

# LISTENING TO THE VOICES OF CHILDREN WITH DISABILITIES IN NEW ZEALAND

Literature Review





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LITERATURE REVIEW

# LISTENING TO THE VOICES OF CHILDREN WITH DISABILITIES IN NEW ZEALAND

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# 1. INTRODUCTION

As a signatory to two key United Nations documents, New Zealand must take into account the perspectives of children with disabilities in the development of policy and law that affects them. To assist with the process of hearing from such children the Ministry of Social Development requested the Donald Beasley Institute (DBI) to develop a practical resource. In the development of that resource it became clear that policy developers could lever off a number of resources currently on the websites of the Children's Commissioner, Ministry of Social Development, Ministry of Youth Development and the Ministry of Health. These departments have guidelines that address consultation with either children or disabled adults, as outlined in subsequent pages. The DBI contribution draws on these documents alongside the literature that addresses children with disabilities' participation in planning and decision-making.

To provide context to the summary of points to consider when seeking the participation of children with disabilities, the relevant components of the United Nations Conventions are outlined, followed by an overview of the response that New Zealand has already made. Throughout the document the words "child" or "children" imply young people up to the age of eighteen, in keeping with the major United Nations Conventions. The terms "young people" or "youth" will be used when that is how they are referred to in the source of the information. The term "children with disabilities" also aligns with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and is utilised in this document for that reason and because it prioritises their child status.

Crucial to the adoption of meaningful strategies is to hear from children with disabilities about whether or not they need to be provided with opportunities that are beyond those available to all children. We will argue that they do but also that they should not be omitted from strategies open to all. Expert opinion and research is drawn upon to identify important issues for consideration when engaging in participatory approaches with children with disabilities. Specific strategies or tools used to elicit the knowledge and opinions of children with disabilities are outlined, followed by ethical considerations. The document concludes with recommendations for seeking the input of children with disabilities into research and policy advice.

While the term 'voice' is used throughout this document, it should not be taken to mean the spoken voice alone. For children with disabilities' opinions can be sought using a variety of communication strategies and the use of the term 'voice' can cloud the reality (Tisdall, 2012).

## 2. INTERNATIONAL DIRECTIVES RELATED TO CHILDREN WITH DISABILITIES' VOICES

Both the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCROC) express an expectation that States will seek out and take account of the views of children with disabilities in matters that affect them. In the UNCRPD this is most clear in Article 7 in the following statement:

*States parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right. (United Nations, 2006)*

Whereas there are three articles in UNCROC that contain relevant sections, these being Article 12, 13 and 23:

*States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (Article 12)*

*The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice. (Article 13)*

*States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. (Article 23) (United Nations, 1989).*

A key intent of the UNCROC document, and one that underpins the following content, is the need for a child-centred approach to the development of law and policy in all nations to

ensure a just society. Putting child-centred thinking central to planning and development is fundamental to achieving this intent.

### 3. NEW ZEALAND'S RESPONSE TO INTERNATIONAL DIRECTIVES

New Zealand is a signatory to both the UNCROC and the UNCRPD and therefore is expected to have policy and practice in place that makes provision for the voice of children with disabilities to be heard. New Zealand legislation and policy that relates to both the Conventions themselves and the voices of children with disabilities can be found in the Children, Young Persons and Their Family Act 1989 where section 5(d) refers to:<sup>1</sup>

*...the principle that consideration should be given to the wishes of the child or young person, so far as those wishes can reasonably be ascertained, and that those wishes should be given such weight as is appropriate in the circumstances, having regard to the age, maturity, and culture of the child or young person.*

A strengthening of the intent of section 5(d) can be seen in The Children's Commissioner's Act 2003, the New Zealand Disability Strategy 2001 (Dalziel, 2001) and the more recent New Zealand Disability Action Plan 2014 (Office for Disability Issues, 2014).

Under section 14 of The Children's Commissioner's Act 2003

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<sup>1</sup> Currently in process is the Children, Young Persons, and Their Families (Advocacy, Workforce, and Age Settings) Amendment Bill, which includes the intent of ensuring that vulnerable children and young persons are able to express their views and have them considered as part of decision-making in individual cases and in the development of departmental services and policy.

