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Beyond glitter and glue: The significance of context in including children with intellectual disability in well-being research

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1 Introduction

1.1 Children with disability and child well-being research

The theoretical approach of children's rights movement and new sociology of childhood emphasise the construction of children as social actors and knowing subjects, and as a distinct social group with their own particular needs, rights and ideas about a good life (see Hunner-Kreisel & Bohne, 2016; Hunner-Kreisel & Kuhn, 2010). This movement has increased the focus on child well-being and driven the imperative for children to be active participants in decision-making about their lives in policy and practice. For example, in the framing of Australian policies on child maltreatment, both child well-being and the engagement of children as participants in decision-making are emphasised (Commonwealth of Australia, 2009; NSW Government, 2006; Queensland Government, 2010). Similarly, engaging children as participants in decision-making has been central to research which repositions children as subjects, rather than objects, of research, able to contribute as experts to knowledge on their own lives and on what constitutes well-being for them (Drake et al., 2019; Fattore, Mason, & Watson, 2007; Goswami, 2014).

While children with disability can be assumed to have the same right as other children to be heard on issues relevant to them (United Nations, 1989, 2006), research suggests that children with disability, especially children with complex needs or communication impairments, are much less likely than their peers to participate in decision- making about their own lives (Franklin & Sloper, 2009; Martin & Franklin, 2010; McNeilly, Macdonald, & Kelly, 2015), at the policy and practice level and in research. At the research level, there have been very few attempts to purposively include children with disability in studies seeking to obtain in-depth knowledge about their lives and well-being - asking children themselves how they understand well-being (see Beresford, 2012). This significant lacuna in child well-being literature has important theoretical, methodological and policy implications. Feldman and colleagues (2013), commenting on developmental research generally, have suggested that the exclusion of children with disability from such research means that they 'are being denied their right to participate in and benefit from' this research.

Additionally, 'excluding children with disability from developmental research questions the validity of such research for all children' (p. 998). It is argued that the exclusion of children with disability from research on childhood raises questions about the validity of normative constructions for developmental scales (McFadden, 1996), based for example, on the construction of stage theories of development (Piaget, 1936). Scales used to assess the development of children with disability, often include only ‘normative’ research samples that exclude children with impairments (for example Luiz, Barnard, Knoesen, et al. 2006). In so doing, these scales do not account for all children, and children with disability are seen as outsiders rather than part of normal human variation. This is because assumptions of universality and an ideal adult endpoint, inherent in normative constructions of developmental stages, ignore the significance of individual differences and of contextual factors that contribute to these differences.

In developmental research where children with disability have been the focus, it has typically been as objects of study in terms of understanding, remediating, or supporting their conditions, and where knowledge about their Quality of Life have been sought, it has generally been through parental and professional perspectives (Llewellyn & Leonard, 2010). Where, in research on child well-being, children are asked for their views and experiences (Ben-Arieh & George, 2006; Camfield, Streuli, & Woodhead, 2008; Fattore, Fegter & Hunner-Kreisel, 2016; Fattore, Mason, & Watson, 2012; Goswami, 2014; Savahl, 2009) the lack of involvement of children with disability is evident (Beresford, 2012; Llewellyn & Leonard, 2010). Llewellen & Leonard (2010) note that in the reports on child well-being that consider childhood disability, disability is constructed as a ‘marker of poor health’ (and consequently poor well-being). They highlight that children with disability are ‘a group for whom a distinct consideration of well-being is merited’ (p.6).

In this paper, we present details of an attempt to include and understand the well-being of children with disability in the Australian component of a large multinational study on ‘Children’s subjective Understandings of Well-being’ (CUWB) (Fattore, Fegter, & Hunner-Kreisel, 2018). The multi-national comparative qualitative study ‘Children’s understandings of well-being – global and local contexts’ (CUWB)[1] is currently underway across 29 countries. In implementing this qualitative research project it is acknowledged that the concept of well-being is, philosophically and culturally contested and that the resulting constructions are generally adult-centric, so that children are typically excluded from contributing on what well-being is for them.

The broad project aims to explore how well-being may be defined and understood perhaps theoretically as a normative construct, as a subjective assessment or as an open concept to be interpreted through research (Fattore, Fegter, & Hunner-Kreisel, 2018). The constructions of children’s well-being within the project form the basis for ‘analysing the normativity of their constructions of well-being; by explicitly accounting for the context in which these constructions are developed’ as the project attempts to address the ongoing challenges associated with integrating children’s perspectives on well-being in research, including the relationship between participation and protection (Fattore et al, 2018, np.).

In the next section we place the challenges, that relate specifically to including children with disability in contributing their constructions of child well-being, in the context of our attempt to respond to the imperatives that Carpenter and McConkey (2012) identify for researchers seeking to promote holistic responses by policymakers to the needs of children with disability. The three imperatives identified are: ‘the moral imperative’ to listen to children living with disability: ‘the practical imperative’ to ensure that approaches and methods are designed to

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[1] http://www.cuwb.org/

enable children with different abilities to be heard in research about their lives, and 'the conceptual imperative' to ensure that 'research methods are better integrated, theoretical frameworks more coherent, and that multi-disciplinary enquiry becomes the norm'. Following a brief discussion on how our research responds to these imperatives the main section of this paper provides details of the ways in which we implement the practical imperative, through specific research methods. The final section of the paper discusses the findings on the methodology and methods employed in the study, derived from our reflections as a team as we implemented the pilot. We make some concluding comments on the significance of these findings and the opportunities for further research.

