

# The implications of a non-inclusive education for autistic children and young people

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## ABSTRACT

The foundation of inclusive education is that every learner has the potential to contribute positively to society. A sense of belonging to society is vital to this contribution, and to the growth and development of autistic children and young people. New Zealand has made some positive progress towards inclusive education, with some education institutes understanding that all children have the right to be educated and to receive the best possible education they can, regardless of ethnicity, culture or disability. However, research indicates that there are still barriers to inclusive education, and these barriers have drastic lifelong implications for autistic children and young people. This paper outlines inclusive education, identifies barriers from the perspectives of research through literature, educators and families through a small-scale study, and discusses lifelong implications of a non-inclusive education on autistic children and young people.

## KEYWORDS

Autistic children and young people, inclusive education, barriers, New Zealand

## Introduction

The *Aotearoa New Zealand Autism Guideline* defines autism as a condition that affects social communication, social interactions and behaviour functioning, with a wide range of severity and intellectual ability. Many of those diagnosed with autism have impairments in social communication and social interaction, often along with restricted, repetitive patterns of behaviour, interests, or activities that vary in age and over time with each individual (Whaikaha – Ministry of Disabled People & Ministry of Education, 2022). There are some schools in New Zealand who are providing an inclusive and meaningful education for autistic<sup>1</sup> children that focuses on the strengths of these learners, such as visual processing, logical thinking, detail focused, strong ability to follow rules and routines, and motivation to learn through engaging high interest areas (Altogether Autism, 2018).

<sup>1</sup> The author has chosen to use the preferred language of the autistic community.

However, there are still too many schools where autistic children are experiencing exclusion (Education Review Office, 2022).

New Zealand has the highest proportion of autistic children in mainstream classes, but this does not necessarily translate to these students receiving an inclusive education (New Zealand Government, 2015; Starr & Janah, 2016). The *New Zealand Curriculum*, provided by the Ministry of Education, makes note of inclusive practice as one of the principles that New Zealand educators should abide by (Ministry of Education, 2015). There are conventions and policies that underpin this education document, and in theory, support inclusive practice. The *New Zealand Disability Strategy* is aimed at ensuring that no child is denied access to their local school because of their disability, and that all children have equitable access to resources. Article 24 of the *United Nations Convention on the Rights of Persons with Disabilities* requires New Zealand to promote access, inclusion, empowerment, equity and the right to education for all (Office for Disability Issues, 2016; United Nations, 2019). Articles 23, 28 and 29 of the *United Nations Convention on the Rights of the Child* state that all mentally or physically disabled children have a right to active participation in the community, including the right to education that has equal opportunities and the right to develop to their full potential (United Nations, 1989). The *Education and Training Act 2020* ensures that all New Zealanders have access to the skills, knowledge and capabilities needed to fully participate in the community, and support the health and well-being of all children (New Zealand Government, 2020). Despite these policies and conventions underpinning education in New Zealand, evidence shows us that there is more work to be done to implement effective inclusive education practices in New Zealand.

## Understanding inclusive education

The Ministry of Education (2010) states that “the role of education is to nurture, grow, and realise every child’s potential” (p. 1). Mitchell (2010) and Alesech and Nayar (2020) define inclusive education as students with special education needs being able to engage fully in age-appropriate classes in their local schools, and receiving appropriate adaptations and support services. Inclusive education ensures that learning spaces and activities are developed so that learning can occur together, and gives the opportunity to all children and young people to be engaged in learning by being present, participating and belonging (MacArthur, 2009).

Underpinning inclusive education is the belief that every student has the ability to make a valuable contribution to society, and to achieve this the basic human need of belonging is required for growth and development (Mcleod, 2018). When inclusive practices are used intentionally, children make academic and social gains and improve their self-esteem; neurotypical children gain an appreciation of diversity within society, and an understanding of social justice and equality; and particularly acknowledges that autistic children have a right to be educated alongside their peers as a matter of equity and social justice (Mitchell, 2018).