*(1)The Commissioner must develop means of consulting with children from time to time for the purpose of ensuring the views of children are taken into account in the exercise or performance of the Commissioner's functions (other than the Commissioner's function under section 12(1)(a) or section 13(1)(a).*

*(2)The Commissioner must, where practicable, consult with children, using means developed under subsection (1), before the Commissioner makes any significant recommendation in the exercise or performance of the Commissioner's functions under section 12(1)(f), (g), (i), or (l) or under section 13(1)(d), or (e).*

Section 12 of the Act is predominantly about the general functions of the Commissioner and the sections above relate broadly to advocacy and court or welfare proceedings. Section 13 relates to functions in relation to the Children, Young Persons and Their Families Act 1989.

The Office of the Children's Commissioner, set up in response to the 2003 Act, has developed projects and guidelines aimed at hearing children's voices (see <http://www.occ.org.nz/listening2kids/resources/>). This website offers a comprehensive list of resources from other countries that can be adapted for use in New Zealand. Projects demonstrating the Commissioner's Office adoption of strategies to include young people can be seen in the following projects. From 2003 until 2014 twelve young people were recruited at two yearly intervals to form an advisory group, providing advice to the Commissioner and raising issues that they deemed important. More recently the Voices Project uses online surveys conducted through schools, with a first test survey going out in 2015 (see <http://www.occ.org.nz/our-work/engaging-with-children/>). In addition, Listening2Kids is an online resource, aimed at government agencies but also available to organisations, providing suggestions and practical advice to assist them to engage with children regarding policy and practice. Whilst the Office of the Children's Commissioner notes the need to include children with disabilities in these projects it is not clear that any projects have done so to date.

The Ministry of Social Development and the Ministry of Youth Development published two documents aimed at including the voices of children and young people about the same time that the Commissioner's office was being set up (Ministry of Social Development, 2004; Ministry of Youth Development, 2009), the 2009 document being a revision of that published in 2003. Guidelines for including children with disabilities in the Ministry of Social Development booklet were limited to two considerations, that is:

- There is a range of disabilities – physical, intellectual and psychiatric



- Some children with disabilities need the support, care or interpretation of adults or other children, such as a sibling or a young adult who works with them. (p.18)

Six guidelines are suggested to support participation:

- Recognising that some children with disabilities may choose to be in groups with others of the same ethnicity, age or gender
- Including children with disabilities in decision-making on the same range of topics as other children
- Providing information well in advance and in appropriate formats
- Working with people skilled in communicating with children with disabilities
- Encouraging participation within a physically and emotionally safe setting
- Identifying any physical barriers and removing or minimising them. (p.19)

Similar points are noted for youth with disabilities in the Ministry of Youth Development document.

Despite these initiatives to encourage the participation of young people, Freeman and Aitken-Rose (2005) found that planners for most local bodies in New Zealand were not ready to consider a role for children. Where children might be consulted the topic was most commonly recreation and youth councils were the predominant method for the relatively few bodies that actually engaged young people at all.

The New Zealand Disability Strategy, published in 2001, is currently undergoing review. In 2001 it was recognised under Objective 13.7 that children with disabilities and youth should be involved in decision-making, however the emphasis of the strategy was broad and focused on changing society in line with the social model of disability. The more recent Disability Action Plan requires the direct input of disabled people's organisations in policy and legislation (Office for Disability Issues, 2014). Whilst the move to put disabled people at the centre of developing policy about them is progress, there is no clear statement with regard to children. Indeed, the majority of references to children are related to their protection and safety. Research with children with disabilities in the United Kingdom (Davis, Watson, Corker, & Shakespeare, 2003; Lewis, 2004) demonstrated that ambiguity exists between policy that expects children to be actively involved in decision-making whilst putting in place legislation and rules that create protectionist environments in the interest of their safety. This suggests that there is more to providing a voice than might initially be apparent. Furthermore, a small qualitative New Zealand study conducted in 2004 as part of a wider multinational study about children's sense of citizenship noted that, while children

were apparently gaining greater voice in this country, their rights were being undermined by the level of violence against them (Taylor, Smith, & Gollop, 2009). In other words, there are complex contextual factors that can be seen to interact between valuing the child's voice, as proposed in the two conventions, and ensuring the environment is supportive for all children so that their contribution is meaningful and actually making a difference in the lives of their fellow citizens. Interestingly, the children in the multinational study, of which Taylor and Smith's research was a part, recognised that their decisions should be incorporated within a relational model that allowed for appropriate levels of agency. In other words, they understood that, while they might influence decisions that were made, other people who had an interest in those decisions would also be part of the process and have an influence. Ideally, in a relational model the parties reach mutual agreement.