1.2 Responding to the moral, practical and conceptual imperatives for involving children with disability in research on well-being

The moral imperative for understanding what well-being means for children with disability is the necessary response to the contemporary social contexts of the lives of these children. Firstly, as a result of improved health care, more children are "surviving severe and chronic conditions" (Moore & Oberklaid, 2014), which in the past may have led to premature death. Other children live with terminal conditions under the constant care of health services and with health professionals as regular persons in their lives. While some children may prosper and manage these challenges, for others achieving a reasonable quality of life with illnesses or disability can be difficult and problematic, and young people with intellectual disability are at higher risk of developing mental illness (White, Chant, Edwards, Townsend, & Waghorn, 2005). The impact of disability on children's quality of life is poorly understood but needs to be considered in the light of research that has shown the disabling effects of structural, social and attitudinal barriers on the lives of the disabled. These environmental impediments to well-being cannot always be separated from individual experiences of physical, cognitive or sensory impairments (Morris, 2001; Oliver, 1996).

Secondly, notions of disability are often pervaded by assumptions about children's well-being (2010, p. 6). For example, decisions to abort on the basis of positive pre-natal test results are often made on the judgement about the child's expected quality of life (Gillam, 1999).

Thirdly, the increasing delivery design of services to children with disability within community must include understanding of the child's well-being within complex and changing social ecosystems including family, educational, recreational and employment arenas. The societal context including the physical, attitudinal and communication milieu in which children with disabilities live their lives has important social policy implications (Watson, 2012). The complexities of understanding the well-being of children with disability within these social contexts, and in developing appropriate service delivery strategies, make it vital that the child's perspective is heard and understood in planning supports, and other interventions in their lives that effectively respond to their needs and well-being.

Responding to Carpenter and McConkey's practical imperative of ensuring that research 'approaches and methods are designed to enable children with different abilities to be heard in research about their lives' is the focus of the study reported on is this paper. As part of the Australian segment of the broader research project on children's understanding and experiences of well-being (CUWB), we treated this smaller study as a pilot, trialling various qualitative research methods in a way that enabled us to be flexible in the strategies used for communication with the children who participated.

Carpenter and McConkey describe the conceptual imperative as ensuring 'that research methods are better integrated and theoretical frameworks more coherent and that multi-disciplinary enquiry becomes the norm'. In terms of our approach to the design of the study and our theoretical framework, we based the design of our pilot study on the original CUWB protocol (Fattore et al., 2019) which involves 'two intersecting analytical dimensions – a child-centered dimension and a socio-cultural context dimension'. Conceptually our pilot study, like the broader study, 'interrogates from children's perspectives the meanings of well-being to determine how different dimensions of well-being are understood within and across different contexts', by focusing on the context of children who are in an Australian school specialising in educating children with disability. Like the broader study 'we are starting from a position that constructs children as social and moral actors who can provide narratives about their understandings and experiences of well-being'. While the broader study focuses on 'reconstructing the social and normative ordering of children's concepts of well-being', and this conceptually influences our approach in this study, we are here focused on the participatory dimension of the broad study, exploring, within the broad study's methodological approach, methods to enable children with disability to participate on the topic of well-being.

2 Implementing the practical imperative

2.1 Methodology

In order to engage children with disability in research, an inclusive participatory approach should be considered in the early design stage (Feldman, Battin, Shaw, & Luckasson, 2013). It has long been said that inclusion is not a single fixed entity (Clough & Corbett, 2000) with clear parameters, but 'a bewildering concept which can have a variety of interpretations and applications' (Avramidis, Bayliss, & Burden, 2000, p. 158). For the purposes of explaining our research approach, processes and methods, our definition of inclusion (and inclusive research) is based on the notions of identifying and reducing barriers (Booth & Ainscow, 2002), while increasing flexibility and supports in order to facilitate research participation. With this in mind, we commenced the pilot study with the clear objective of making our research approach accessible to children with a range of cognitive and communication abilities at a school for children with intellectual disability.

In this process, additional to being informed by the childhood sociology (James, Jenks, & Prout, 1998; Prout & James, 1990) as the broad CUWB project is, the epistemological basis to our inclusive approach was informed by critical disability studies (Barnes, Mercer, & Shakespeare, 1999; Oliver, 1992; Thomas, 1999), which are complimentary, both concerned with rights and participation, and the active agency of those with whom they research (Watson, 2012). Further, this study has taken account of previous research combining the principles of disability and childhood studies, which have shown that children and young people with learning or developmental impairments (Connors & Stalker, 2007; Kelly, 2007) and Autism Spectrum Disorder (ASD) (Mogensen & Mason, 2015) can significantly contribute to understanding children's lives from their own experiences.

