Is inclusive education really for everyone? Family stories of children and young people labelled with 'severe and multiple' or 'profound' 'disabilities'

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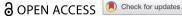Kathy Cologon

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ABSTRACT

Article 24 of the *Convention on the Rights of Persons with Disabilities*, along with *General Comment 4*, explicitly outlines the right of every person to an inclusive education at every level. And yet, even amongst supporters of inclusive education, it is not uncommon for some students to be considered 'too disabled' to be included. In this research I draw on the views and lived experiences of 10 parents, living in Australia, who identify their children as having been labelled with 'severe and multiple' or 'profound' impairments. I ask what inclusion means to these parents and their families, and whether inclusion and inclusive education is important to them. Drawing on these parent perspectives, is the notion of inclusive education for *everyone* realistic and desirable, or only idealistic? Should inclusion *be* inclusive or is it ultimately conditional? The perspectives of the research participants hold implications for the realisation of the right to inclusive education.

Introduction

Inclusive education has been a contentious key issue in education at all levels for some time now. The importance of inclusive education for both positive educational outcomes and as a moral imperative has been widely acknowledged, and inclusive education has been recognised and articulated as a fundamental human right of every person (United Nations 2006, 2016). Indeed, Nutbrown and Clough (2009, 192, emphasis added) argue, 'respectful educators *will* include all children'. However, despite the right to inclusive education for all (United Nations 2006, 2016), even amongst supporters of inclusive education it is not uncommon to believe that 'some students' are 'too disabled' to be included (Graham and Sweller 2011). This belief, and its implicit hierarchy of humans, impacts on policy and practice and, tangibly, on the everyday lives of students and their families.

Limited reporting and a common lack of disaggregation of reported data make precise percentages difficult to determine, but it is clear that the majority of students who are labelled as having 'severe and multiple' or 'profound' impairments continue to be

segregated (Graham and Sweller 2011; Kleinert et al. 2015; Kurth, Morningstar, and Kozleski 2014).

Whilst in no way denying or devaluing any aspect of human diversity, in this paper I acknowledge that the definition of 'severe and multiple' or 'profound' impairments and, importantly, the very processes of categorising and labelling humans with such terms, and the ongoing application of such labels is beset with deeply troubling tensions. Robinson and Goodey (2018, 428) argue:

> *'Any definition of "profound and multiple"/"severe and profound' is arbitrary, whether coming from an expert (an educational psychologist) or a manager (a headteacher). Nevertheless, scepticism about labels is hardly useful: arbitrary or not, they are still employed to denote real individuals subject to a really existing discrimination. These are the children whose presence is most often challenged, and before whom a personal or institutional commitment to inclusive education most frequently crumbles.*

It is in this sense of recognising the particular forms and extent of discrimination visited upon those of us who are labelled in such a way that the use of labelling terminology is applied within this paper. Additionally, given the diverse use of terminology across the world, it is relevant to indicate that in this paper I adopt a social model understanding of disability as socially imposed oppression (rather than as a within-person trait), and therefore use the term 'impairment' where appropriate to denote individual bio-social 'differences' (Thomas 2004) that are distinct from the oppression that constitutes disability.

In this paper, I explore the perspectives of 10 parents, living in Australia, who identify their children as having been labelled with 'severe and multiple' or 'profound' impairments. With a focus on experiences within education settings, I ask what inclusion means to these parents and whether inclusion is important to their families.

Those of us who experience disability are frequently conspicuously left out of dialogue about our own lives (Annamma, Connor, and Ferri 2013; Erevelles 2000; Thomas 2004). This is a clear limitation of this present study and an area for further research. However, the 'insider perspectives' of families are also important and parents play an influential role in the lives of their children (Ruppar, Allcock, and Gonsier-Gerdin 2017). Families often experience considerable challenges, including stigma and discrimination, when advocating for the rights of their children (Lilley 2013). Engaging with the perspectives of people who experience oppression is essential to genuinely considering ethical and political aspects of knowledge (Freire 1973). Furthermore, in research with parents of students labelled as having 'severe disability', Soodak and Erwin (2000) found that meaningful engagement with parents is one key aspect of inclusive education.

Inclusive education

George Orwell (1946, 112) pithily, and now infamously, expressed the crux of politely framed oppression in his allegorical book *Animal Farm* with the line, 'All animals are equal, but some animals are more equal than others'. In reference to the human experience, this statement rings true as ever. But as emancipatory movements are corralled into marketable sound-bites and existing systems, practices, and even beliefs, are smoothed over through the adoption of 'politically correct language', absent of the

underpinning transformation required, the fuel to ignite resistance is anesthetised and the 'fight lines' get murkier. In relation to inclusive education, as exclusionary practices are re-named 'inclusion', with no further transformational change, and terms such as 'special education', 'integration' and 'inclusive education' are used simultaneously or interchangeably, it seems the satirical intention in the would-be statement that 'all people should be included, but some people should be included more than others' is lost in an earnest, convenient, or cynical misinterpretation of 'inclusion'. The question then becomes, what does this mean for those of us who are relegated into a category of the 'least possible/desirable/required to include' – or, to put it another way, those of us for whom it is the easiest to justify excluding?

A clear and comprehensive definition of inclusive education is provided in *General Comment 4* on the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) (United Nations 2016). This international definition of inclusive education is adopted in this study, meaning that inclusive education is understood to be for all students and to occur only within 'mainstream' settings with all necessary adaptations and accommodations to ' ... 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' (United Nations Office of the High Commissioner (OHCHR) 2016). Segregation and integration are not inclusion, thus when students are placed into 'mainstream' settings, but within separate classes or activities, or where pedagogy and practice are not changed to include all, this does not constitute inclusive education (United Nations Office of the High Commissioner (OHCHR) 2016).

