

ORIGINAL ARTICLE

Caregivers of Children With Disabilities in the Northern Territory, Australia: Experiences of Educational Non-Inclusion[†]

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Abstract

Inclusive education is enshrined in law and supported by the literature as best practice in education. Inclusive education has been shown to provide better academic, social and behavioural outcomes for children with disabilities than segregated learning environments. In the Northern Territory, Australia, however, the dual system of mainstream and special education persists and so too does segregation and exclusion. The Northern Territory education strategy commits to strengthening inclusion and empowering families in educational decision-making by listening to their voices. In this paper, we highlight some of these voices, examining the experiences and perspectives of caregivers of children with disabilities as they participate in education in the Northern Territory. Caregivers' experiences were coded into categories of inclusion and exclusion. Those that were not clearly inclusion nor exclusion were identified and the theme of non-inclusion was created. Non-inclusion was analysed thematically and is discussed as a nebulous space that exists for caregivers, presenting significant challenges that threaten their child's inclusion at school as they navigate this dual system. If Australian education systems are to provide genuine inclusive education, we need to understand the experiences of caregivers better so we can remediate the issues creating non-inclusion for children with disabilities and caregivers.

Keywords: inclusion; education; disability; caregiver; exclusion; non-inclusion

It is well documented that quality education is a crucial determinant of health connected to positive social and economic outcomes for all children (Hehir et al., 2016; McLachlan et al., 2013; United Nations, 2022; United Nations Department of Economic and Social Affairs, 2020). In Australia, the Alice Springs (Mparntwe) Education Declaration (Education Council, 2019) sets forth a vision for excellence and equity in education for all students in line with conceptions of education as a human right (United Nations, 1948). However, children with disabilities remain some of the most educationally disadvantaged in Australia (Australian Institute of Health and Welfare, 2020; Commonwealth of Australia, 2021; Department of Education, Skills and Employment, 2021).

Education was not a right for children with disabilities until the 1970s (Chambers & Forlin, 2021). Since that time, educational practices for children with disabilities have moved from exclusion and segregation to various forms of segregation, integration, and inclusion (Chambers & Forlin, 2021; Graham, 2020) as disability paradigms have shifted from a medical model towards social and human rights-based models. These changes have been supported by international and Australian education

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and disability policy (Chambers & Forlin, 2021; Disability Discrimination Act 1992, Cth; Disability Standards for Education 2005, Cth; Graham, 2020), and agreements (Education Council, 2019).

In 1994, the Salamanca Statement affirmed the ‘necessity and urgency of providing education for children, youth and adults with special educational needs within the regular education system’ (UNESCO, 1994, p. viii). Fourteen years later, the right to inclusive education for all children with disabilities was enshrined in international law (United Nations, 2008), classifying the grouping of children on the basis of disability as discriminatory (de Bruin, 2022). In 2016, the scope of governments’ obligations to enact inclusive education was specified in General Comment No. 4 (United Nations, 2016), outlining the features of inclusive education and clarifying that inclusive education ‘is not compatible with sustaining two systems of education: mainstream and special/segregated education systems’ (p. 13).

The benefits of inclusive schooling for children with disabilities, their peers and teachers are well documented (Cologan, 2019; de Bruin, 2020; Hehir et al., 2016; Kart & Kart, 2021). Despite the evidence, and ongoing legislative changes, a dual mainstream/special education system persists in the Northern Territory and elsewhere in Australia that continues to exclude and segregate children with disabilities (de Bruin, 2022; Poed et al., 2022).

Of the 153 government schools in the Northern Territory, five are specialist schools and eight have specialist centres (special education satellite classes or annexes within mainstream schools; Northern Territory Government, 2022). These schools are all located in major geographical centres (e.g. Alice Springs, Darwin), despite remote locations servicing 44% of the student population (Northern Territory Government Department of Education, 2019). These specialist schools and centres are separate environments for eligible children with disabilities as a part of their overall educational planning. Within the mainstream system, 26% of children were identified through the Nationally Consistent Collection of Data on School Students with Disability as having a disability, the highest proportion in Australia (Milne et al., 2018). This demonstrates a need to ensure that all children have access to quality inclusive education in the Northern Territory.