Sociology of childhood theory is important when researching with children, because it recognises children 'as active in the construction ... of their own social lives, in the lives of those around them and of the societies in which they live' (Prout & James, 1990). In researching with children with disability, the principles of critical disability studies - grown from the social model of disability (Oliver, 1990) are equally important in framing disability in terms of social relations (Watson, 2012), enabling the differentiation of disability from impairment, and recognising the effects of both on the lives of people with disability. The disabling effects of structural, social and attitudinal barriers on the lives of people with impairments – ‘the disabled’, are understood as often being more problematic than the direct effects of physical, cognitive or sensory impairments (Morris, 2001; Oliver, 1996). For this research, differentiation between disability and impairment is significant as we focus on addressing the typical [disabling] barriers in research that may inhibit children with intellectual disability from engaging with the research methods. This epistemological approach is evidenced in the strategies outlined in this paper. We use the term ‘children with disability’ rather than ‘disabled children’ in the acknowledgement that the children in this project did not identify as or refer to themselves as disabled.

2.2 Recruitment and Setting

Recruiting children to research typically occurs through social structures and adult gatekeepers in the spaces that children occupy, whether it be the family home, community or places of education. Lambert and Glacken (2011) suggested that while many studies were acknowledging children as knowing and agentic individuals, the discourse of the vulnerable child still dominates most research. As such, this discourse is in conflict with the construction of children as agentic and competent, that underlies our research methodology, and much other research where children are participants. Recruitment becomes particularly complex when seeking to involve children who ‘occupy a more liminal position within childhood’ (Cocks, 2006), such as children with disability, whom are typically excluded from general research about children (Feldman et al., 2013).

In commencing this pilot study, we took into account our earlier unsuccessful attempts to gain access to child participants with disability in mainstream settings, despite emphasising in our participant information and protocol that all children including those with disability were invited to partake in the research. The requirement to access children through multiple adult gatekeeping institutions in itself emphasises the construction of children as vulnerable, dependent and incompetent, requiring the protection of adults. The particular emphasis on vulnerability and need for protection of children with disability typically means for us as researchers, the need to proactively develop approaches specifically tailored and focused on inclusion. For this study, we also needed to satisfy additional child protective requirements of the university ethics review board, which also defines children as a vulnerable rather than agentic population.

When recruiting vulnerable children to research, developing trust is also even more important than with children generally. For this reason we utilised the personal connections the team members had with a special education school to facilitate access to this population for the purposes of inviting parents and children to participate. Access to the children involved negotiations with the executive personnel at the school, who after agreeing to partake in the study, decided which children and parents could be approached. We then needed to negotiate with the parents of the children, and the teachers in classes where the children were participants.

The majority of children with disability in Australia are educated within mainstream settings, whereas around 10% are educated in schools for special purposes both within the private and public education systems (Australian Government, 2016). These special schools cater for children with higher educational support needs related to intellectual disability, physical disability, sensory impairments and Autism Spectrum Disorder (NSW Legislative Council, 2017). The school we approached is a private, faith-based school that specialises in educating children with mild to moderate intellectual disability. The school is located on acreage in a semi-rural location, outside the main town, and offers preschool, primary school, and high school education as well as an early intervention program and a post-secondary pathways program for school leavers. For enrolment, the children do not need to be of the faith on which the school is based. Rather, the school seeks to enrol children they estimate as likely to benefit most from their teaching approach, and offers fee scholarships for disadvantaged children.

The school management team was instrumental in recruiting participants by distributing the study information to the school community and obtaining parent/carer consent. In hosting the research, the school limited recruitment to two school classes both of which included children with a range of diagnoses, communication and cognitive abilities. The decision to limit the research to two classes was pragmatic for the school, in terms of scheduling research visits in between other school activities. The school staff approached the parents of the children in these two classes and provided them with information about the study. After this formal contact, aspects of the participatory approach were implemented, whereby parents were asked to talk with their children about the study and to give their consent to allow the researchers to approach the children and engage with them as part of the research process, if the children themselves agreed.

The dilemmas that can arise in the process of gaining children’s consent to participate in research, due to the juxtaposition of the conflicting constructions of children’s competency (Bradbury-Jones & Taylor, 2015; Tisdall, 2012) were in this study heightened by societal understandings of children with disability as doubly vulnerable. The researchers experienced a particular conflict when some children, for whom participation had not been consented to by their parents, wanted to participate in the research along with their friends. When we were not able to include these children in research activities, the teachers had to manage their disappointment and engage them in other ways. As inclusive researchers, we found this exclusion of children wishing to participate challenging. We sought to find ways to let them engage with us and with their friends in activities outside the research. For example, one day a few of the children, for whom consent had not been granted, had experienced an incident in the school yard that they were keen to tell us about. We sat with them and listened, but this information was not treated as part of the research.