Higgins et al. (2008) state that inclusion requires an equitable and socially just education system that meets the needs of diverse learners. Social justice can be explained as relating to ideas of “fairness,

equity and inclusion” (Hargraves, 2021). Social justice is a basic human right, and inclusive education is an issue of this right being met. Equity assumes that people do not all begin from the same place, and therefore each person needs to be provided with what they need to be successful, based on their individual needs and abilities (Hulett, 2019). When everyone is treated as though their diversity is a strength, it eliminates issues of inequity, intolerance and discrimination (Hargraves, 2021; Kearney, 2009; Ministry of Education, 2014).

## Methodology

The data for this study was collected through an anonymous online survey and gathered educator and whānau voices around personal experiences of non-inclusive environments for autistic children. Participants needed to either be a whānau member or an educator (educators included teachers, teacher aides, and specialists such as speech language therapists) with experience of autistic children and were found through social media advertising across New Zealand. The purpose of the survey was to gather data from participants about what their perspectives were in relation to their understandings of inclusive education, experiences of barriers to inclusion, and possible lifelong implications of these barriers.

Responses were received from 41 educators and 10 whānau. Data was analysed with both whānau and educator responses, using Google Forms. Whilst this study was deemed to be low risk and therefore did not require formal ethical approval, ethical considerations were taken into account. These included ensuring that participants remained anonymous when completing the survey, participants being allowed to withdraw their responses by not submitting the survey, and data being deleted within a three-month timeframe from the completion of the survey.

## Findings and discussion

This study focused on the lifelong implications of a non-inclusive education for autistic children. The findings are discussed with links to wider literature, with the following themes being identified: barriers to inclusion, and the lifelong implications of an non-inclusive environment.

### ***Barriers to inclusion***

While New Zealand seems committed at policy level to inclusive education, practices often fall short (Education Review Office, 2022). We are now reflecting in 2022 on how inclusive education, while coming a long way since the *Special Education 2000* policy, still has areas of concern for autistic children and young people (Alesech & Nayar, 2020; Macartney & Morton, 2013; New Zealand Government, 1997). Throughout literature and educators’ perspectives and whānau voices, the main barriers were identified as being: (1) the attitudes and beliefs of the teachers, with views of autism often stemming from a medical model of disability; (2) limited knowledge and understanding of autism and what inclusive practice is, often due to insufficient training and professional development for educators; and (3) limited access to funding for this specific training and development (Alesech & Nayar, 2020; Goering, 2015; Kearney, 2009; Kwari, 2020; Macartney & Morton, 2013).

The study undertaken showed that 60% of participants (out of 51 educators and whānau) identified deficit views as a barrier to inclusion. One educator commented that they felt “inclusion is not valued, and some feel as though it doesn’t affect them”. A parent mentioned that “there is frustration and grief over what my child is experiencing at school. He is missing out on everyday experiences because they don’t see him as being capable”. The medical model of disability conceptualises disabilities as a disadvantage. It focuses on disability being a biological product, and that the person has deficits and therefore should be fixed, which then allows the person to function in society (Jenson, 2018). Autistic children are often perceived as being disobedient and defiant, rather than their emotional and behavioural symptoms being seen as part of their individual needs and sensory sensitivities (Goering, 2015). If children are seen as needing fixing, then this belief does not lend towards teachers being effective with inclusive practices (Goering, 2015; Higgins et al., 2008; Kearney, 2009; Starr & Janah, 2016). Kearney (2009) and Reagan (2012) both identified that teachers were found to hold low expectations of autistic students due to the underlying belief of their deficits and viewing them within this medical model. In a study conducted by Guldberg et al. (2019), it was reported that autistic children were aware that their own difficulties with relationships and communication could be an issue, and this combined with limited teacher knowledge of autism was a barrier that affected their right to an inclusive education.