While this definition has been clearly articulated and internationally accepted, general confusion about the meaning of 'inclusive education', and common misappropriations of the term, have been well documented and occur in Australia and elsewhere (Slee 2018). Despite the articulation of inclusive education as a fundamental human right for all and the widespread mantra of universality, in reality inclusive education is commonly interpreted as 'conditional'. This appears, at least in part, to reflect a perception that the ways in which current systems of education are set up makes inclusion for all 'impractical', without consideration of the pressing need for systemic change nor the affordances within current systems – flawed as they may be. A belief often intertwined with the perception that inclusion constitutes 'additional' work performed by educators to address the 'additional needs' of a particular student, rather than an understanding of inclusion as valued full participation and belonging of all people – with benefits for all people (Cologon 2014b). Additionally, it has long been documented that even when people who experience disability are present in 'mainstream' or 'regular' settings, micro-exclusion frequently occurs and conditions are often placed upon the continuation of such, so-called, 'inclusion' (Cologon 2019; D'Alessio 2011; Ruppar, Allcock, and Gonsier-Gerdin 2017; Soodak and Erwin 2000). Once relegated to a segregated setting, there is little likelihood of movement to a more inclusive placement (Kurth, Morningstar, and Kozleski 2014).

The ongoing myth of 'the normal student' and the emphasis placed – directly or indirectly – on ensuring that students are 'the same enough' to 'fit' within existing settings, systems, or practices is a fundamental barrier to inclusion (Cologon 2014a). However, such beliefs are persistent and often present when inclusion is viewed as being

about assimilation (Slee and Allan 2001). This leads to an emphasis on changing the student, not the setting (Lalvani 2013; Rietveld 2010), and is at the core of approaches in which interventions designed to 'normalise' students are presented as the key to bringing about 'inclusion'. The underlying ableist belief that there is something 'wrong' with a person who experiences disability is a source of ongoing grief for many families (Cologon 2014b, 2016; Derbyshire 2013; Goodley 2007; Green 2003). As Bridle and Mann (2000, 11) articulate, '[a]s mothers we have been challenged by the struggle between how we see our children and how the world sees them' within systems that construct people who experience disability as 'different, defective, as a patient, a consumer or client'.

Viewing inclusion as assimilation leads to the experience for students and their families of a perpetual and demeaning 'question mark' over the right of a student to be 'included' (Bridle 2005; Cologon 2013a; Mann 2016; Rietveld 2010; Runswick-Cole 2008). The subsequent belief that inclusion is a privilege, not a right, and thus an optional extra based on 'charity', or 'kindness', illustrates the subtle and insidious stigmatisation of people who experience disability (Cologon 2014a). This notion of inclusion as both conditional and an 'additional extra' jars uncomfortably with individual and family perspectives of inclusion as 'ordinary' and 'everyday' and as something that should be presumed and provided for everyone (Cologon 2014b; Haraldsdóttir 2013).

Beyond the common belief that inclusion is conditional assimilation, previous family stories indicate that inclusion is also commonly perceived to be 'permission' to be present, rather than as valued full participation and belonging (Bridle 2005; Cologon 2014b). The paradox of the very notion of 'inclusion' *into* 'mainstream', rather than equitable anti-biased education for everyone, serves to highlight the current reality within which many students are excluded. By contrast, families highlight that inclusion involves belonging, participation, equitable opportunities, and recognition of the valuable contribution that each person makes (Cologon 2014b). From these family perspectives it can be understood that inclusive education involves ensuring that educational opportunities are provided in a way that enables all people to learn whilst embracing and celebrating all aspects of human diversity. This requires substantial attitudinal, structural, relational, and environmental changes (Cologon and Mevawalla 2018).

Despite the many barriers, families share that inclusion can and does occur. Often families report that inclusion or exclusion is dependent on the advocacy and willingness of key individuals such as a particular teacher, counsellor or school leader (Bennett et al. 2015; Lilley 2013).

The outcomes of inclusive education

Robinson and Goodey (2018, 428) argue that 'Rather than being a "position" of any kind, inclusion is a natural *apriori* state in which we all begin', and it is only through processes of demarcation and dehumanising 'othering' that exclusion of *some* of us occurs. Robinson and Goodey (2018) theorise 'inclusion phobia' as the basis for this justification and acceptance of the exclusion of some students, particularly students labelled with 'severe and multiple' or 'profound' impairments. Inclusion phobia being historically constructed 'systemic, legally sustained segregation' (Robinson and Goodey 2018, 428). When identified as a phobia, opposition to inclusion is viewed as irrational and therefore

as unable to be addressed through the provision of relevant evidence. Nonetheless, in holding out hope for rationality, I summarise below the evidence base for inclusive education.

A considerable body of research dating back many decades has investigated the outcomes of inclusive education, particularly in relation to students who experience disability. However, many studies, whilst intending or claiming to examine inclusive education, are based on practices of micro (and sometimes macro) exclusion. Nonetheless, research provides considerable evidence of benefits of inclusive education for students who do and do not experience disability, with improved quality of education for all, that is more sensitive to student needs (e.g. Jordan, Schwartz, and McGhie-Richmond 2009; Jordan, Glenn, and McGhie-Richmond 2010; Purdue, Ballard, and MacArthur 2001). This is in direct contrast with the absence of evidence to suggest any benefit of segregated ('special') education over inclusive education (Cologon 2019; Hehir et al. 2016; Jackson 2008).