The Ministry of Youth Development has initiated and continues to provide a number of avenues for youth to participate in decisions within their community (see website <http://www.myd.govt.nz/young-people/>). In 2011 the Ministry led a survey of young, disabled people to establish their viewpoints so that they could be included in the report that the Office of Disability Issues was preparing for the United Nations in accordance with the requirements of signatories to the UNCRPD (Ministry of Youth Development, 2011). Aimed at young people 12 to 24 years of age, the survey was administered electronically, with an option to complete a hard copy. Parents were able to complete the survey for their child, with the proviso that they responded from the young person's perspective. In total, 138 surveys were analysed, with 76 of these surveys having been completed by a parent. It is interesting that the Ministry selected just the one method of data collection despite their own guidelines for people with disability that suggest that multiple methods might be necessary when seeking the voice of children with disabilities. Furthermore, it was evident in the report that the Ministry understood that proxy reporting by parents needed to be cautiously interpreted, raising the question of why it was included as a means of data collection in this instance.

In addition to the guidelines for children and young people, the Ministry of Health has recently published guidelines for community engagement of people with disabilities (Ministry of Health, 2016). These guidelines offer a range of ideas from planning through to evaluation of the community engagement process. While not specifically aimed at participation of children, the guidelines do provide principles that could be adapted for children.

One thing is clear, there have been attempts from various Ministries within New Zealand to hear from young people and it would seem that some young people are finding their way to

contribute to policy. What is less clear is the degree of participation and whether or not children with disabilities are taking part, unless specifically targeted.

## 4. ARE CHILDREN WITH DISABILITIES' VOICES DIFFERENT TO ALL CHILDREN'S VOICES?

In both the NZ Youth Parliament and the Commissioner for Children's Office, children with disabilities have been included alongside other children. As a model for a more inclusive society, that would appear to be a reasonable way forward, however it is not without risk that the issues particularly relevant to children with disabilities might be lost or their voice in decision-making about these issues weakened. In order to address the UNCROC and the UNCRPD, there is a need to be inclusive of children with disabilities but also provide opportunities to hear from them separately when the policy or practice is directly related to their needs. Balancing the competing demands for the input of children with disabilities to policy is not necessarily easy but policy developers need to keep in mind Tisdall's (2012) concern that they do not become "ghettoised", with their voice only seen to count on issues that have been determined by others (p. 187). Furthermore, Morris (2003) reminds of the importance of developing communities where all views are respected, rather than engaging in formal processes with children just to meet the requirements of others.

As a group, children with disabilities are no more homogenous than all children. In addition to the social and cultural differences of the whole population, children with disabilities cannot be categorised together. In the 2004 document, *Living with Disability in New Zealand* (Ministry of Health, 2004), types of disability for children were classified into eight specific groups with an additional "other" group. The specific groups included children receiving special education support and technical aids thereby assuming a type of disability, while also naming as categories: chronic conditions/health problems; psychiatric/psychological; hearing; seeing; speaking and intellectual disabilities. There will be different issues to the forefront of children both within and across each of these categories, oftentimes reflecting their cultural and social diversity more so than diversity of disabilities (Davis et al., 2003). Yet, diversity of disability might also generate different issues (Carpenter & McConkey, 2012), which should not be ignored. In addition to their diverse issues, as suggested by the varied recommendations in the recent guide to community engagement with disabled people

(Ministry of Health, 2016), the type of impairment they have is likely to have an impact on the approach that might best elicit the views of the disabled child.

That children with disabilities can contribute to decisions about issues that affect them was confirmed in Cavet and Sloper's (2004) literature review, although they felt that child participation was underdeveloped and absent on many topics at that time. In the intervening years since that review, a body of literature has addressed ways in which children's voices could be heard both in policy development and in research. Many build on one or other of the various models for child participation in decision-making that have been proposed. Fundamentally, the research approaches can be categorised as "on children, with children, and by children" (Clavering & McLaughlin, 2010, p. 605), with the models of Hart's ladder (Hart, 1992) and Shier's pathways (Shier, 2001) being the most often cited that illustrate the various levels and considerations.<sup>2</sup> In both of these the minimum for meeting the expectations of UNCROC and UNCRPD are the higher levels that incorporate children's involvement in decision-making. The move to a more emancipatory style of children's involvement is seen in the approaches taken by the Office of the Children's Commissioner and the Ministry of Youth Development in New Zealand for all children, as well as a few projects from the United Kingdom and Australia that have focused on disabled or disadvantaged children (Michail & Kellett, 2015; Rome, Hardy, Richardson, & Shenton, 2015).