The participant sample for this pilot study included 15 children; seven girls and eight boys, aged 12-16 years. They were children from the two classes selected by the school, who had parental consent, and whom, following the ‘meet and greet’ stage described in a subsequent section, indicated by assent that they were willing to engage in the research activities. Assent involves gaining the individual’s agreement or willingness to participate in the process when others (in this case parents) have given consent (Lewis & Porter, 2004). Seeking assent in an inclusive framework is then understood as an ongoing process which, when working with children with varying cognitive and communication abilities, requires the researchers to remain observant of each child’s responses and actions throughout the research process and to be alert to signs of discontent or boredom from the child. Cocks (2006) argues that:

> “the process of seeking ‘assent’, when used within an ethical framework, is a more comprehensive method of gaining the agreement of children in research, which transcends language, ability, cultural, social and international borders” (p. 247).

In this study, the children were informed that they could choose whether they wanted to participate, and could refuse questions by saying ‘no’ or using flash cards with ‘no’ printed on them. The children themselves were in control of what information they shared. As researchers we respected their right to be silent or refuse to respond, though this right sometimes had to be reiterated with the teaching staff, who work under a somewhat different premise to engage children.

2.3 Developing methods and strategies to include children with a range of abilities

Flexibility in research design and sensitivity in implementation of methods were built into the original CUWB protocol, with considerations that the approach needed to be inclusive of children in many different contexts across countries, languages, and cultures. This protocol included a range of methods (interviews, drawings, photos, videos, group activities), which were offered to children in two stages (Fattore et al., 2018).While several of these methods were considered appropriate for the children in this pilot study, we also needed to consider how best to engage with children with a range of cognitive and communication abilities. Flexibility and adaptation during the research processes has been found to be of major importance for facilitating meaningful engagement in research with children with cognitive and communication impairments (for example Davis, Watson, & Cunningham-Burley, 2000; Kelly, 2007; Mogensen & Mason, 2015). We made several visits with the children to build rapport, and iteratively revised topics and approaches in response to the way the children responded. We also made changes to the methods as a consequence of reflection and discussions of fieldwork experiences by the researchers.

Table 1 outlines the activities used to engage with the children in various ways in this study. The first four activities were semi-structured exercises led by the researchers within the classroom to facilitate children’s views on different aspects of well-being. Activities 1, 2 and 4 were part of the original CUWB protocol, activity 3 was added as the children were used to working with emoticons as part of their school days. The resources provided for these activities included white and coloured paper, crayons, pencils, coloured markers, glitter, glue, stickers, and scissors. The ‘Guided tour’ of the school was a child-led method developed by the researchers to learn about children’s everyday experiences of well-being through observations and engagement, and to include children who did not use speech or other formal methods of communication.

Table 1: Activities for engagement

Method	Process	Purpose
1.‘About me’ questionnaire	Guided, semi-structured conversations with children	To gather data on demographics and individual context
2.Personal Maps	Drawings and artworks using glue, textiles and glitter	To talk about the things, people and places that made children feel good or well
3.Emoticon prompted drawings	Drawings and artworks using glue, textiles and glitter	As prompts to talk about feelings: What makes children feel happy/good/well or Sad/worried/angry
4.Small focus group discussions	Guided discussion - drawings and artworks on recognised child wellbeing concepts as chosen by children: school,	To explore children’s views and understandings of these concepts derived through surveys in the Children’s World study.

	safety, money, agency, being listened to	
5.Guided school tours	Student led tours of the school – 2-3 students	To ask questions about daily activities in the school that children said made them feel good or well and engage with the children in some of these. - to observe the children’s interactions with each other and staff who happened to be in those spaces - to observe how children negotiated their friendships

2.4 Reflexive Analysis

The use of a reflexive approach (see Davis, 1998) to analyse our use of inclusive methodology was a key aspect of this pilot study, in which we continually considered the ways in which children engaged with activities and responded to three researchers (LM, JMc and ME see acknowledgements), who have different disciplinary backgrounds. All three also have clinical and/or professional experience in working with children (developmental paediatrics, occupational therapy and social work, social policy), as well as training and experience in interviewing children with disability. The different backgrounds in working with children allowed reflection from multiple disciplinary perspectives, which were captured in team discussions of field notes and of the research methods and engagement with the children after each visit.

This included noting which activities more successfully engaged the children and which activities they shied away from. We also discussed the interactions between children and teachers, children and researchers, and the potential influence of official school notices and rules, classroom decoration and ethos on children’s responses to the research activities. We amended methods and communication strategies as we felt necessary and new ideas, in particular the guided school tours, were trialled.

At least two researchers were present at each visit to guide activities, with a teacher and/or education assistants present when working in the classrooms. The researchers asked the children and the teachers for permission to record the visits, and to take photos of the maps and drawings created during the activities. These artefacts supported analysis of the verbal transcripts. Some children wanted photos of themselves and with their friends or with the researchers, while others did not want to be photographed. Most of the recordings were transcribed by a professional service. When excessive schoolyard noises or limited speech by some of the children meant a few recordings from the guided tours were difficult to transcribe, additional field notes by the researcher present at the time were included as data. Recordings of the research team’s reflective dialogues following each visit were also transcribed for inclusion in the analytic process. Preliminary analysis of the data generated by the children on the topic of well-being has at this point just commenced, and will be completed with review by the children if feasible, before being included in the CUWB findings. Our focus in this article is on the analysis of the use of methods in the pilot study, and we present our reflection of these in the next section.