As has been identified in numerous recent reviews and meta-analyses (For example, see: ARACY, 2013; Cologon 2013b, 2019; Hehir et al. 2016; Szumski, Smogorzewska, and Karwowski 2017), research provides evidence that inclusive education has far reaching benefits for students who do and do not experience disability. Indeed, as outlined in these reviews, research with students who have been ascribed with a wide range of impairment labels provides evidence that the outcomes of inclusive education include: a) benefits for academic development; b) inclusive education has been found to facilitate positive behaviour development, including increased independence, patience, trust, acceptance of diversity, and responsiveness to the needs of others; c) communication and language development is enhanced through inclusive education; d) and physical development has also been found to be stimulated through inclusive education. Additionally, concerns are frequently raised regarding whether including students who experience disability could impact negatively on the academic outcomes of students who do not experience disability. However, again as detailed within recent reviews, research demonstrates that this concern is unfounded and students who do not experience disability benefit from inclusive education and demonstrate equal or better academic outcomes than students educated in non-inclusive settings.

While prevention of teasing and bullying is often cited as a motivation for students attending segregated 'special' settings (e.g. special education classrooms or schools), research provides evidence that all forms of bullying occur in 'special' settings and segregation is a key factor in increasing bullying (Davis and Watson 2000; Rose, Monda-Amaya, and Espelage 2011; Torrance 2000). There is growing evidence that inclusive education is an important strategy for reducing bullying through the promotion of positive social development; facilitation of friendships that may not otherwise occur; and support for the development of a strong sense of belonging (See: Cologon 2019 for review).

Beyond the school years, inclusive education has been found to be a positive predictor of increased engagement in tertiary education and positive outcomes for employment and independent living (Test et al. 2009). As Kurth et al. (2014, 228) argue, 'current research points to inclusive experiences as a critical predictor of both in school and postschool outcomes'.

Nonetheless, the question is often raised as to whether this larger and broader body of evidence in support of inclusive education is relevant or applicable to people labelled as having 'severe and multiple' or 'profound' impairments. Kurth et al (2014, 227) argue '[t]he segregation of students on the basis of disability has historically rested on assumptions that some students cannot learn in or benefit from participation in a "regular" classroom'. However, the evidence specifically in relation to students labelled as having 'profound' or 'severe and multiple' impairments, also reveals the positive outcomes of inclusive education. Inclusive education has been found to have benefits for academic development, communication, and positive behaviour and social development for students labelled as having 'profound', or 'severe and multiple' impairments (e.g. Boutot and Bryant 2005; Browder et al. 2008; Carter et al. 2011; Dessemontet, Bless, and Morin 2012; Feldman et al. 2015; Fisher and Meyer 2002; Foreman et al. 2004; Kurth and Mastergeorge 2012; Ruppar, Allcock, and Gonsier-Gerdin 2017). Inclusive education has also been found to have additional benefits not only for learning but also for maintaining and generalising learning compared with 'special' education settings (Causton-Theoharis et al. 2011). Furthermore, benefits are also found for students with and without disability labels (Kurth and Mastergeorge 2010).

In sum, the evidence is clear that inclusive education holds positive benefits, and yet, segregation of students labelled with 'severe and multiple' or 'profound' impairments continues (Graham and Sweller 2011; Kleinert et al. 2015; Kurth, Morningstar, and Kozleski 2014; Morningstar et al. 2016). Indeed, students labelled with 'severe and multiple' or 'profound' impairments are at greatest risk of being segregated throughout education (Draper, Brown, and Jellison 2019; Kurth, Morningstar, and Kozleski 2014). In considering why, one important 'insider perspective' that this paper contributes to investigating further is that of families.

Methodological overview

Slee proposes that inclusion involves questioning 'Who is in and who is out? How come? And, what are we going to do about it?' (2013, 905). In responding, at least in part, to these questions, I draw from critical pedagogy to inform my analysis of the participant stories.

While knowledge is often presented as a series of linear and unquestionable 'truths', in reality, knowledge is co-constructed and addressing the questions of whether inclusive education is really for *everyone* requires engaging in dialogue with people who are directly impacted by the the ethical and political dimensions of inclusive and segregated education. Critical pedagogy aims to 'expose how relations of power and inequality, (social, cultural, economic), … manifest and are challenged in the formal and informal education of children and adults' (Apple, Au, and Gandin 2009, 3). As noted above, families who experience disability frequently report experiences that constitute forms of oppression. From a critical pedagogy standpoint, my role as a researcher involves listening, reflecting and acting to disrupt unjust dominant discourses and practices, thus contributing to possibilities for transformative praxis. In analysing the family stories, it is therefore my goal to listen and seek to draw meaning that accurately reflects the diversity of the family experiences of the participants in this study and then to reflect

on what these family stories reveal in light of the dominant discourses and practices, and whether or what action for change is needed.

In this paper the experiences of and perspectives about inclusion and inclusive education of 10 parents who have one or more children labelled with 'severe and multiple' or 'profound' impairments are explored. These participants included 8 mothers and 2 fathers. For practical reasons the data collection occurred and was recorded online in individual sessions. Most families completed their participation in one session. However, two families chose to participate over two sessions. The study was granted ethics approval by Macquarie University Human Research Ethics Committee.

The family members participating in the research reported within this paper were participants in a larger study of 121 families (previously reported, see Cologon 2014b, Cologon 2016) in which all participants were invited to indicate if they would like to participate in a follow up interview. The sample for the present study were parent participants who identified their children as being labelled with 'severe and multiple' or 'profound' impairments, who were also willing to participate in further research.

Before engaging with the perspectives of the participants in this study, it seems pertinent to acknowledge that while the use of labels from an identity perspective indicates a strength-based positive celebrating of human diversity, the use of labels such as 'severe and multiple' or 'profound' impairments jars uncomfortably with disability studies and inclusive education approaches. However, given the rife exclusion of students to whom such labels have been applied (as discussed above) there is an important potential benefit of such a 'category' based exploration.