Keeping the above points in mind, a starting place when seeking a child's perspective might be whether or not it is the specific child's situation that is of interest, or whether the child is being asked to contribute a wider viewpoint that will be seen as representative of a group of children. Franklin and Sloper (2006) suggest a place for both but with different strategies

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<sup>2</sup> Further information on Hart's ladder and Shier's pathway can be found in the cited references but there are also links to information about these at <http://www.myd.govt.nz/working-with-young-people/youth-participation-in-decision-making>

involved. In their survey of social service departments in England, 60% of the returned responses indicated that children with disabilities were making decisions in their own care and in service development, with a further 40% in one or the other process. Personal reviews were the main avenue for children to be involved in decisions about their own care. While children as young as five were contributing, the likelihood of being asked about their interests in their care increased as children aged. Involvement in decisions about service development was more likely for teenage children, although some services noted the participation of younger children. A main point of Franklin and Soper's study was to ascertain the impact that participation had on service development. From their survey, they identified that 44% of services had made some changes as a result of the children's input. For some services it was too early to identify changes. Fifteen of the initiatives had resulted in a change to leisure activities, with information provision being the next category at a total of seven initiatives. These changes do, of course, reflect the topics for which the young people's opinion was being sought. Interestingly, there was dedicated funding supporting 64% of the reported service development initiatives, raising the question as to whether or not there would be commitment to such strategies if they needed to be funded out of the service's own budget.

Whether for service development or local or national body planning, a key first step in seeking the voice of children is a genuine desire to hear what they have to say (Cockburn, 200; Freeman & Aitken-Rose, 2005), an emphasis that can be seen in Shier's pathway (Kellett, 2011). Successful studies have provided time and regular contact for relationships to develop, identification of shared concerns and an ability to take the broad issues and translate these into specific, focused projects that are achievable (Badham, 2004; Beresford, 2012; Michail & Kellett, 2015; Murray, 2012). As Cockburn identifies, true consultation with children will aim towards their empowerment, conflict can be expected as parties work through their different perspectives. In many instances consciousness-raising will be a necessary beginning, but as Pascal and Bertram (2009) have found in their research with young children, that can be a challenge for the adults in their sphere. In their opinion and that of Kembhavi and Wirz (2009), who worked with disabled youth, it is important to provide education and support for the adults to acknowledge and work through their anxiety about children's empowerment. This step might go some way to address the ambiguity between protection and empowerment mentioned earlier. In addition to providing opportunity for children with disabilities to reflect upon their own life, consciousness-raising will involve familiarising them with their rights as expressed in documents like the UNCRPD. Of note, the Ministry of Youth Development (2011) survey indicated that the UNCRPD was unfamiliar to the majority of respondents. Furthermore, simply listening to children will not mean that they

feel they have been heard (Kellett, 2011). To feel heard, there needs to be a response and change that reflects that the child's concerns were taken seriously or, as Lewis (2004) notes, if change has not happened then they need to know why not. If adults are serious about hearing children's voices, it will only be from such responses that children will feel empowered to attain the top of Hart's ladder, whereby they take the lead in decision-making.

Within the United Kingdom, the Disabled Children and Young People's Participation Project (DCYPPP) emphasised young people with disability expressing their views while creating a supportive environment in which to do that (Murray, 2012). Drawing together the experiences of the members, through carefully built relationships, led to a much greater understanding of the needs and wishes of disabled youth and was seen as one of the great successes of the project. Through taking this approach to the research the young people developed their confidence, which was integral to them expressing their views. Other important factors included good facilitation, advanced IT services to help young people with difficulties in communication, and for youth with disability to be made to feel that they are equal partners in the research process as a whole (Murray, 2012). In the more recent English project, The eXtreme Group, agenda days run by children with disabilities without adult involvement, provided opportunity to hear the views of a wide group of children with disabilities. To aid communication, a variety of techniques were used, including graffiti walls, post-it notes and drawing, in a venue that was accessible and promoted informality (Rome et al., 2015). There were important lessons from the Australian study with disadvantaged children, there was the need to be able to work through challenges, such as behaviour that needs moderating in order for all children participating to feel comfortable, and it was important that the child-led nature of the study was successfully implemented (Michail & Kellett, 2015).