The results of the study showed that 72% of participants felt that not knowing enough about autism was a barrier to implementing a fully inclusive classroom, and 66% also felt that not understanding inclusive practices was another barrier. There is currently no official requirement in New Zealand for mainstream teachers to have any training in working with autistic children and young people. 41% of participants stated that a child being placed in a class with peers and being given the same opportunities with no adaptations is inclusion, which highlights the continued need for robust professional development in this area. Exclusion is not just the physical aspect of not being able to attend school, but also an inability to access the curriculum (Kwari, 2020).

78% of participants identified limited funding as being an issue. An educator commented that “lack of funding and resources to be able to provide appropriate support for the child to be involved with their peers is a barrier”. A study conducted by Reagan (2012) showed that training has a significant impact on a teachers’ comfort level and their knowledge when implementing an inclusive classroom. There are often limited funds for professional development opportunities and limited release time and/or funding for teachers to attend (McRae & Warner, 2019; Starr & Janah, 2016). Starr and Janah (2016) also recognise that waitlists for funding can be very long due. Often autistic children do not meet the criteria for the Ongoing Resourcing Scheme (ORS)<sup>2</sup> funding, and therefore they do not receive the external support required. This combined with teachers’ limited knowledge can be a barrier to successful inclusion of students with autism.

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<sup>2</sup> The Ongoing Resourcing Scheme (ORS) helps students to join in and learn alongside their peers. It is for students who have a high ongoing level of need for specialist support at school and meet the criteria. Once a student is funded, it stays with them for their time at school (Ministry of Education, 2021).

### ***Lifelong implications of a non-inclusive education***

A recent report from the University of Birmingham's Autism Centre for Education and Research identifies many lifelong implications for students with autism who do not have access to an inclusive education, and their families (Guldberg et al., 2019). For the student these include impacts on self-esteem, isolation from friends, impact on academic performance and the child feeling stigmatised. These impacts fit into two categories as identified by 93% of participants within the study: a lack of belonging and social exclusion from society.

It can be argued that one of the most concerning lifelong implications is a limited sense of belonging. A sense of belonging addresses how deeply individuals feel included, accepted and supported in social settings (Pesonen et al., 2015). Students' sense of belonging in the classroom and within their peer group can either be supported or diminished within the school environment by the way the curriculum is set up and also the physical environment of the learning space (MacArthur & Kelly, 2004). Within a New Zealand context, a sense of belonging is identified as vital to children's growth and development from the early years. Belonging contributes to wellbeing and is enhanced by an accessible and inclusive education (Ministry of Education, 2017). One parent stated that "without inclusion, their sense of self is shaped by negative experiences". Another commented that "early inclusion was about placement in mainstream, with pressure on the whānau to 'normalise' the child or make them fit in at the cost of their self-esteem and identity". Not experiencing an inclusive education, and the accompanying sense of belonging, can cause a range of emotional problems, such as negative feelings about themselves. It can cause flow on effects and become detrimental to their social, academic, health and psychological outcomes (Alesech & Nayar, 2020; Kearney, 2009; MacArthur & Kelly, 2004; Mcleod, 2018). A recent study from the United Kingdom shows a correlation between the exclusion of young people with autism and ending up in the criminal system (Rogers, 2019). Given the nature of autism, and the ways it may impact empathy and social understanding, autistic children who do not experience an inclusive education can be at a higher risk of offending against the law, simply by being misunderstood (Ministry of Health & Ministry of Education, 2016). These young people can experience a limited sense of belonging and their mental health can suffer dramatically from a lack of inclusion, which 90% of participants identified as being a lifelong implication of a non-inclusive education. Autistic children and young people are already at a higher risk of mental health problems, such as anxiety and depression, and being in non-inclusive environments can increase the severity of these issues (Ministry of Health & Ministry of Education, 2016).