Secondly, it is noted that as the families self-identified these labels there may have been additional families within the larger study with labels that would also fall into such a 'category', but who did not identify as such. Chiming in part with Robinson and Goodey, as Draper et al. (2019, 29) explain, while such terms are used within 'special education vernacular, there is no agreed-upon definition. ... definitions have focused on children's functional capabilities (e.g. mobility, communication) or the degree to which environments contribute to the disabilities or accommodate children's needs'. Within the present study, the students had all been labelled with 'intellectual disability' (often referred to as 'learning disability' in international contexts) along with a combination of physical and sensory impairments, diverse communication approaches, and complex medical issues. Additionally, the student labels included various combinations of Autism, Attention Deficit Hyperactivity Disorder, Cerebral Palsy, Sensory Processing Disorders, Language Disorders, a range of chromosomal differences including Down syndrome, and Global Developmental Delay.

Acknowledging the significance of the multitude of arenas of privilege or disadvantage, and the impact of cultural privilege (such as white privilege and class privilege, for example) on family experiences of and perspectives on inclusion and exclusion, it is important to note that the families in this study come from diverse cultural and contextual backgrounds and reside in urban and rural settings in Australia, predominantly within the large and complex State of New South Wales. However, due to practical constraints, only English-speaking parents were invited to participate. This is a limitation of the present study.

The participants were between 36 and 65 years of age and had a range of education levels from completion of grade 10 (two years prior to the end of formal schooling in Australia) through to post-graduate study.

The use of the term 'children' in this paper is in no way intended to infantilise the students whose parents participated in this study, but rather as a reflection of the parenthood of the study participants. The participants' children who were labelled 'disabled' ranged in age from 6 to 17 years, along with the son of one participant who was 26 years of age. While this means that the 'child' of one participant was indeed an adult, the use of the term child in this sense means only that this man was the child of the parent participating in this study. While it would be 'neater' to exclude this family on account of the age of the student, the perspective of families as their children pass through different stages of education systems and beyond is valuable to a broader and deeper understanding of inclusion.

In this study I set out to explore how inclusion and exclusion are or were understood and experienced by the participants in this study, situated within the participant family experiences within and beyond education settings. While participants were free to expand and branch out in their responses, question prompts included:

- How would you define inclusion/exclusion?
- Is inclusion important to you and your family? Why/Why not?
- Can you describe an experience of inclusion?
  - How did this experience impact on your child and your family?
- Can you describe an experience of exclusion?
  - How did this experience impact on your child and your family?

No definition of inclusion or exclusion was imposed, instead participants were asked to describe what this meant in the context of their family experiences.

It is important to acknowledge from the outset that our understandings develop in an ongoing way over time and thus the views of the participants reported in this paper are not fixed (Goodley 2007; Runswick-Cole 2008). Nonetheless, they provide insight into parent interpretations and lived experiences of disability.

In analysing the data initially I read and re-read the participant responses in full to enable immersion and facilitate strong familiarity. After revisiting the full dataset multiple times I then began to develop codes to enable me to begin to recognise emerging categories. As I re-immersed myself with the stories of each family I revisited these categories and began to identify relationships between, and diversities within, categories. Additionally, I compared participant responses in relation to the major focus areas evident in the guiding questions. Engaging in constant comparison enabled identification of repetitions and patterns emerging from the data as themes (Ryan and Bernard 2003). Through this process I refined and added to the categories, slowly building an understanding of the themes emerging from the participant responses. I repeatedly reviewed and refined the themes and contrasts and then considered these in light of the extant literature.

The extent to which the participants engaged with notions underpinning experiences of, and resistance to, oppression revealed an alignment with the writings of the Brazilian educator and philosopher, Paulo Freire (1970, 2004), in particular to Freire's writings on a pedagogy of indignation (Freire 2004), which therefore emerged as a useful tool in understanding the study findings, as discussed below.

Parent perspectives on inclusive education

Importance of inclusion

Each of the participants in this study identified inclusion, and inclusive education, as important to them and their families. However, in exploring the reasons for its importance, participants emphasised both the need to recognise the 'sameness' that comes from our shared humanity and the importance of valuing and accepting 'difference'.

The participants shared a range of factors that motivated their valuing of inclusion for them and their families. The significance of equitable opportunities and participation emerged as a key reason for the importance of inclusion. This was intertwined with the importance of inclusion on account of the human need for belonging, friendship, dignity, acceptance and happiness.

Inclusion was identified as a facilitator in enabling a person to both be and become. For example, one parent shared that her children:

> '… give so much but they can only do this when the people around them make the space for it. Exclusion prevents this and teaches them that they are "disabled"'. (Mother, Family #7)

Indeed, the theme of being a valued person emerged in relation to participants expressing the value of their child to them and to society. For example, families outlined that inclusion is important because:

> 'We are all dependent on each other and the world is better if we value everyone. Everyone is different but we are also alike to each other and everyone has something to give, this just isn't always recognised by those around.' (Mother, Family #4)

> 'Because we value each member of the family.' (Father, Family #8)

One family shared the belief that inclusion was important simply because they have a '*child with disability*' (Mother, Family #2), while for many families who do not experience disability inclusion may be taken for granted and not something to think about since *ex*clusion is not a common part of their lived experience.

In exploring the reasons that the participants believed inclusive education, specifically, was important, the participants discussed the benefits that they have experienced and their hope for their children and for the community. For example:

> 'Inclusive education is important to show the wider community that all people are different and are of equal value.' (Mother, Family #9)

The benefits of inclusive education for access to educational opportunities and the power of peer modelling were reported. Participants reported experiencing inclusion as making a positive difference in small everyday ways, thus enabling access to greater learning opportunities for all and contributing incrementally to positive attitudinal change. For example:

> 'It [inclusive education] provides greater opportunities for the child, and everyone involved learns to see people with disabilities as members of the community and so wider trends and attitudes slowly change.' (Mother, Family #1)

> 'School is one of the major places we learn about life and people. If everyone is included in their local school and in ordinary classrooms we get to know about difference in a concrete way. We

get to have relationships with diversity and to know that everyone is more the same than they are different.' (Mother, Family #6)

Some participants also raised the right to inclusive education as an key rationale for its importance. For example:

'Because everyone deserves the same rights no matter what your abilities and people with disability are always underestimated.' (Mother, Family #5)

The strongest theme that emerged in the participant responses regarding why inclusive education is important is the role that inclusive education can play in facilitating embracing of human diversity and valuing all people. Neatly summed up in the statement:

'Society is the less if each person isn't fully included.' (Mother, Family #7)

Understandings of inclusion

The rationale for the importance of inclusion to the families in this study reveals much about what these participants understand inclusion to mean. In further unpacking the meaning of inclusion, the notion of belonging emerged as a strong theme in the participants' perspectives on what inclusion means. All participants talked of inclusion as *belonging* either directly or in the form of being welcome, being a valued community member, and experiencing togetherness. A key aspect of belonging identified by the participants was valuing of difference as a positive aspect of human diversity, rather than seeking sameness or some construction of 'normal'. For example, one father shared:

'Inclusion means being a part of the group in the same way as other people, like in a family, in groups where difference is valued and the range of difference among the participants is recognised and accepted.' (Father, Family #8)

'Being welcome to participate in any community activity or attend any educational organisation that typically developing persons would normally be eligible to participate in.' (Mother, Family #9)

Access, opportunity and participation was another strong theme identified by all participants. For example, one mother explained that inclusion involves:

'Offering the same opportunities for all – for children who are disabled and children who are not.' (Mother, Family #6)

However, this was strongly linked to the need for appropriate support and assistance wherever needed to enable genuine opportunities. For example, one mother defined inclusion as:

'Everyone having the opportunity to do the same things together with whatever supports in place to make it possible.' (Mother, Family #1)

The participants strongly identified the importance of inclusion as occurring between people who do and do not experience disability, although two parents emphasised that this should not be to the exclusion of people who experience disability also experiencing togetherness, for example:

'*Inclusion is important to us as a family as we want our son to be accepted and welcome at school and in the wider community. We want him to have friends and to be able to participate in activities within our local community (in addition to having friends and participating in activities with other people with disabilities).*' (Mother, Family #9)

All of the participants returned again and again to the problems of prejudice and negative beliefs and attitudes at individual and systemic levels.

'*There are many loud anti-inclusion voices, with lots of support. The less blatant "it would be nice, but not practical" or "would if we could" brigade too. People assume we fall into that category, but for us if inclusion doesn't include everyone then is it really inclusion? How can people say they believe in inclusion and then exclude [child's name]? That's not inclusion.*' (Father, Family #10)

For the families in this study, inclusion requires freedom from such prejudice. This was particularly salient in relation to the provision of support for inclusive education. For example, one family explained that inclusion involves:

'*Being a member of the community who is able to do as others do with the assistance and adjustments needed to be able to do those things without being judged and without prejudice.*' (Mother Family #5)

Beyond the absence of such discrimination, the families in this study identified inclusion as the genuine valuing of each person – in all our diversity – such that each person has the opportunity to both contribute and have that contribution recognised. For example:

'*I know I keep coming back to it but being included is about fully participating and being appreciated and valued. It is about noticing and valuing difference. When everyone contributes and everyone's contributions are recognised, noticed, valued. We are all different and inclusion means valuing differences and the way people contribute through their differences.*' (Mother, Family #7)

Experiencing exclusion

These understandings of inclusion were both informed by family experiences and also served as drivers for change in striving towards more inclusive future experiences. The parents who participated in this study shared that their children and families had experienced both inclusion and exclusion, with exclusion and segregation often used interchangeably. Consistent with previous research findings (Lilley 2013; Mann 2016; Mann, Cuskelly, and Moni 2018; Poed, Cologon, and Jackson 2020), the families in this study reported gatekeeping, laced with a deep sense of othering, including exclusion during enrolment processes. For example:

'*A school we were making enquiries with, to enroll, in a preschool program repeatedly didn't return calls and made elaborate excuses when asked about it face to face.*' (Mother, Family #1)

'*Being told that the special school nearby would be better so our child would be with other people like her … As if she was her own species.*' (Mother, Family #3)

'*Being asked to leave the setting. The fact that there was a special unit made it impossible for him to be included in the mainstream as the staff were hell-bent on convincing us that really he should be in the unit.*' (Mother, Family #2)

Families reported being requested or required to have their child attend for only part of each school day, suspension, and frequent micro-exclusion in which a student was present but segregated with an aide or prevented from playing with other students. For example:

> '*Not being allowed to play with the other children as they may get hurt by the wheelchair and also not being allowed to go on excursions as they weren't wheelchair accessible venues and transport.*' (Mother, Family #5)

> '*My child attended a horrible (understatement) high school for just over 2 years ... they kept repeatedly suspending her and the suspensions kept getting more frequent and longer. ... Also, they kept asking me to pick her up and take her home whenever they alleged she had misbehaved. They seemed to always be angry with her and blaming it on me and always looking for excuses why she needed to be excluded rather than showing any effort to try to find ways she could be included.*' (Mother, Family #3)

These experiences also included family and community exclusion. For example:

> '*Excluded by relatives, friends, made to feel not welcome in community spaces.*' (Mother, Family #2)

> '*Being pushed to leave a sports team because other parents concerned that our child was bringing down the level of the team.*' (Mother, Family #9)

The participants reported experiences of exclusion both in terms of feeling they had no option but to 'choose' segregated settings and activities for their children and their family, against their own preference, but also experiences of exclusion within segregated, or 'special', settings and experiences. The sense of being at the bottom of a hierarchy within and outside of 'special' settings and experiences was evident. For example:

> '*It's like being at the bottom of the heap everywhere. In the mainstream people think he should be with "people like him" and in the special school people think he's pulling their kids down or like to let us know how much more advanced their kid is.*' (Mother, Family #2)