There would appear to be general acceptance that older children can contribute meaningfully to decision-making and policy development. It has to be noted that there is also growing evidence that very young children can make meaningful contributions provided the method of eliciting their opinions is appropriate. However, studies need to be well-funded to ensure that they can be flexible in how they work with young people (MacNaughton, Hughes, & Smith, 2007; Michail & Kellett, 2015; Tisdall, 2012). As Tisdall further notes, children also need access to funding, the authority to enter the field and the necessary research skills if they are to be fully participatory. An important consideration to the inclusion of child researchers are the policies that might exist that can prevent or compromise children's participation in research (Badham, 2004).

Regardless of whether the attempts to hear from children take a fully participatory/emancipatory approach or not, methodologically it is suggested that

researchers and policy developers consider carefully their sampling or inclusion strategy. Convenience samples can be challenged in terms of the validity and generalizability of opinions (Carpenter & McConkey, 2012). Carpenter and McConkey's recommendation is to ensure wide representation of children with disabilities, however, Tisdall (2012) warns that data from children with disabilities should be seen as no more representative than would be expected if the research related to adults. Carpenter and McConkey also commented on the gap in research that explored children's voices about their immediate care needs, raising the concern that policy might change but that might not lead to the desired change in practice. Therefore selection of participants needs to consider both policy advice and implementation and who will best inform both aspects. As suggested above, to demonstrate to children that their voice has been heard they need to see a change in practice. Pascal and Bertram (2009) suggest that this requires "innovation, documentation and development within 'real world' settings" (p. 259). As will be evident in the next section on strategies that have been used to encourage children's participation, there is no shortage of ideas for innovation, but for momentum and continuity, ideas need to be replicable in a variety of contexts.

If children with disabilities' voices and perspectives are to be fostered and enabled in developing policy and legislation their views must first be ascertained through active engagement with them in research. The focus on children's rights following the UNCROC has led to developments in research processes such as improved consultation methods, active and participative inclusion of children along with a greater willingness to listen to children. Methods of working with children have developed from a consultative to a participative paradigm in order to avoid tokenism and allow children to truly share in decision-making (Kellett, 2011). Traditional research places children as the object to do research on whereas participatory research allows the child to have a say (although not necessarily the final say) into certain aspects of the research project, for example how it is designed, implemented, evaluated and what is done with the findings (Kembhavi & Wirz, 2009). Fundamental to the participative approach is the attempt to shift the balance of power (Ajodhia-Andrews, 2016). Whatever the approach, it is important to plan well and ensure that resources and supports that will be required are available.

## 5. RESEARCH METHODS FOR CHILDREN WITH DISABILITY

Whilst the focus of this report is on research strategies utilised with children with disabilities, there are many approaches adopted widely with all children that remain relevant. These

include play-based methods (for example dressing up and role-play) to gain their views along with story telling and the use of puppets (Kellett, 2011). The Mosaic approach which allows children to draw from different tools and learning styles in order to bring across their perspective, recognizes the many different ways that children communicate (Pascal & Bertram, 2009). Tools identified by Pascal and Bertram in their Children Crossing Borders project included bookmaking, maps, tours, story telling, wishing trees, photography and film making, listening posts and cultural circles. Other researchers have identified particular strengths in artistic methods that include visual art, performance, narrative, music and poetry as they "have resonance with children's lives and day-to-day activities" (Carter & Ford, 2013, p.96), noting that these can lessen the intensity of the interview process. With older children individual interviews (structured, unstructured and semi-structured) and focus groups become more acceptable (Kellett, 2011). To foster a participative approach and encourage dialogue with children, Pascal and Bertram used videotapes within focus groups. As noted earlier, children are not a homogenous group and the arts based approach along with the mosaic approach can provide several different activities through which children can utilise their different abilities and communicate their views.

