discrimination. Adhering to this official definition allows

the findings of this ethnography to remain valid outwith the realm of anthropology.

The Equality Act (2010) includes disability as one of the nine “Protected Characteristics.” There can be “Direct Discrimination” of disability and “Indirect Discrimination.” For example, if a pub prohibits people with disabilities to order drinks, this would be characterised as direct discrimination. On the other hand, indirect discrimination would be if the pub gives a drink to the first person to reach the bar, which might put physically disabled people at a disadvantaged. Disability is the only characteristic that has two additional special provisions within the Equality Act. This includes the requirement to make reasonable adjustments for disability, and the particular act of “Discrimination Arising from Disability.” The legal definition of “Discrimination Arising from Disability” is as follows:

“Section 15

(1): A person (A) discriminates against a disabled person (B) if:

(a) A treats B unfavourably because of something arising in consequence of B’s disability, and

(b) A cannot show that the treatment is a proportionate means of achieving a legitimate aim.

(2): Subsection 1 does not apply if A shows that A did not know, and could not reasonably have been expected to know, that B had the disability.” (“Equality Act 2010” 2019)

Even with this legal definition, discrimination of children with additional support needs remains ambiguous. Footnotes will be used throughout the report explaining how each experience

discussed shows discrimination by this definition, and therefore is unlawful discrimination.

The Universal Human Right to an Education

“ ...

She has the Universal Human Right not to be raped.

So she walks to work at night

And frightened as he grabs her paper sleeve and slaps her face, rips her paper pants apart and

Disgraces her, she slumps against the wall, pulls up her paper skirt and matches up the words,

Ripped up pieces of her paper pants which say:

‘You have the Right not to be Raped’

But she is safe.

She has the right to education. But her paper school just blew away.

...

But she is fine.

Lying 10 feet below buried safely under brand new copies of the

Universal Declaration of Human Rights.”

Papers by Hollie McNish (2012)

Katie is playworker, Pupil Support Assistant in a mainstream school and an autistic woman. We sat in the kitchen of her workplace to get away from the chaos of the playroom. We were responsible

for watching the gingerbread men made by the children that afternoon that were cooking in the oven (by the end of our conversation, we realised we had let them burn by accident).

We started talking about Katie’s wealth of experience, eventually discussing the disparity between the appearance of inclusion and real inclusive practice. Katie talked about how the treatment of autistic people in educational settings has followed a similar trajectory to other protected characteristics. Autism was once largely taboo yet is now being celebrated; however, it is now discrimination that has become taboo.

Katie argued that the point we are at now is just as damaging. Celebration of neurodiversity and pressure for educational institutions to be fully inclusive has not given us acceptance and inclusion, but rather a false image of acceptance and inclusion. Katie described how the mainstream school that she currently works in boasts about their inclusivity because they have an autistic pupil. They were so proud to include an autistic student that they even included it in their weekly newsletter to parents. Katie is occasionally responsible for looking after this boy. She described a typical school day for him: ‘He arrives at school, punches me in the face and plays with Lego for the rest of the day.’

Seemingly, the school does not even attempt to give this student an education. They use the presence of the child within the school walls as evidence of their inclusivity. However, by not providing any appropriate provisions they are denying the child the right to an education—because of his disability.

The denial of this human right may be down to the lack of useful, directive action

in human rights policy. Anthropologist and physician, Paul Farmer argues that the Declaration of Human Rights (including the right to an education) is redundant when there is no active movement to translate these rights into articulate demands (2005: xxv). Human rights are just empty promises when we lack the resources to provide them. The actions of this school serve as an example of an institution attempting to portray an image of inclusivity, whilst not making any real change nor upholding the rights of the child.

Hence, it is understood that every child has the right to an education and, it has been demonstrated that this right is often compromised for children with additional support needs. Katie's story shows how schools preclude any real inclusion by deeming it sufficient to simply include the child within the four walls of the school. Farmer emphasizes how easy it is to not provide these rights when the rights are not underpinned by an explicit obligation.