3 Reflecting on methods and strategies

3.1 Pre-research consultation with children

When seeking to include children with diverse cognitive and communication abilities, it is very useful to get to know the children ahead of data collection to help prepare the research methods well in advance (Mogensen, 2010; Mogensen & Mason, 2015). This meant that the more typical way of commencing the research process with children in the broad CUWB study (Drake et al., 2019; Fattore et al., 2018), was modified in this pilot study. The engagement with children and teachers during a first visit, which had functioned as an icebreaker and 'getting-to-know-you' activity in the broad CUWB study, was supplemented in this pilot study by more focus on gaining rapport with the children, to enable us to begin to understand their individual communication abilities, preferences, and requirements, in order to plan appropriate research activities.

The researchers visited one classroom at a time. While seated in a large group, the children were introduced to the researchers and the study. They were given photos of the researchers to hang on their noticeboard for scheduling visits. The children were then asked to introduce themselves by creating 'maps' of their daily lives, to include the things, people, places and activities that were important to them, and those that made them feel well or good. While children were working on these maps, the researchers individually approached one child at a time inviting them to talk about their 'map' and about themselves using the 'about me' conversation tool. The conversation tool was a proforma of prompts used to guide conversations with children about themselves, their families and people of significance, kept flexible to support engagement and understanding. While most children were able to respond verbally or through their artwork to questions about parents, siblings and pets, as discussed in the next section, it became clear that some children required additional communication support to ensure that we understood each other correctly.

3.2 Communicating and engaging with the children

Young people with complex communication and cognitive impairments are typically those excluded from or silenced in research (Beresford, 1997; J. M. Davis, 1998; Jenny Morris, 2003; Preece, 2002), and a specific aim of this project was to find ways to include the participants meaningfully. In communicating and engaging with the children who participated in the project we were influenced both by what we understood to be their specific abilities and requirements, and the culture of the special school in which they were situated for the research process. The participating children represented a spectrum of capacities, with varied cognitive and communication abilities, and included children diagnosed with Autism Spectrum Disorder (ASD), Intellectual Disability, Down Syndrome and other genetic disorders.

Strategies for engagement and any communication support methods already in place were discussed with teaching staff in the pre-research consultation meeting. Most of the participants were able to communicate verbally to some extent. Several participants did not use spoken language for communication but could understand and respond to simple questions. Two participants used Augmented Alternative Communication (AAC) in the form of individualised illustrated communication books that were used by the researchers. Another two children did not use any formal methods of communication and required significant support from their teachers both in terms of communication and in completing art activities.

The main researcher communication strategies included providing materials for drawings and artworks (using glue, textiles and glitter), and questions on recognised child wellbeing concepts supported by emoticons and flash cards. The researchers found it useful to keep their language simple and direct, and to match the length of sentences with those of the child, pausing and repeating, combining with visual aids, and following each child's leads in conversation. How and why questions, were often broken down to more direct questions where children could respond 'yes' or 'no', or use flash cards displaying these responses. The children were eager to be agreeable, so positive responses to direct questions were interpreted with caution, as also described as necessary by others (Ponizovsky-Bergelson, Dayan, Wahle, & Roer-Strier, 2019).

The children's communication strategies included their artwork and verbal responses, gestures, facial expressions and other non-verbal messages such as walking or turning away. The verbal responses ranged from detailed stories about family outings and favourite pastimes to monosyllabic replies. Overall, the importance of flexibility of research methods was emphasised in this context, as spontaneous verbal and non-verbal responses generated the most information about their understandings of well-being. Spontaneous responses offered researchers opportunity to engage children in discussion about well-being outside of the research protocol. For example, when they talked about or illustrated concerns about burglars, fear of darkness, and experiences of death in the family. With the children in this study, we also found that they would often not respond with a direct answer to our questions. Instead most would give a specific example that we would then need to tease out the meaning for well-being, thus requiring a little more work on the researchers' part.

All the children used the art materials enthusiastically. While some children drew pictures, many glued on images, and used stickers and glitter provided by the researchers. Interestingly, only a few of these children drew 'maps' with paths and directions in the way others have done in the broad project. Their pictures were more like collages, or drawings or illustrations of individual things, people or places. In other respects, the content of this artwork was in many ways similar to what other children have focused on in the broader CUWB project (Drake et al., 2019), such as the importance of relations with others - family, especially parents (biological and foster), siblings, friends and pets. Engagement with technology such as games, movies and computers were also a common favoured activity, with a focus on superheroes or characters from children's television shows.

While most of the children seemed to be comfortable with the large group activity and were eager to engage in conversations and craft activity for about 30-40 minutes, a few children were only able to participate for shorter periods of time (5-10 minutes), before they lost interest or seemed bored. Some children needed to move frequently, or were easily distracted. It was also a little difficult to talk with some children individually, while they were seated at the table with other children. A few seemed worried about others hearing what they were telling the researchers. Talking to children about their illustrations became easier when children were invited to move, to chat with the researcher away from the large group table.