Whilst there is a significant body of research demonstrating the usefulness of a range of modalities for researching with non-disabled children, it is less common to see children with disabilities involved in research. Young children with disabilities, in particular, have been underrepresented in research. Thus, their voices often become obscured and superseded by the voices of the adults in their lives (Underwood, Chan, Koller, & Valeo, 2015). Children with disabilities might require specific communication and access aids in order for them to participate effectively. Adaptable methods that can be adjusted for particular individual needs are important for involving children with many different kinds of disability. Inclusion of children with severe communication or cognitive impairments often does not occur because specific efforts must be made to involve this group in research projects (Morris, 2003). Despite assumptions about children with disabilities' inability to participate in research and communicate their opinions a whole body of research suggests otherwise and reveals many communication strengths of this group and a willingness to be included in decisions that affect them. There are two important aspects to maintain if this group is to be effectively included in the research process (Rabiee, Sloper, & Beresford, 2005). The first is recognizing that "communication is a two way process" (p.386) and this means rather than forcing adult forms of communication that require speech onto children with disabilities we must learn how they communicate and reveal their opinions and views. The second aspect is creating methods of communication, which can amplify children with disabilities' personal forms of communication and thus allow them to express themselves.



There have been some attempts to draw together what is known about children with disabilities' inclusion in research and the strategies used to elicit their views and perspectives. In one systematic review of 22 research papers, methods included drawing, photography, talking mats, cue cards, pictures and tape recordings (Bailey, Boddy, Briscoe, & Morris, 2015). These methods can be used to include children with disabilities that require non-verbal forms of communication. A report that drew on the themes from five seminars in the United Kingdom identified additional strategies (Carpenter & McConkey, 2012), including large-scale questionnaire surveys (although these assume the child can express their views in writing which is not always the case for children with disabilities) through to a conversational analysis to examine interactions between two "non-speaking" young boys.

Tisdall (2012) reveals how problematic it can be to focus on "voice" over other forms of communication as this can silence children with disabilities who do not use speech as their primary form of communication, suggesting other forms of communication such as photography, role play, observation and drawing. Added to these methods are talking mats. Two studies describe the effectiveness of talking mats (Germain, 2004; Rabiee, Sloper, & Beresford, 2005). Talking mats are tools for people who have communication difficulties to express themselves. They utilise picture symbols that represent certain emotions, topics and options, which are then matched up together to reveal how the participant feels about their lives. Findings from both studies noted the simplicity of these tools and suggest that children use them with ease, that they find them enjoyable, and that they provide the non-verbal child with the ability to express their own opinions.

Rabiee et al (2005) developed their talking mat following a first stage whereby children with similar healthcare needs but who were able to use speech were interviewed along with their parents in order to develop the themes that would be used in the talking mats. The talking mats were then used with 11 children with a variety of physical and cognitive impairments, none of whom communicated through speech. The technique was effective in all cases in discovering the child's choices and feelings about services provided to them (the focus of the research). Supporting the independence with which the children could report was the finding that parents were often surprised by how involved the child became and how expressive they could be.

Photography has been used in a number of studies, generally supported by other methods. For example, Germain (2004) used photographs along with the talking mats in her study with nine 16-year-olds with disabilities. She argued that "in using photographs the potential exists [...] to find ways of thinking about social life that escapes the traps set by language" (p.170). This study found that giving participants a camera empowered them because it put them in

control of expressing themselves and painting a picture of their worlds. Photographs also helped remind children of certain events and memories and thus aided the research process. Photography was also described by Ajodhia-Andrews (2016) as a positive method of allowing children to express themselves, made even more effective if paired with the child's own descriptions.

The mosaic approach frequently includes photography, for example, cameras were part of the "tool box" for Gray and Winter (2011) but they also included "Molly the ragdoll," drawings, stickers and tape recordings. By having a range of tools to hand, the researcher can select a means of communication suitable for the child (Gray & Winter, 2011). Ajodhia-Andrews (2016) suggests that multi-method approaches make the research process more inclusive and allow different children to play to their varying strengths. In that multi-ethnic study the six children were found to more easily communicate their views through numerous creative methods than through just one. Creative mediums used were artistic writing, story telling/story games, visual narratives through photography, and drawings. The DCYPPP outlined earlier in this document, also utilised a multi-method approach including in that study, drama, digital media, music, and various media and IT (Murray, 2012).