The current Northern Territory government strategy makes no reference to General Comment No. 4 (United Nations, 2016), which defines inclusive education as being incompatible with segregated schooling. The strategy appears focused on maintaining the dual system until 2029 (the duration of the strategy), although it recognises the imperative of inclusion to ‘ensure all students’ wellbeing and equitable access to learning’ (Northern Territory Government Department of Education, 2021, p. 15). Beyond that time, it is unclear if genuine non-segregated education will be the goal. Without the intention to move towards genuine inclusive schooling, maintaining the dual system while appropriating the language of inclusion risks the integration of children into a system not designed for them (Graham, 2020). What we have at present is system-sanctioned macro- and micro-exclusion (Cologan, 2019) and ultimately poorer outcomes for children. If there is the intention to move towards inclusive schooling, strengthening inclusion in mainstream schooling now could offer more children the opportunity to learn alongside their peers.

The Northern Territory Government Department of Education (2019, 2021) recognises the importance of listening to families and forming strong school–family partnerships, one of the nine features of inclusive education (United Nations, 2016). Parents, families and caregivers play a vital role in their child’s education (Gonski et al., 2018; Henderson & Mapp, 2002; Northern Territory Government Department of Education, 2021; Smith et al., 2020), particularly for those children who are deemed *at risk* (Dearing et al., 2008; Education Council, 2019). As noted by Mann et al. (2020), a ‘parents’ authority gives them a legitimate and critical place in school communities and at the decision-making table’ (Mann et al., 2020, p. 336), thus listening to families’ lived experiences of education can provide essential insight into what is working and where improvements can be made so the rights of children with disabilities may be ensured.

This paper focuses on stories that sit in the space between inclusion and exclusion at school. Here, we explore the narratives of caregivers in the Northern Territory by examining their experiences and perspectives of mainstream education within the context of their lives.

Table 1. Diagnosis Categories by Education Type

Diagnostic category	Education type				
	None	Early learning	Mainstream	Special school	Combination
Attention-deficit/hyperactivity disorder (ADHD)			1		
Autism spectrum disorder (ASD)		3	16	12	1
Cerebral palsy (CP)			1		
Down syndrome (DS)	2		2	1	
Other: Global developmental delay (GDD), chromosomal, genetic, speech delay, etc.	1	1	6	1	
Total	3	4	26	14	1

Methods

The data reported in this paper are drawn from analyses of 40 conversational interviews conducted by the second author with caregivers of children with disabilities in the Northern Territory. These interviews are the first interviews in a longitudinal study designed to follow families as their children engage with health and educational systems across their childhood. The semistructured interviews explored caregiver perspectives on raising children with disabilities using a narrative enquiry methodology (Clandinin & Connelly, 2004). Families were recruited through a local disability service provider and snowball sampling. Within the interviews, caregivers were asked about their child, their diagnosis, any therapeutic service provision, engagement in community life, and experiences of education (early learning through to high school). Although questions were asked by the interviewer, participants often led the conversation with topics that were important to them and their unique situation. For the purposes of the current paper, only interview content and codes related to education, including early learning, are presented.

Participants

This research was approved by the Human Research Ethics Committee of Charles Darwin University (H17006).

Forty families (with 48 children with disabilities) residing in the Northern Territory were interviewed for the first phase of this longitudinal study. Thirty-nine of the interviews took place in person and the caregiver provided written consent. One interview took place on the phone and the caregiver provided verbal consent. All participants received a \$50 gift certificate to a major supermarket brand for their time.

Of the 48 children, 12 were female and 36 were male, and the age range was from 4 months to 14 years, with the average age being 5 years and 9 months. Family demographics are shown in Table 1.