3.3 The significance of context in the implementation of methodology

The use of various strategies in this study, to facilitate communication between researchers and children, in a special school for children with communication and cognitive disability, highlighted the significance context had for the children's discussions of well-being. In particular, the structure of interactions between teachers and children in and by, the classroom influenced the ways children engaged with us and their topics of conversation. Changing the context by implementing methods that took the research outside the classroom affected children’s engagement with their peers and us and in particular their exercise of agency.

The most pervasive context in the engagement of child participants was the culture of the ‘special’ school. In reflecting on communicating and engaging with the children in a special school, it became evident that the extent to which the children relied on supportive relations with teachers, created a distinct cultural difference compared to the one found in mainstream schools, whether state or independent, in the broad research of the Australian CUWB project were located. Walmsley (2004), Nind (2008) and others have pointed out that it is not unusual for people with intellectual disability or learning difficulties to require some support from researchers and others in the research process. Walmsley argues however, that it is imperative for researchers to clearly explain the roles of supporters in inclusive research. Firstly, because it helps to progress knowledge and skills in research; and secondly, because the power imbalances between the researcher and the researched, especially those with communication impairments, may be “camouflaged” in the “rhetoric of participation” (p. 32). We note that this might also apply to imbalances between children and teachers, children and other supporters, and also between teachers and researchers in this context.

The presence of teachers during the first meetings seemed important for some children’s sense of security and therefore the way they engaged with us. When needed, teachers helped us to communicate with some of the children, and other children also offered assistance with communication. For example, it was difficult to be sure that some individual children understood our questions. Here teachers were helpful in providing prompts to children, or relating the question to an issue, context or recent event with which the child was familiar. Friends would also sometimes jump in to add information or context, for example by extending a story about a common activity. With some other children, it was difficult for the researchers to know whether they had understood their responses accurately. Here teachers, and siblings attending the same class, were helpful in explaining with or for the child, especially where family and care situations were complex. While the support from the teachers was invaluable to conducting these early meetings with children, the challenge for the researchers in later meetings was to tactfully manage the enthusiastic support of the teachers and assistants in the class, who would sometimes try to direct the children in their activities and responses.

We learnt how significant context was to the topics the children talked about, when we used methods based on some of the well-being concepts identified in conducting surveys with children in the Children’s Worlds study (Dinisman, Fernandez, & Main, 2015), by providing the children with flashcards showing the words ‘school’, ‘money’, ‘safety’, ‘agency’ and ‘being listened to‘. We asked the children to pick one word at a time to draw and talk about. The children all first chose the word school, which was clearly a well-known concept to them, and most seemed to find it relatively easy to talk or draw about school activities that they enjoyed, friendships and peer relations, and favourite teachers. Some children then chose safety, which was often considered in the school context, though safety was also drawn or talked about in relation to parents or carers. For example, children indicated school as a safe place and teachers were also named as people who keep you safe. Some children showed the researchers the safety signs and messages posted on the walls of the classrooms and corridors. We connected these responses with a strong emphasis in the school culture on being safe and acting in a safe manner. For example, the school environment had many symbols and visual reminders of safety and protection, such as being enclosed areas, high fences, locked gates and swipe entry only doors. That children chose to talk about school, and to talk about safety in the context of school, reinforces our finding of the significance of the context in which research is conducted for the way in which children respond on issues of well-being. The safety measures at the school, while appropriate for the context, reinforces the idea of vulnerability and children's need for protection.

None of the children chose to talk or draw about 'agency' or 'being listened to' even when researchers explained the meanings. It was difficult to know whether the children had no consideration for these concepts as they were presented, or whether the context of the research being carried out within the classroom setting may have rendered the topics less relevant for the children at the time.

It was in discussions with the children about emotions, that that the extent to which the culture in this special school differed from the culture of mainstream schools became evident, with significance for our findings on child well-being. As only a few children, in the large groups had responded to direct questions about what made them 'happy' or feel 'good', we decided that small group discussions and individual interviews would possibly more directly engage children in dialogues on their understandings of well-being. Therefore, in our second visit to further explore well-being concepts and individual understandings and experiences of well-being, we attached emoticon stickers to drawing paper and asked the children more directly about what made them feel 'happy', 'good' and 'well'. We also asked them what made them feel 'sad', 'worried' or 'angry', and gave them some examples about ourselves. With the aid of a teacher or teaching assistant as facilitators of a group, this method was very effective in engaging with the children with the topic, and in enabling them to express, through drawings and story-telling, how they connected well-being and emotions.

Almost all the children were able to draw or otherwise indicate what made them feel happy or good and found it easy to tell us about situations that elicited happiness. Most were also able to explain what made them angry, and a few were able to explain or illustrate things and situations that worried them. Significantly, their explanations accorded with those given by children in the broad study. Where the responses of children in this study diverged significantly from those in the broader project was in their response to introduction of the concept of sadness.