There are times when observation of the child in different situations over time can reveal certain aspects of a child's experiences. Morris (2003) termed this "being with" (p. 345) a child as a means to understanding their experience. This can be particularly useful when the researcher is with the child in a range of different settings and can observe the child's experiences in each. However, there is the risk with this method that a researcher will impose their own views and interpretations onto the actions of the child so it is important to be very careful about what observations are made.

Further information regarding specific approaches to working with children with disabilities can be found on the following websites:

- [www.voicesofchildrenwithdisability.com](http://www.voicesofchildrenwithdisability.com)
- [www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research\\_ACCESSIBLE.pdf](http://www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research_ACCESSIBLE.pdf)
- [www.talkingmats.com](http://www.talkingmats.com)
- <http://picturemyfuture.com>

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## 6. INTERVIEWS AS A RESEARCH METHOD WITH CHILDREN WITH DISABILITIES

A wealth of information can be gathered from children with disability when an interview involves a range of activities that utilise different forms of conveying information, for example arts based and play based activities. However, interviews themselves can also be an effective form of eliciting children's views if done sensitively and appropriately. They must also be tailored to each individual child and their particular impairment.

Rapport building was identified by Underwood (2015) as a significant component of interviewing young children. This consisted of giving the child the ability to understand and be a part of the research process, thus allowing the researcher to follow the child's lead and build on their particular interests. Rapport building was made possible by the use of two separate interviews with the same researcher. Underwood also commented on the need to focus on verbal and non-verbal communication in an interview and in order to do this the interviews were recorded. However, in this study only four children were included, excluding a wider range of children with different disabilities. Morris also discusses the need to watch for non-verbal forms of communication such as the child's expressions and hand gestures as these can reveal whether the child wants to say more, has finished, and whether they feel positively or negatively about the question (Morris, 2003).

In her 2003 Gulliford Lecture, Lewis (2004) identified a number of points to consider when interviewing children with learning disabilities. These points were based on her extensive research experience. Amongst her key points Lewis suggested allowing 'don't know' responses and requests for the rephrasing of a question. The interviewer should make it clear that they do not know the views of the child because children tend to assume that if the questioner is an adult they will know the answer. One possible answer to this is using a soft toy to ask the questions. Interestingly, Lewis found that there is almost no evidence that children with learning difficulties are more likely to be suggestible and they are actually less shaken by negative comments than were non-disabled counterparts. Using statements rather than questions has been shown to draw more complex answers from children and, if asking questions, making questions more general (rather than specific) has been shown to be better for children with learning difficulties. Avoid repeating questions as this may send a signal to the child that their answer was incorrect. Similarly, avoid yes/no questions as children have an "affirmative bias" (p. 5) and tend to answer "yes" and this applies also when giving a limited set of alternatives as the child will often choose the later alternative given. Interestingly, and supporting research mentioned above, Lewis found that this does not



happen when pictorial approaches are used thus talking mats and cameras have a lot of potential in the interviewing process. She also suggests that successive prompts are not used, as children tend to fill in gaps in memory with made up details. Sequential questioning can lead to imagined detail that then becomes fixed as a "memory" (this is a particular issue for children with learning difficulties). Some fine-grained issues to do with interviewing children with learning difficulty are the use of referents, pronouns, and modifying terms. Modifiers are adjectives or adverbs and children may understand modifiers that are limitless such as fast but may find it more difficult to grasp the concept of a limited modifier such as "slow." Children (and especially children with learning difficulties) can often misunderstand referents such as "they," "those," and "there." One way to gain an "uninterrupted narrative" (p. 6) and avoid constantly having to prompt the child is to use cue cards without comments (Lewis, 2004).

Morris (2003) draws on her research experience with children with disabilities when making suggestions for interviewing those with communication impairments. Recognising that the interview situation might be challenging for novice interviewers comes the recommendation not to counteract feelings of uncertainty by attempting to take control. Slow down and be guided by the child. It is important to wait and not fill in every silent moment with talking, allow the child time to finish stating their ideas. Keep eye contact with the child instead of equipment they use or their support person, although note that this is about reference to their communication aid/support, it might be that eye contact needs moderating as suggested above through the use of other strategies to lessen the intensity of the situation. Children with hearing impairments or autistic spectrum disorder, in particular, might have difficulty picking up subtleties such as in the tone of voice to indicate what is meant by a question or comment. There is a similar problem if body language or expressions are used to indicate meaning when talking to someone with a visual impairment. It is important to always keep in mind the impact of the disability on the child and for the interviewer to change how they interact with them accordingly.