Analysis

Audio recordings of the interviews were professionally transcribed, reviewed for accuracy and uploaded into NVivo 12 (QSR International Pty Ltd, 2018) for thematic analysis. They were read through initially without coding by the first and second authors. In a second read-through, examples of inclusion and exclusion as related to participation or engagement with education systems and staff were highlighted in NVivo. First-cycle coding (Saldaña, 2016) focused on clear examples of categories of exclusion and inclusion. For this study, inclusion refers to experiences of children in non-segregated schooling that demonstrate

systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences. (United Nations, 2016, p. 4)

Initially, exclusion was defined as those examples where a child was ‘directly or indirectly prevented from or denied access to education in any form’ (United Nations, 2016, p. 4). Examples that did not fit clearly into exclusion or inclusion were labelled by a third code or category: non-inclusion.

In second-cycle coding (Saldaña, 2016), two subcategories of exclusion were created: micro-exclusion, which refers to integration and ‘exclusionary practices within so-called inclusive settings or experiences’, and macro-exclusion, which ‘refers to segregation outside of “mainstream” education settings or exclusion from any formal schooling’ (Cologan, 2019, p. 13). Examples of micro-exclusion in this dataset include,

They refused to move him out of the toddler’s room. (Caregiver 1)

She conducts a separate class for him. (Caregiver 15)

Examples of macro-exclusion in this dataset include,

I don’t want him going to mainstream. (Caregiver 1)

The school was just, like, we can’t deal with her, just go away. (Caregiver 32)

All experiences relating to children attending (or not attending) or being moved to special schooling were categorised as macro-exclusion and not reported here. In this paper, our focus is on the examples of non-inclusion. The definition of non-inclusion evolved through this coding process and data analyses as we identified those experiences that were not inclusionary and not clearly exclusionary (where a child was denied education or segregated; e.g., not allowed to attend preschool because they are not yet toilet-trained).

Non-inclusion was associated with exclusionary practices that have occurred, are a concern, or may occur in the future. Non-inclusion encompasses a caregiver’s feelings, attitudes, or actions that indicate they do not feel like they belong, are welcome, or valued in that educational context or situation. Three subcategories of non-inclusion were created: behaviour and wellbeing, belonging and judgement, and segregation acceptance.

Results

The aim of this research was to investigate the experiences of caregivers of children with disabilities in the Northern Territory. Here, we focus on experiences related to participation in the education system. From the 40 interviews, we found 18 examples that were coded as inclusion or inclusive practices, whereas there were 65 examples coded as exclusion. Of these, 46 were considered macro-exclusion and 19 were considered micro-exclusion. Thirty-three examples were coded as non-inclusion.

Given the purpose of this paper was to explore the anomalies or perspectives that don’t fit neatly into either inclusion or exclusion, it is only the non-inclusion results that will be discussed here. This is a fertile space for considering change in practice in a dual education system of specialist and mainstream schools.

Non-Inclusion

Non-inclusion revealed caregiver experiences and feelings in their interactions with education that posed a risk to the inclusion of their child. Data coded as non-inclusion was categorised into the following themes:

Theme 1: Behaviour and wellbeing

Behaviour and wellbeing narratives ($n = 12$) were central to almost all the non-inclusion experiences. This might be anticipated given that restrictive practices commonly used to manage behaviour in schools are a significant cause of stress, worry and frustration for caregivers (Poed et al., 2017). In this dataset, a punitive behaviour management approach was commonly described by caregivers. This appeared to be sanctioned by schools and teachers and supported by policy, regardless of the child's requirements:

I got an email saying if she continues to do this, we will follow these behavioural procedures and basically forwarded me the behaviour policy documents ... when you read through them, it's suspension. (Caregiver 21)

Sensory considerations would be quite significant for my little fellow. You can't punish a child in sensory overload. The older style of punishment-based learning doesn't work for ASD¹ kids. (Caregiver 25)

For caregivers, there is an acceptance that behaviour management is a part of school. One caregiver, whose child's behaviour has been the source of school exclusion, commented,

You've got to look at it from the other perspective. If you've got a hardworking, high-achieving child who wants to do well at school and the teacher is busy managing behaviour over here, it's taking away from that child as well. I can see both sides. (Caregiver 32)