> '*Even when we go to groups for people with disabilities we get told that our child is too disabled. We have been told, this group is just for mild and moderate. Sometimes they don't say anything but just totally exclude [child's name], like left to the side doing nothing.*' (Father, Family #10)

> '*Special education is not special or education – it only serves to reinforce that students in these classes or classrooms are of less value than other students.*' (Mother, Family #7)

One parent summed up the everyday occurrences that add up to an ongoing experience of exclusion:

> '*Exclusion happens every day – not being invited to social events, being ignored when you speak to someone, being ostracised or bullied.*' (Mother, Family #6)

These experiences took their toll on the families in this study. While some participants addressed the practical strain imposed by exclusion, such as the drain on time and finances, all participants noted the deeply negative emotional impact. Participants reported that experiencing exclusion led to a realisation of the deeply devaluing attitudes of society. Parents reported trying to shield their children from the brunt of these experiences. However, this was not always possible. For example:

'We kept this from our child. It made me realise that not everyone will see her and her potential and be enthusiastic about trying stuff out.' (Mother, Family #1)

'It was very miserable. Two-and-a-bit years of hell really. Endless meetings with the school and with support services . . . It was intolerably difficult to see how this was affecting my child and how her resultant angry behaviours were impacting on everyone at home.' (Mother, Family #3)

Pedagogy of indignation

The participants reported that experiencing or witnessing the exclusion of their children led to a series of difficult emotional responses for all family members. One participant reported sometimes reacting to exclusionary experiences with a despairing desire to 'give up' and reject her child herself. Expressing that it made her feel *'Like I wanted to put my child in a home so I could have a normal life with my other child'* (Mother, Family #2). The participants reported experiencing disappointment, loss of confidence, and feelings of isolation and pain. Feelings of anger emerged as the strongest theme in the participant responses regarding the impact of exclusion. Anger that, as Freire (2004, xi) argues, is 'an appropriate response to obscene violations of human rights and social injustices'.

'It angered us, especially our other children as they didn't want to see their sibling miss out on the exciting experiences the other children were getting.' (Mother, Family #5)

'It is painful to witness exclusion and has the potential to make the vulnerable person feel worthless.' (Mother, Family #4)

'He was very hurt. He expressed anger, he lost confidence. The family felt the pain that goes with knowing that your loved one is not seen or valued.' (Mother, Family #7)

When asked what factors the participants believed led to this exclusion, strong themes emerged around the impact of fear, and prejudiced and ill-informed attitudes, including the assumption that *'the child doesn't understand what they are missing out on when in fact they did'* (Mother, Family #5). Participants emphasised the negative impact of lack of education and societal devaluing of people who experience disability based on a historical and ongoing acceptance of segregation. For example:

'Society is deeply unconscious of its rejection and devaluation of people who are different but this plays out in the way society treats vulnerable people individually and as groups particularly by segregating and congregating vulnerable people away from ordinary life.' (Mother, Family #6)

Inflexible practices and attitudes were also identified as leading to exclusion, even when this resulted in flagrant disregard for legislation and policy. Competitiveness at any cost and concerns about funding were also raised. For example:

'The key factor was a very rigid and unrelenting attitude by the principal, vice-principal, head teacher and some other key staff. They refused to budge and their attitude was fully condoned by the regional staff who added to the problem. They also refused to follow any procedural fairness.' (Mother, Family #3)

'Competitiveness on the part of the parent and a focus on winning at all costs, plus a stereotyped view of our child's abilities.' (Father, Family #8)

And yet, again echoing Freire, with a deep sense of resistance to the disabling discourses and material barriers presented in ongoing ways to these families, this anger was not without hope.

> 'We made the decision to send our profoundly disabled child into mainstream education and after some resistance from the staff at the school and some excellent and unexpected results from our child and also with a lot of support from our family they are seeing the benefits for our child as well as the other children in the school.' (Mother, Family #5)

The parents who participated in this study expressed hopefulness for their children's future, alongside a strong commitment to provide every possible support that they could to realise these hopes.

> '… every day we strive for life to be inclusive for our family member – an inclusive life or experience is not a program or an event. There are no 'special' programs or 'special' groups as part of the inclusive life. Opportunities are limited by the expectations, or lack thereof, of others.' (Father, Family #10)

In the face of the dominant, deficit, and disabling discourses imposed upon these families, the families expressed hope that ultimately their children would be included within and beyond education settings and thus flourish as valued and recognised participants in the world:

> '… to experience the fullness of life in the same ways as siblings and other family members and peers.' (Mother, Family #6)

> 'To be a member of his community and to contribute and add value to his community.' (Mother, Family #4)

Discussion and conclusions

> 'The radical, committed to human liberation, does not become the prisoner of a "circle of certainty" within which reality is also imprisoned. On the contrary, the more radical the person is, the more fully he or she enters into reality so that, knowing it better, he or she can better transform it. This individual is not afraid to confront, to listen, to see the world unveiled. This person is not afraid to meet the people or to enter into dialogue with them. This person does not consider himself or herself the proprietor of history or of all people, or the liberator of the oppressed; but he or she does commit himself or herself, within history, to fight at their side.' (Freire 1970, 39)

The parents who participated in this research, in fighting alongside their children for even basic human rights, frequently found themselves in something akin to the role of the 'radical' that Freire describes. A role within which these parents experienced multifaceted everyday exclusion of their child and family, identified many barriers at interpersonal and systemic levels, and yet saw also the hope, possibilities and benefits of inclusion. Fuelled by the seeds of a pedagogy of indignation, these parents shared of their active resistance to exclusion and segregation and ongoing battle for their children to be valued members of their educational and wider communities. In listening to these parents it is clear that this was not a role they anticipated or set out to fulfill, nor a role they ought to have to fulfill given the human and legal right to inclusive education. Rather it is a role these parents found themselves forced into in the face of systemic and interpersonal

barriers which are influenced by, and which influence, the commonly narrow and exclusionary attitudes that many in society hold towards people who are labelled with 'severe or profound' impairments. There are many facets of this experience. However, in this paper, the focus is specifically on the participant views about, and experiences of, inclusion and exclusion in education.