Illusion of Inclusivity: The Community

The pressure to be inclusive is not just felt by educational institutions but by the wider community as well. I met with Heather, I know her son, Luke, who is autistic. In the past Heather and I have often spoken about autism, education and discrimination. We met to discuss this project and she described an incident last year when Luke had a meltdown and assaulted two teachers, drawing blood.¹

Heather described how the local community responded to this event. She claimed everyone was very, very kind. Friends sent her letters and chocolate, and someone even left a batch of fresh eggs on her doorstep. One close friend offered to get all the other parents together to write

a letter to the local authority, advocating for Luke's transition to a special school in the area. I could sense Heather's anguish, then and now, to this kind of response. It is subtly implicated that Luke should be sent away because of behaviour arising from his disability. Her perhaps well-meaning suggestion can be interpreted as "out of sight, out of mind."

Presumably the parent does not think of herself as being exclusive. However, her suggestion that Luke be removed from the school community because of his disability reveals underlying misunderstanding and prejudice. This strengthens my argument that the illusion of inclusivity can exist, even when the reality is not at all inclusive.

Anthropologist Cristina L. Ortiz discusses the illusion of inclusion in relation to race relations at a rural school in America. The school had explicitly committed to racial inclusivity in its mission statement. Accordingly, white parents believed that they had achieved the goal of inclusion. However, Latino students reported that they believed their inclusion was conditional to their assimilation of American culture within the school and wider community (Ortiz 2016: 265).

Using Ortiz's ethnographic findings, it is evident that to gauge inclusion it is essential to analyse the lived experiences of people with protected characteristics. In addition, claiming to be inclusive is not enough. Institutions must be critical in the way they approach and enact inclusive practices, if they are to be effective.

The Importance of Social Validation

Aside from the discriminatory practices in schools and communities, another key theme that manifested as I spoke with families is what made the pain of discrimination subside.

¹ This may sound shocking, but for people who know autistic children, this can be quite common behaviour. Imagine that something is causing you enormous distress or fear and you cannot communicate this verbally to the adults around you.

I spoke to Ruth, about her 8-year-old son, Sean's, experience in education. Sean does not have a diagnosis but is suspected to be autistic. We talked about many distressing experiences Sean has been subjected to in school. During our discussion of one behaviour strategy employed by a class teacher, "The Secret Pupil," Ruth became very emotional and started crying. On Fridays all the children who had been "good" had their names put into a hat.

One name was pulled out. The chosen child would get to make a hot chocolate. Sean's name never made it into the hat. This was due to his "bad behaviour," such as not sitting down in his seat. This caused significant trauma for him. He would come home on Fridays very distressed and would be affected for the whole weekend.

This is by no means the "worst" kind of discrimination I have heard about throughout my research. Many of Sean's other challenges in school have been significantly worse. But Ruth's emotional emphasis on this specific behaviour policy made sense. Maybe it was because other issues are too personal to bring up when we are strangers to one another. Or, maybe, it is because this distress was a relentless pattern in that it occurred every week. Most likely, however, the subtlety in this discrimination is what made Ruth so emotional. The situation is not overt discrimination (and for that reason hard to fight against), rather, it suggests a massive lack of understanding, which adversely affects Sean's everyday experience in school.

The extreme emotion concerning implicit discrimination, compared to explicit discrimination, makes sense when we look at the need for social validation of a person's distressing experience. In their review of the anthropology of emotion, Catherine Lutz and Geoffrey M. White

discuss the importance of social validation. Anthropologists who consider emotion a social product, rather than a mere bodily function, theorise: 'Emotion is embedded firmly in the real by virtue of the fact that emotional judgments are seen to require social validation or negotiation for their realization' (Lutz and White 1986: 407). Thus, the emotions felt by families arising from discrimination can only be realised when they are socially validated.

My experience has taught me the importance of social validation. At the age of ten I witnessed my own brother being psychologically and emotionally manipulated and discriminated against in our primary school. I was sixteen by the time education authorities publicly acknowledged the mistreatment and neglect of my brother's needs. The feeling of elation in response to this news matched no other. Even though I watched it all happen and even though I knew it was wrong, I only started to heal once we got this social, public, and legal validation. My father described his own grief at the lack of social validation over many years:

"The very distressed autistic child was scapegoated in the community – instead of being helped. It felt as though discrimination of hidden disabilities was the one remaining discrimination that middle-class liberals were still comfortable with – some in the community just didn't realise how appallingly they were acting."