Behaviour and the way it's managed and perceived impacts children and creates significant worry for caregivers. One parent reported being 'horrified' (Caregiver 27) having to come into the school because her child had climbed into a tree and was growling at the other children. Another caregiver reported that teachers were 'hassling' her (Caregiver 32) because of her child's lack of participation. Caregivers are in a tough place, loving and advocating for their child, while also navigating often negative and critical feedback from school and other parents:

I've spoken to the school and at parent teacher interview. I only chose one interview that was a maths teacher. I didn't want to talk to the other teachers to hear how bad my daughter is. (Caregiver 32)

It's just stressful for everybody. I'm dreading going to school every day. My phone goes and I'm like, oh, is it the school? What's happened? A mum comes up to talk to me and they are like you're Matt's² mum and I'm like, oh no, what is it? (Caregiver 6)

Caregivers also felt a burden to provide support to the school when their child was not demonstrating behaviour conformity. Caregivers described creating resources to encourage behaviour conformity in class (e.g., Caregiver 27), being contacted frequently throughout the day to be told of behavioural incidences (e.g., Caregiver 21) and being called upon to solve behaviour issues when they arise (e.g., Caregiver 32). Caregivers described the hope and the frustration of the burden. For example, when support for her child was put in place by the school, one caregiver commented,

Hopefully it means there won't be as many phone calls around 'this is what your child has done'. (Caregiver 21)

Another spoke of the expectation to continue to provide sticker charts for the classroom:

Now the teacher is writing to me saying, 'Can you do that again? Can you send another sticker chart?' I'm going, 'No, you do it'. Honestly, how hard is it? . . . Why am I having to do all this? Why is the teacher asking me? (Caregiver 27)

Two caregivers with children, for whom behaviour conformity is an issue for school, commented that their child's wellbeing was more important than academic achievement. One caregiver focused on her son's enjoyment and engagement at school as a priority. She said,

I'm not really fussed about academics or him being at a certain level. As long as he can enjoy school . . . Whatever is built on top of that is built on top of it. (Caregiver 4)

Contrasting this was a perspective of school survival rather than education, enjoyment or engagement:

If he gets out of school with an education, that's fine, but for me, I just want him to get through unscathed. (Caregiver 34)

Central to these experiences is an understanding that the child is not the issue; rather, it is the one-size-fits-all behavioural paradigm. This system-sanctioned approach doesn't work because 'not every kid fits in the box' (Caregiver 4). One caregiver described succinctly how a child's opportunity to thrive can depend totally on one adult in that classroom and the approach or attitude they choose to have:

If someone is very responsive to her needs, she really thrives, so I guess at the moment I'm very confident because her teacher is really amazing, but I don't think that will always be the case. I guess that's a concern. (Caregiver 2)

Theme 2: Belonging and judgement

Belonging and judgement is another theme determined from this analysis within the examples of non-inclusion ($n = 10$). Within belonging and judgement, we found that caregivers feel they, or their child, are unwanted in their school community, or feel judged by the things they do (or, more often, don't do). Caregivers utilised terms like 'naughty child' (Caregiver 21) or 'naughty kid' (Caregiver 23) to convey how they felt their child was viewed at school. One caregiver spoke of the stigma already attached to her child because of behaviour that led the parents to consider school exclusion:

. . . we were like if the stigma already is that she's the naughty child or she's immediately the one with the issues or the problems, what's that going to do for her? (Caregiver 21)

Caregivers also spoke of feeling judged by education providers. Some caregivers reported that education providers had suggested their child's behaviour was their fault:

Early on it felt like I was doing something wrong with his first teacher, like I wasn't able to control him. (Caregiver 22)

If children had behavioural issues, they frequently told us that the child was behaving badly, and [asked] what were we doing at home? (Caregiver 17)

A family's sense of belonging in their school community may be tenuous. Some caregivers felt it was dependent on whether their child conformed to the school's behavioural expectations:

Personally, I feel like they're trying to push me out of the school because she's too hard. (Caregiver 21)