Each of the participants in this study reported that inclusive education is of considerable importance to them and to their families, but that the fight for inclusion is frequently a long, arduous, and often painful one. These parents revealed aspects of their own battles to bring about inclusion for their families.

While the participants in this study all expressed the importance of inclusion and inclusive education, it is important to note that this may not be the case for all parents of students who experience disability. After all, parents of students who experience disability are subject to the same processes of enculturation into an ableist society as anyone. Additionally, the experience of exclusion can lead parents to believe that formal segregation may be less detrimental than the segregation frequently experienced through micro-exclusion mis-labelled 'inclusion' (Cologon 2014b; Mann 2016; Runswick-Cole 2008). The constant challenge of continually fighting for inclusion can wear parents down to a point of feeling unable to persist with such advocacy (Cologon 2014b; Mann 2016; Runswick-Cole 2008). Furthermore, parents may not even be aware that inclusion and inclusive education is an 'option' (human right) for their family (Cologon 2014b). However, it is clear from the families who participated in this study that it is not the label or 'level' of impairment that determines the desire for, or possibility of, inclusion and inclusive education. This study contributes to further understanding parent perspectives and experiences and, in doing so, deepens our understandings of what inclusive education means in the lived experience.

Given the findings of previous research, as discussed earlier in this paper, it was unsurprising that the parents who participated in this study shared that they found important benefits of inclusive education for their children and their families.

As noted earlier in this paper, it has been previously identified that a belief that students labelled with 'severe and multiple' or 'profound' impairments are 'too disabled' to be included is common (Graham and Sweller 2011). In contrast, the participants in this study all identified the importance of inclusive education and shared of their family experiences of inclusion. Participants identified being valued and valuing human diversity as key to inclusion and inclusive education. Within this, parents identified inclusion as being important for and resulting in belonging, friendship, dignity, acceptance and joy. Opportunity and participation, made possible through support as needed, were experienced as both the outcomes and the means to inclusive education. Participants shared that inclusive education involved both being and becoming as a process of growth for everyone involved. The participants also reported working hard and tirelessly in seeking to obtain an inclusive education for their children.

Based on the participant perspectives, inclusive education can be understood as occurring with diverse groups of people in non-segregated settings. However, some parents in this study were keen to emphasise that identifying the problem of segregated settings and systems is not in any way to devalue shared and voluntary leisure time between people who experience disability. The participants in this study experienced and understood inclusion to mean belonging, togetherness, access, opportunity,

participation, and valued and recognised contribution. Underpinning and guiding this inclusion was a valuing of difference and human diversity – without pretence or efforts towards sameness – and the adoption of an actively anti-biased approach to education and human interaction, including addressing ableist prejudice and discrimination.

However, consistent with previous research (Graham and Sweller 2011; Kleinert et al. 2015; Kurth, Morningstar, and Kozleski 2014), the participants in this study indicated that exclusion and segregation were a common part of their experiences as they encountered frequent misunderstandings of inclusion, along with micro and macro exclusion. This included negative interpersonal interactions with adults and peers, such as bullying, both within so-called 'inclusive' settings, as well as within segregated settings, and the expectation that inclusive education was conditional and dependent on the student changing to fit the setting, rather than on providing inclusive settings for all. The notion of the continual question mark placed over the right of the student to be 'included' (Bridle 2005; Cologon 2013a; Rietveld 2010) was echoed in this research.

Also consistent with previous research (Poed, Cologon, and Jackson 2020), gatekeeping was a common experience reported by all participants in this study, as were demands for partial attendance, frequent suspensions, and of students being segregated (physically and/or within the curriculum) within the classroom (both in 'mainstream' and 'special' settings). Participants shared that the experiences and threats of exclusion, and the ongoing need to battle for inclusion, were wearying and painful, with the illusion of 'choice' between inclusion and segregation experienced as a furphy and seemingly 'salt to the wound', as segregation was foisted upon these families. Some participants expressed the view that the very existence of parallel systems of education ('mainstream' and 'special') constitutes a major barrier to inclusion. This finding runs counter to the argument that the provision of parent 'choice' is a justification for segregated education.

In considering 'who is in and who is out' (Slee 2013) it is clear that the experiences of the families who participated in this study chime with that of extant literature in that, while certainly not alone in being excluded, those of us who are labelled as having 'severe and multiple' or 'profound' impairments are often the first to be counted out of the inclusion equation (Kleinert et al. 2015; Kurth, Morningstar, and Kozleski 2014). Following Slee, the question then becomes 'how come?' Robinson and Goodey's (2018) theorising of a historically constructed and dehumanising 'inclusion phobia' is illuminating here. For the participants in this study, this was expressed in regards to the violation of the presumption of inclusion that is afforded to most students who are *not* labelled and constructed as 'other' to the mythical 'normal student'. The seemingly frequently unexamined and continuing, though historical, assumption that there are some students who will not benefit from education in a 'regular setting' is revealing of the 'othering' nature of segregation and of a fundamental shift in thinking and practice that participants identified as being required to bring inclusive education to a reality. Indeed, the notion that 'some students' will not benefit from inclusive education belies the now internationally accepted definition of inclusion and is certainly confounded on account of the micro-exclusion that is frequently mis-labelled inclusion.

Similarly to previous research identifying the challenges for families of stigma and discrimination (Lilley 2013), the participants in this study expressed the pain and anger that was caused by exclusion. A pain that sometimes led to overwhelming anger or

despair and sometimes, as noted above, to what can be understood as a 'pedagogy of indignation' (Freire 2004) – anger and resistance to exclusion, infused with determination and hope in advocating for inclusive futures.