In considering children's discussions of sadness in relation to the way in which the context of this particular school was reflected in our findings, we gained further insight into how cultural norms are associated with experiences of well-being and communications about these experiences. Only two children talked and drew specifically about being sad, while others refused, or pushed away the paper with the sad face emoticon. That most children declined drawing or talking about being sad puzzled us as researchers. While we understand that this emotion might be difficult for many children to talk about, we had not expected this direct refusal, when the children were on the other hand, able to engage in talking about anger and worries. We reflected on this refusal to respond to issues of sadness, in discussing general findings with the school teachers and executives some days later. They alerted us to the fact that within the school, the teachers use the word 'sad' when disciplining the children about poor behaviour: *"That was a SAD choice you made!"* This finding demonstrated to us clearly the necessity for researchers to use reflexivity in questioning the meanings inherent in interviewee data (Davis, 1998) in both the implementation and analysis of methods and strategies. It also illustrates how the context in which research takes place may well be reflected in the ways children engage with research topics, and the need to take the influence of the context into account in terms of research findings (Carpenter & McConkey, 2012;

Ponizovsky-Bergelson et al., 2019), with implications for discussions of well-being and the significance of context more broadly.

3.4 The significance of context for facilitating children's agency in research

The significant impact of context on children's responses to experiences of well-being was highlighted during the 'guided tours' in relation to their use of agency. Our use of this method is an example of how changes, even at the micro level of context in which the research is conducted, may facilitate children to be heard differently and different children to be heard. It certainly provided greater opportunity for the children's use of agency than in the classroom. Our use of this method to engage with the children was a response to the need to avoid unexpected distractions occurring within the classroom setting on some of our research visits. Guided tours as a method has been previously used in other research, for example with pre-school children (Clark, 2005, 2017; Clark & Moss, 2005). In this different setting outside the classroom, we asked the children to guide us through other areas of the school and show us the places and people that made them feel good or well. Two or three children at a time took two or three researchers on a tour of both indoor and outdoor areas of the school showing us different places in the school that held meaning to them.

As researchers invited to the school, we had been given swipe cards, necessary for moving from one area to another within the school and to exit the school grounds. It soon became clear that the children acknowledged the access provided by the swipe card, and when one of the children was given responsibility for the swipe cards for the guided tour, the tours soon became a mostly child-led method and thus an enactment of the topic that had not had particular focus in the classroom - agency. Children decided where to go, what to do, with whom and for how long. Some children took the researchers for extended visits to their favourite places, but also to places that were usually 'out of bounds' for them. The playground dedicated to the younger students was such a place, and a common favourite destination to the children leading guided tours. The children often requested that the researchers engage with them in climbing the equipment, playing ball and running. Some children led the tour to indoor areas of the school such as the library, the kitchen and the computer rooms where children were typically only allowed in the company of an adult. The guided tours facilitated conversations about things the children enjoyed doing with their friends or on their own. With children who did not communicate verbally, we observed their interactions with peers, where clearly there were social hierarchies, friendships and allegiances, and interest in romantic relations. Importantly, these tours enabled us to observe the importance of 'agency' and 'being listened to' in the children's interactions with each other, with us, and with staff who happened to be in the spaces they showed us, in ways that had not been possible when engaging with the children in the structured classroom activities.

Facilitating children's agency by asking them to lead us on a tour changed the dynamics of the researcher/participant relationship, from the more structured interaction in the classroom. It was clear that some children were better able to express themselves through this activity, while others perhaps had felt more at ease with the classroom activities and the known expectations within that context. On the guided tours, some of the ways in which children behaved clearly challenged the rules of the classroom for example, hugging and talking in ways not permitted in the classroom. This behaviour also created a challenge to us in our roles as adults not conforming to their teacher's role. Such role challenging behaviour was experienced by Mandell (1988) when she attempted as a researcher to be 'least adult' in her engagement with young children. On a more technical level, the guided tours also presented some data collection difficulties in terms of capturing conversations and engagement with children in recordings. This was, however, balanced by recording the reflective dialogues between the researchers following each visit with the children.

Our observations and interactions with this small group of children revealed insights into their motivations, feelings, peer and family relationships and school environment. Listening to and watching these children revealed the factors that contribute to their well-being. While very similar to the factors identified in the broader international study of children's well-being, the special school context and the research methods appeared to strongly influence the children's responses.

4 Discussion

In this article, we have described and reflected on the methodology and methods used to engage children with disability in a multinational project on children's understandings of well-being. Our study, framed conceptually by the approaches of the 'new' sociology of childhood and critical disability studies, in aiming to be inclusive of children with cognitive and communication impairments, is innovative in the field of childhood research. It also contributes to the increasing body of literature on innovative use of methods (Huang, O'Connor, Ke, & Lee, 2016). Further, the findings demonstrate how, when facilitated to express themselves in different ways and various contexts, children with disability can competently contribute, alongside other children, to our understanding of what well-being means.

That children can participate when methods appropriate to them are used, has significance beyond research with children with disability for facilitating children having their voices heard in practices affecting their well-being, such as in child protection. The findings highlight, as Komulainen (2007) has pointed out, that children's voices are constantly constrained and shaped by multiple factors such as our own assumptions about children, our particular use of language, the institutional contexts in which we operate and the overall ideological and discursive climates which prevail.