The caregivers described interactions conveying that the child is of little value to the school community, that they will be managed or will not be nurtured if they choose to stay. This appears to be a relatively common experience for this cohort, who found behaviour conformity is a central issue for a child's participation in schooling. One caregiver's experience demonstrates this and the ease with which segregation and exclusion of children with disabilities can occur:

We had a meeting a few weeks ago and they just said to me, 'Look, your choice, you want him to stay here, we'll just deal with it the best we can, but there is still an option for you to go to the other [special] school'. (Caregiver 6)

Caregivers enrolling their child in school also reported feeling as though the school didn't want them there:

They were a bit standoffish. (Caregiver 23)

I kind of felt like she was just giving me a gentle nudge, to say it'd be good if you actually left. (Caregiver 24)

Theme 3: Segregation acceptance

Segregation acceptance ($n = 10$) was the theme coined to describe responses that suggest caregivers have a commonly held belief that segregation is better or necessary for some children with disabilities (de Bruin, 2020). Quotes coded under this theme tend to fall into several categories:

1. That children need to be at a certain (undefined) level to attend a mainstream school — for example,

We were thinking he's never going to draw; he's going to have to go to [special school]. (Caregiver 17)

2. Segregation is better for some children with disabilities — for example,

If they find it hard and she can't do anything, let me know and I can put her into [special school] . . . you go there, you try there, if you can't, then you can go to the other [special] school. (Caregiver 18)

This demonstrates the caregiver's acceptance of the role of special school as a backup for her daughter if mainstream schooling ('they') found her daughter with Down syndrome 'hard'. Here, we see the parent positioning the mainstream school's perceived difficulty as the determining factor about where her child should experience her education.

3. Segregation is the accepted path if criteria are met — for example,

He'll be mainstream. I don't think he will meet the requirements for [special school] at all. It's a lot more work but he's learning. (Caregiver 9)

Yeah, [special school]. I don't think our kids warranted it, you know; I don't think they were that bad really even though there were a lot of problems. (Caregiver 19)

He did change schools for a little bit; he went to the [special] school out here for about a term and a

bit and then his teacher left the school and they said he could go back to [mainstream].
(Caregiver 28)

What is striking about this example is that the caregiver didn't know or understand why the child was changed from mainstream to special school, and then back again. When asked why the change to the special school, she said,

Not sure why but they said that even though he didn't really need to, that they'd like to take him there. Even his teacher at [mainstream] said she was fine with him staying, you know, if that's what I wanted, and I just said I'll listen to the experts, and they said that he should go there.
(Caregiver 28)

In these quotes, we see an acceptance of the idea that schools know what is best for children and are acting in the child's best interests, even when the language often indicates decision-making is around what's easiest for schools and educators.

There were no examples where caregivers expressed a clear understanding of their child's right to attend mainstream education. Use of words like 'hoping' (Caregiver 40) or statements like 'if the school agrees' (Caregiver 11) were used when describing thoughts around their child attending mainstream schools. This suggests that caregivers do not know or believe that the choices around their child's educational inclusion are their choices to make.

There was one additional coded example not categorised into one of these three stated themes within non-inclusion. The quote described the impact of therapy session times and location on the child's schooling.

Discussion

The purpose of this paper was to describe the reported educational experiences of caregivers of children with disabilities in the Northern Territory. We used their narratives to identify the themes underpinning the concept of non-inclusion, the grey space that exists for children and families between an inclusive educational experience and exclusion or segregation. We interpret that children and families who sit in this non-inclusion grey space face three primary challenges.

First, that behaviour conformity and how behaviour is managed at school places stress and burden on caregivers, who constantly balance the need to advocate for their child and maintain relationships at school. Second, that caregivers are receiving the message from education providers that their child and, by extension, they themselves are not welcome and don't belong at their mainstream school. Third, that caregivers accept segregated schooling is better or necessary for some children and may not know or feel they have the power to enforce their child's right to attend mainstream schooling.