Alongside inclusive attitudes, the participants in this study emphasised the importance of the provision of appropriate support, as needed, in order to enable access, opportunity and participation as a key to facilitating inclusive education. Previous research identifies that concerns regarding inadequate support in 'regular' settings are commonly raised as a barrier to inclusive education, with a need to address the financial and practical concerns regarding providing appropriate supports across education settings (Kurth, Morningstar, and Kozleski 2014).

Segregated education is frequently justified as 'better for some' on the basis of a series of assumptions about the typical differences in school structure between 'regular' and 'special' school settings. For example, the seemingly logical, though unsubstantiated, belief that the higher teacher to student ratios, intensive resourcing, and more specialised teacher education expected in 'special' settings would result in better outcomes (Kurth, Morningstar, and Kozleski 2014). Additionally, it is sometimes argued that inclusive education may be detrimental to the education of so-called 'regular' students. However, in contrast to these assumptions and arguments, the extant body of research investigating the outcomes of inclusive education provides evidence to demonstrate that inclusive education has equal or better outcomes *for all students*, and the more time a student is included, the greater the benefits for educational outcomes (Cosier, Causton-Theoharis, and Theoharis 2013). Of particular relevance to this paper, this includes equal or superior outcomes for students who are labelled as having 'severe and multiple' or 'profound' impairments, as noted above. In relation to the benefits of inclusive education for all, the participants in this study focused on the importance for all of belonging, valuing human diversity, and recognised contribution, as well as benefits of inclusion for quality educational opportunities for all.

In addition to the outcomes-based evidence in support of inclusion, as noted earlier, Article 24 of the CRPD clearly stipulates that it is the right of every person to access an inclusive education from the early years onwards. With 162 signatories to this Convention at present (United Nations Treaty Collection, 2019), this means that the right to inclusive education has been accepted as international law by the overwhelming majority of the nation states of the world. Since almost all of these signatories to the CRPD have also ratified the Convention, this means that they have also made a formal agreement to bring the rights contained within the CRPD, including the right to inclusive education, into national legislation, policy and practice, resulting in a national and international legal imperative for inclusive education. The findings of this study are illustrative of violations of this human right.

In 1999 Lipsky and Gartner argued that '[t]he manner in which we choose to educate students with disabilities is a consequence of the ways in which we view disability' (14). The experiences shared by the participants in this study indicate that two decades later dominant social discourse continues to present a strongly negative perspective from which, at best, those of us who experience disability are viewed patronisingly as 'poor things' in need of 'charity' or 'pity' with charitable acts on the part of those of us who do not experience disability underpinned by an often unspoken sense of 'thank goodness it's not me' (Cologon 2014a). At worst, people who experience disability are fully dehumanised to the point that total 'eradication' or 'elimination' of the 'problem' is viewed as the

only desirable course, to the point that death is often viewed as preferable to life with disability (no matter how carefully couched in dehumanising terms to reduce the conscious horror of such a course of action) (Cologon and Thomas 2014). Clearly this dominant discourse holds extremely negative implications for students and their families who experience disability, and the participants in this study highlighted the practical as well as the painful emotional toll of this discourse.

In relation to education, even at the mildest end of this spectrum, these 'tragedy' views of disability and conditional understandings of 'inclusion' prevent inclusion and provide the groundwork for a 'circle of certainty' (Freire 1970) within which some of us are viewed as unable to be included and whereby, as illustrated through the participant stories in this study, certain pre-requisites are required of a person, *rather than of an education setting*, in order for 'inclusion' to occur (Hodge and Runswick-Cole 2013). Troublingly, this 'circle of certainty' becomes a taken for granted 'truth' that then sits, unexamined, at the base of individual and systemic decisions regarding the education of students – who, by way of being labelled, become subject to the question of whether inclusion is possible/permissible for that individual, and under what conditions, rather than the presumption of inclusion that is generally afforded to those of us without labels. As noted above, this process then underpins the illusion of 'choice' presented to parents regarding the education of their children (Lilley 2013; Mann 2016; Mann, Cuskelly, and Moni 2018). In the face of this 'circle of certainty' families, such as the participants in this study, for whom inclusion is important often find themselves either forced into the role of 'radical', or into accepting ongoing segregation and exclusion. While many families do resist these tragedy perspectives (Calderón-Almendros and Calderón-Almendros 2016; Cologon 2016) – and the exclusion that comes with them – as identified by the participants in this study, this is not an easy task for these families, nor is it a justifiable expectation. Indeed this situation is tantamount to laying the 'blame' for oppression on students and families, rather than recognising that the systems and societies we live in are ableist. This highlights the need for substantial social change in relation to disability and inclusion, within and beyond education. 'Listening' to the perspectives of the participants in this study as they shared their family stories brings into sharp focus the inadequacy of current approaches to inclusive education, and the need to fully engage with *inclusive education as transformation* – a transformation to education settings and experiences that enable and are underpinned by a genuine valuing of all people in all our diversity and a flexible and responsive approach within systems and individual settings. 'Hearing' these family stories highlights the change that is needed and can be understood, ultimately, as a call to action. Taken together with previous research it is clear that inclusive education for all is not only possible, but has positive outcomes and is of considerable importance to many families.

As Freire (1970) argued, the political act that is education reflects the principles and values of the people and society of each time. The question then becomes what values do we hold, as individuals and as a society, and what values do we wish to hold going forward. Reflecting on the experiences and perspectives of the families who shared their stories in this study, and their understandings and experiences of inclusion as a valuing of human diversity, let us return to the challenge posed by Slee (2013), in which inclusion involves questioning 'Who is in and who is out? How come? And, what are we going to do about it?'

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Disclosure statement

Notes on contributor

Kathy Cologon is an academic in inclusive education at the School of Education, Macquarie University, Australia. Kathy's research focuses on inclusive education and disability studies.

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