Autistic children and young people with a diminished sense of belonging also report feeling excluded and undervalued, which can lead to social exclusion due to their impairments being seen as a deficit (Goering, 2015). Social exclusion highlights a lack of resources, rights and services, and the struggle to participate in the usual activities and relationships that are available for the majority of people in a community. This is compounded by attitudes, behaviours and beliefs from society that make it difficult to fulfil their potential and contribute to society, which can occur when neurotypical children do not have the experiences of diversity in society that an inclusive education provides them with (Appleton-Dyer & Field, 2014). An educator from the survey stated that "inclusion benefits everyone. So without an inclusive education, opportunities are lost for both neurotypical adults and those living

with a disability". McRae and Warner (2019) state that the lack of an inclusive education can result in a lack of social skills, autistic children and young people being left behind, and it creates a barrier to acceptance by peers. These are unlikely to decrease without intervention, and can become more evident and create further long term issues within the communicative, social and ritualist aspects of autism (Ministry of Health & Ministry of Education, 2016).

80% of participants believed that autistic young people were more likely than their peers to leave school without qualifications, and to feel as though they have no place in society as adults. Autistic children and young people can become less functioning in society as adults if their potential goes unacknowledged by not being provided with relevant opportunities as others (Martin-Denham, 2022). The *Aotearoa New Zealand Autism Guideline* states that work for autistic people should be considered as an option regardless of their intellectual ability (Whaikaha – Ministry of Disabled People & Ministry of Education, 2022). Their future employment opportunities can become even more limited, and independent living can be restricted without supporting them to acquire the skills needed to function independently and belong to society (Guldborg et al., 2019; MacArthur & Kelly, 2004).

For families, it may already be overwhelming at times to care for an autistic child (Karst & Van Hecke, 2012). The lack of inclusion can exacerbate these feelings by causing more stress, having to take time off work, impacting on finances, and it can cause problems for siblings (Guldborg et al., 2019). It can also cause a lack of belonging for the family, as they can be ostracised in the community due to the needs of their child (Karst & Van Hecke, 2012). This can limit social interaction and community engagements for the whole family, therefore restricting a sense of belonging for all (Ferraioli & Harris, 2009; World Health Organization, 2011). A parent stated that their child had to deal with "social exclusion, no job possibilities, no skills and no support". Taking time off from work to collect their child from school when a deficit view of the child is held (for example, the child being seen as a behaviour issue, rather than their needs not being met in an inclusive setting), has financial impacts on the caregivers and family. Finances may need to be stretched further for various support systems to help the child who does not have access to an inclusive education, such as therapy, and support groups (Saunders et al., 2015). 58% of participants identified that this flow-on effect impacts on siblings who often carry the additional task of supporting their autistic sibling, which can be detrimental to their own learning and development (Ferraioli & Harris, 2009).

## Conclusion

Research informs us that the issue of social justice should ensure that autistic children and young people are able to learn in an inclusive environment and that educators should be able to address their varying needs (Kwari, 2020). All children have the right to an education that develops each individual to their best potential, and prepares them for a full life of belonging to society (McRae & Warner, 2019; United Nations, 1989). Implementing inclusive education practices is about making system-wide changes. Educators must adapt to the needs of the child, and not let a medical view of disability drive us (McRae & Warner, 2019). Access to funding and training needs to be addressed to allow for teachers to gain a better understanding of autism and inclusive practice.

The detrimental lifelong implications of a non-inclusive education for autistic children and young people is evident across literature and through the voices of families and young people. The importance of hearing students and whānau voices on this issue is paramount. A lack of belonging and social exclusion can cause devastation with the right to an inclusive education not being acknowledged for autistic children and young people (Alesech & Nayar, 2020). Children must feel a sense of belonging to be successful in life (Higgins et al., 2008; Ministry of Education, 2017). All children and young people need to be able to be with people and receive what they need from within a community, to be able to communicate and not be isolated because of differences, to bring about a deep sense of belonging to enable them to function in society (Drury, 2019).

Educators have the scope to make major changes by implementing and sustaining inclusive practices for autistic children and young people. All children have the right to an inclusive education, and educators need to create environments where belonging is paramount, allowing all children the chance of a successful, fulfilled and accepted life in the community.

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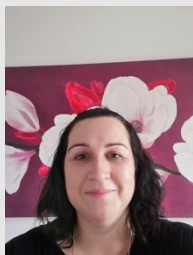
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