## 7. ETHICAL CONSIDERATIONS

Whatever the process chosen to seek out children's contribution, ethical standards must be addressed. In the case of research, ethical review by an independent committee would be a necessary step. While children might also contribute within less formalised mechanisms, those responsible for the process must still apply ethical principles. Using the three most



common ethical frameworks, Alderson and Morrow (2011) suggest the following considerations:

- Justice – are the aims and methods right and fair?
- Are possible benefits and burdens of research shared fairly?
- Do researchers treat children as they themselves would like to be treated?
- Might the research be harmful or useless?
- Do the researchers respect the children's rights to:
  - What is so far known to be the best available treatment, care or resources?
  - Protection from harm, neglect or discrimination?
  - Self-determination, such as informed consent or refusal?
  - Non-interference and to research that is not too intrusive or restrictive?
- How can the researchers reduce or prevent harm and increase the chance of benefit from their work?
- How do they decide the best outcomes to aim for?
- Whose interests do they put first, the child's, the parents', the interests of the research or society?
- Might there be harm in not doing the research, or in not involving children and only listening to adults? (adapted from Box 1.7, p. 17-18)

As noted in the previous section, interviews, focus groups and observation can be used when doing research with children however, whichever method is used, they must be done sensitively. The abilities of each child must be taken into account and interview techniques must be adapted to them. Some elements to pay attention to when conducting these activities with children include; the length of time the child can keep attention, clear and understandable language, making sure that the child understands, easily understood explanations, the location of the research, and the ability to identify with the child and their experiences (Carter & Ford, 2013).

## 8. RECOMMENDATIONS

1. To meet the UNCROC and the UNCRPD expectations, children must be involved in decision-making about policy and law that affects them.

2. When asking children to participate, there must be clear goals, a willingness to listen, and the intention to facilitate change.
3. In challenging the current policy or procedures, all parties need to be acknowledged and supported. It is important to recognise the ambiguity that exists between safety and autonomy for children.
4. Children generally recognise that there will be limitations in regard to their agency and they value support in decision-making from people with whom they have a meaningful relationship.
5. Children with disabilities cannot be seen as a homogenous group. When consulting children with disabilities, socio-cultural and disability specific variables must be considered. The purpose of the consultation might best define which children's voices or opinions should be sought.
6. When planning research or consultation, ensure that strategies take into account the financial cost in time and materials in order to be effective.
7. Ensure as wide a representation as possible so that policy makers see the contribution of children with disabilities as important to include. Avoid the use of "convenience" samples.
8. Consider who is setting the agenda. The issues at the forefront of the mind of policy makers might not be the most important issue for the disabled child.
9. Ensure that the children who participate know the outcomes in terms of policy change and when relevant that they have the opportunity to evaluate the change as it relates to practice.
10. Research led by children needs to be supported by ensuring the children have the resources that they need and any necessary access agreements are in place.
11. To encourage children with disabilities' participation and develop their role as a citizen, involve them in decisions about their care from a young age and move on to involvement in decisions about service and policy over time.
12. Emancipatory approaches take time to develop, therefore consider carefully the best approach for the intended purpose of seeking children with disabilities' input, the resources available, and the timeframe. When advice is required within a short



timeframe, or on a topic where the child's voice will be one of many, an emancipatory approach might not be helpful, however the suggestions below can be followed for seeking information from appropriate participants.

13. Multiple strategies might be required for a full representation of children with disabilities' perspectives. Tailor communication to the child and be prepared to use specific devices that are familiar to the child if necessary.
14. Strategies that have been shown to be effective include: drawing, talking mats, photography, cue cards, pictures, tape recording, questionnaires with adaptations if necessary, dolls or similar toys, story-telling, drama, digital and other media, music, and observation.
15. When interviewing allow for more than one meeting to assist with building rapport, be guided by non-verbal as well as verbal communication, be familiar with and use questioning strategies that encourage the child to accurately share their opinion and knowledge, and allow the child time to answer. Some children might have difficulty "reading" body language and tone of voice, therefore verbal communication with them needs to be clear.

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