As demonstrated in the quotes above, behaviour was a common thread throughout the non-inclusion theme. It is clear that behaviour poses significant inclusion challenges for teachers managing classrooms with diverse needs. This challenge isn't new for teachers (Avramidis et al., 2000; Croll & Moses, 2000; Hodkinson, 2006; Lifshitz et al., 2004). A variety of factors contribute to this, such as negative attitudes towards children with behavioural challenges (de Boer et al., 2011), more conflict and less emotional connection in the relationship (Ewe, 2019), limited resourcing (Hodkinson, 2006), and teachers' differing beliefs and levels of training regarding behaviour and inclusion (Main & Hammond, 2008; Monsen et al., 2014; Nemer et al., 2019). More recent research suggests significant challenges still exist for the inclusion of children for whom behaviour conformity is an issue in general education (Alkahtani, 2022; Bemiller, 2019; McGuire & Meadan, 2022; Warnes et al., 2022).

Caregivers in this study spoke of behaviour management policies and practices that were designed for the majority, are punitive, and/or do not reflect an understanding of disability or behaviour as a symptom of an unmet need. Commonly referred to as *restrictive* (Poed et al., 2017) or *manage and*

discipline (Armstrong, 2018), these punitive, reactive methods are not working for their children, are not evidence based (Kapalka, 2008; Main & Hammond, 2008) and are not ‘inclusive or equitable as they do not recognize the individual needs of each student’ (Lynch et al., 2020, p. 42). Further, they create significant stress and burden on families as caregivers attempt to advocate for their child, while also maintaining the relationship with school staff, offering their support to teachers and responding relentlessly to incidences, with little hope that the situation will improve.

The entrenchment of these practices in education, indicated by examples of standard policy applied to all children regardless of individual needs, contravenes the foundations of inclusive education (United Nations, 2016). General Comment No. 4 calls for a whole system, education, and person approach that responds to the learner’s needs, values diversity and creates a learning-friendly environment, as well as partners with families. More importantly, it demands a commitment to reasonable adjustments, which is reflected in the Disability Standards for Education 2005 (Cth), to ensure inclusion of people with disabilities and making a one-size-fits-all approach to behaviour management discriminatory.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) heard expert testimony specifically imploring the manage and discipline model to cease because it’s

part of that inadequate process of responding — meeting kids’ behavioural needs ... and oftentimes when we see children like Jack and others, it’s failed, the practice has failed. And we see the suspensions, exclusions, or self-exclusions where a student simply stops attending as a result of that. (The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020)

What is evident in these caregiver narratives on behaviour and wellbeing is an underlying knowing that these policies and practices are not right or fair.

Caregivers’ experiences of stigma and judgement highlighted in this study are not uncommon in the literature (Green, 2007; Lilley et al., 2023; Mitter et al., 2019). The pervasive face of stigma is its relationship to the increased burden that caregivers feel, and in some cases, it is the cause of considerable emotional distress (Green, 2007; Mitter et al., 2019). The judgement described by caregivers in this paper perhaps reflects the system’s failure to move beyond the historical context of disability, rooted in limitation, remediation, and segregation (Chambers & Forlin, 2021; Graham et al., 2020) — a position that does not acknowledge the role that marginalisation and negative societal attitudes play in increasing caregiver burden (Lalvani, 2015).

For children and their caregivers, belonging within the school community is recognised as being important for positive outcomes (Bond et al., 2007; Korpershoek et al., 2020) and is reflected in General Comment No. 4’s features of inclusive education (Cologan, 2019; United Nations, 2016). Yet we see that mainstream education options in the Northern Territory continue to present a small window of possibility into which children and their caregivers must fit. When children do not fit, do not conform, or are considered outside the norm, such as those in this study, *othering* occurs (Borrero et al., 2012).

The separation of othering is incongruent with belonging, which is acceptance and being valued (Willms, 2003) by the group you wish to belong to. Importantly, belonging is a fundamental human need (Baumeister & Leary, 1995), so when caregivers are feeling so easily discarded from their school community because their child is perceived as ‘too hard’, that fundamental human need isn’t being met, and their child is at risk of exclusion. As Poed et al. (2017) found in their Australian study on gatekeeping practices, ‘every hurt that occurred to the child was a deep hurt to the parents also’ (p. 24). Caregivers are ultimately the decision-makers of where their child attends school in the Northern Territory, but the reality, demonstrated in this study, isn’t so clear. The strong undercurrent and historical context of disability in society shapes the beliefs of parents, schools and systems that are invested in the idea that segregation is best, for at least some students with disabilities (de Bruin, 2020).