Returning to Heather's experience, the importance of social validation also proved evident. At first, the school said they were looking to permanently exclude Luke. A few days later the head teacher said that they would not as they realised that this would be unlawful.³ Following on from this, the head teacher acknowledged that they must consider

the inadequacy of their knowledge and the inappropriateness of their initial course of action. I was surprised and happy at the school's response even though this was, in fact, the legal course of action. However, it is the only example of a legal, inclusive response given by an educational institution that I heard of during this research. I am beyond pleased that they got it right for Luke. But it is Heather's reaction that interests me most. At first, Heather talked about her sheer embarrassment over her son's behaviour and anger at the parents' response. However, Heather then described how her embarrassment and anger dissipated following the school's ensuing decision.

Lutz and White claim that because emotions are tied to social validation, wider power structures, such as institutions, play a vital role in the realising of emotions (1986: 407). In Heather's case, the school's response validated her pain, which enabled her to realise and confront her emotions.

Conclusion

This ethnography was driven by a personal need to understand the treatment of children with additional support needs within the Scottish education system. The position of educational institutions and professionals I have spoken to seems to be one of inclusion. However, this is not evidenced by the lived experiences of families who face regular misunderstanding and unlawful discrimination.

The gap between the practices exhibited by educational institutions and families' experiences and opinions of inclusion (or lack thereof) has been demonstrated. The anthropological theories discussed point to a lack of articulate demands in ensuring the protection of human rights and a

culture of false inclusion, placating those who do not feel the negative consequences of discrimination.

Ethnographic evidence shows that the acceptance of emotions arising from discrimination is reliant on the social validation of the discrimination. This social validation is tied to the power structures in society and the role of institutions.

The experiences collected could be more fruitful had there been a longer time frame for the research. Going forward, I think the issues raised here absolutely have a place in anthropological research. The implications of the two key findings could be used to influence both the creation of policy protecting children against discrimination and to provide effective support strategies for people who have experienced discrimination.

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APPENDICES

Appendix A

Scenario 1: 'It Works for Him'

I have a friend who is a playworker. One day during the holidays, she and her boss were taking a group of children out to Pizza Hut to make their own pizzas. One of the children had ADHD. The children were all lined up waiting for their pizza dough and they were told not to touch any of the ingredients. The boy with ADHD put his hand in a bowl of olives, picked up an olive and put it in his mouth. My friend's boss then shouted at the boy and put him under 'time out' so he was sat away from the other children, not allowed to talk to them and not allowed to eat his pizza.

What do you think about the teacher's response? Do you think it's discrimination?

Then carry on with the story: when they were back at the youth centre, my friend gets to ask her boss about the incident. She explained that she was told in her training never to put a child with additional support needs in isolation. Her boss replies with something along the lines of 'oh I know, but it's the only thing that works for him.'

What do you think of the boss's response? Do you think her response is appropriate if it's what 'works for him'? What else could she have tried?

Then I'll explain that this is likely to be illegal discrimination based on disability. The boss should have accepted that due to his additional support need, the boy could not have followed the instructions. Therefore, she should not have responded at all when he ate an olive, if she was protecting him from discrimination.

Appendix B

Scenario 2: Inclusion at what cost?

There is a young girl who is autistic. She went to a mainstream school and this was deemed appropriate by her local authority because she was extremely smart, had good communication skills – although she did struggle with sensory and social differences. At her school she is known as a 'no-contact child' which means if she is having a meltdown, all the other children in the class must leave the room. This has only happened a few times in school before, but when she moves into primary 4, she starts having up to 1 or 2 meltdowns a day. As the whole class must leave the classroom each time, staff and parents start to question her place in the school. They all claim to be inclusive but are worried about the impact of the child's needs on other children learning.

What do you think of the story? What can the parents/child/staff do to rectify the situation? What would you advise?

Now think of another scenario: A young girl is a wheelchair user. The primary 4 classrooms in her school are not as accessible as her previous classrooms. And since moving into the primary 4 classroom, every time she has to go to and from the classroom, all the other children need to leave the classroom for her to get to her table. As the whole class must leave the classroom each time, staff and parents start to question her place in the school. They all claim to be inclusive but are worried about the impact of the child's needs on other children's learning.