It became clear in this research that, as Hunner-Kreisel and Kuhn (2010) and Fattore et al. (2018) argue, children's perspectives reflect the social orders in which they are positioned. The extent to which children's voices are heard in research, is dependent on their social positioning. In this study the participants are children and disabled, and constrained by their position at school. For example, the gatekeeper process enable some children and not others to contribute their perspectives.

The multiple levels of gatekeeping experienced in this study reflects the positioning of children as vulnerable - children with disability even more so (Stalker & McArthur, 2012). This positioning of children in relation to adults, and for children with disability in relation to those without, is reflected in the decision-making approach of ethics boards and reviewers authorising research with children, and children with disability (Lambert & Glacken, 2011), and decisions by schools to facilitate or not, children's participation in research.

It was as a consequence of the gatekeeping process that it was necessary for us to directly approach a school with which we had personal connections. In negotiating our research with this school, our findings reflected a context, common to schools as a social organisation, where there are certain structures and norms, within which children's status, as Mayall's (2002) research has shown, is such that their experiences are shaped by structures over which they have little influence. This school, while most helpful in enabling the research, in implementing their socially assigned role, assumed responsibility for choosing which children should participate in the research activities and which classes could be accessed for child participants. Researchers and children had to respond in accordance with the school's and parents' decision-making about which children were able to participate, and how. Inevitably, as noted by Alderson and Goody (1996) such directions place some restrictions on the research and invariably excludes some children from participating. In this research, however, this direction by the school also provided opportunity to work with teachers who had good knowledge of the children and their communication strategies. As Nind (2008) has also suggested, the use of proxy information may help extend the 'vocabulary' of some children, which in our case was supplemented with information from friends and siblings.

One of our dilemmas in working within school classes was that a small number of children did not have parental consent, but still wanted to engage in the research activities, like their friends. This dilemma highlights, a problematic area of children's participation in research, in that formal ethical determination processes do not generally take account of the child's perspective. Children are not afforded the same rights in relation to research consent issues as adults, and as Kelly (2007) notes "are unable to make a decision to participate when their parent/carer has already chosen to refuse access" (p. 25). As also discussed by Alderson and Goody (1996) the dilemma faced by researchers is whether it is right and just to 'collude in silencing' these children by refusing their engagement. Conversely, the question is whether we put children potentially at risk by engaging them in research of which they may not fully understand the consequences. Our intent, as childhood researchers, is to facilitate children's right to have their voices heard, but by inviting them to participate we also assert our power as adults in a different manner, and contest the rights of parents to refuse. Lambert and Glacken (2011) have argued that while 'there is the risk of protecting children to the extent of silencing and excluding them, there is also the risk that children's right to participation could result in coercing or exploiting children's involvement'. Again, these ethical dilemmas are particularly strong when involving children with disability as their social positioning tend to be further marginalised than their peers without disability.

Context had particular significance in the way the culture and discourse of this particular special school influenced our use of emoticons as a method facilitating expression of emotions. The children's responses to the emoticons expressing sadness, were apparently influenced by a very specific and wide-ranging use of the word 'sad' within the special school culture. Exploration by the researchers of a possible meaning of their surprising responses avoided misinterpretation. The implied basis for children's non-responses to this emoticon underline the complexity of using a tool like the emoticon, and extend the finding that symbols of emotional expression illicit varying responses across cultures of different countries (see for example Takahashi, Oishi, & Shimada, 2017).

Similarly, context in terms of place within the school was significant in the extent to which children exercised agency, increasing considerably with their engagement in child-led tours in contrast with the classroom milieu. Such findings on the way contexts contribute to the voices that we hear from children, point to the importance not only of the provision of opportunities for child expression through flexible child-inclusive methods, but also of the necessity for reflexive and judicious interrogation and interpretation of data by researchers.

5 Concluding comments

This study contributes knowledge to the sparse body of literature on children's understandings of well-being that is inclusive of children with disability. In doing this, it is challenging the barriers that exclude children with disability from participation in research as a consequence of denying competencies where they may be expressed in ways differing from normatively defined competencies. As a pilot, this study, engages with the challenges Carpenter and McConkey (2012) pose in identifying the 'practical' and 'conceptual' imperatives of researching with children. This study demonstrates the importance of exploring research methods and communication strategies to respond more effectively to the 'moral imperative' of listening to children with disability, it clearly illustrates that proactive efforts are needed to ensure that children with intellectual disability are included in child focused research and their views taken seriously.

At the same time, our findings have implications for research with children more generally, in supporting Tisdall's (2012) argument that 'research with disabled children should not be perceived as a specialist activity, but rather one that has wider lessons for research methods and analysis. By questioning effective communication, research claims, and ways of participation, research with disabled children adds to research more generally' (p.189). This study demonstrates the significance of context for children's discussions of well-being and strategies that facilitate communication between researchers and children. The next steps for this research are to apply our research methods in different contexts and to compare our findings with children's understandings of well-being more broadly.

Finally, in highlighting the value of being flexible and reflexive in adapting methods when implementing an inclusive approach, our research has significant implications for policymakers and practitioners seeking, for example, to promote child protection and well-being, through engaging children as participants in decision-making processes.

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