This can manifest as caregivers choosing segregated settings, or in gatekeeping practices (Poed et al., 2022), passively allowing educators titled as ‘inclusion experts’ to make schooling decisions for their child. This might be because they don’t know they can choose differently, or they feel coerced or obligated to comply. Sometimes they are putting their trust into the system in anticipation of wanting what’s best for their child, not simply what’s easiest for the school. The term inclusive education is used so broadly that it does not have a meaningful definition for most parents, or indeed educators. It has become a commonly used platitude, applied generically and idealistically without the necessary underpinning of attitude and intention of action that is needed to transform a segregated system into an inclusive one.

The Northern Territory Framework for Inclusion 2019-29 speaks of ‘partnering with parents in the education of their children and ensuring they have real opportunities to contribute their voices to decision-making over matters that affect them’ (Northern Territory Government Department of Education, 2019, p. 8). There may be three challenges with genuine decision-making, however. First, genuine partnership is required and can only exist where caregivers are seen as equal contributors and assets (Mann & Gilmore, 2021). Second, although society and the system still advocate for segregation, as seen by the provision of and ongoing funding of special schooling options, parents and education staff will continue to receive the message that segregation has a place for some children. Finally, until education is meeting its obligations under General Comment No. 4 (United Nations, 2016), many children with disabilities will continue to be subjected to mainstream education practices that are by design exclusionary. For caregivers then, the choice of special schooling becomes the only option for their child, which isn’t really a choice at all (Cologan, 2019).

It is a limitation of this kind of research that the sample size may not represent the larger Australian population of caregivers of children with disabilities. Certainly, the context of the Northern Territory has many limitations related to service provision and educational options. That said, the point of this research is to share the nuanced perspectives of individuals as they navigate health and educational systems. This paper shares the richness of story that speaks to this non-inclusion space and provides valuable insight into the current challenges of the dual system of education, where families grapple with decisions around mainstream or specialist schooling.

In future studies, we intend to explore caregiver perspectives around inclusion and schooling, particularly what their explicit views on inclusive education are for their child (if any).

Conclusion

In this paper, we explored the narratives of caregivers of children with disabilities in the Northern Territory. We examined examples of non-inclusion as grey space that exists between inclusion and exclusion for children and their families as they navigate the dual education system. Although the narratives gathered in this research demonstrated caregivers’ frustration, worry and stress, they also showed immense strength, resilience, knowledge and of course fierce love for their child. These are the resources that families call on to continue the advocacy required to keep their child in school.

Northern Territory education documents place the child and student at the centre of education strategy (Northern Territory Government Department of Education, 2022) as they ‘continue to amplify the voices of our students’ (p. 6). This is a worthy aspiration, given that what we have seen in this sample of data is that many families experience a struggle to maintain a sense of wellbeing for their child (and themselves) under a constant threat of exclusion and segregation. This is particularly true for children for whom behaviour conformity is the primary challenge.

Without a plan to transition out of the dual mainstream and special schooling system, space exists for attitudes, policy and practices that endorse segregation and exclusion in schooling. Significant sociopolitical change is needed to support and fund the move towards genuinely inclusive education practices (Görel & Hellmich, 2022). If the Northern Territory has a genuine desire for inclusive

education, meeting its obligations under General Comment No. 4 (United Nations, 2016) is required as well as cultural and attitudinal change that commits to ending all segregation.

By identifying and ameliorating the issues created by these experiences of mainstream non-inclusion, we could perhaps restore the confidence of caregivers in the education system. This could be an effective starting point if ‘all young Australians [are to] have the opportunity to reach their full potential’ (Education Council, 2019, p. 20).

Notes

1 Autism spectrum disorder (this is a direct parent quote).

2 All names are pseudonyms.

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