

INCLUSIVE PRACTICE FOR RESEARCH WITH CHILDREN WITH DISABILITY: A GUIDE



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PREFACE

This guide presents a set of resources for supporting the involvement of children with disability in research, as well as consultation, policy and service development, monitoring and evaluation. The information was developed as part of a two year research project that focused on the human rights priorities of children with disability in two countries. The ‘Voices of Pacific Children with Disability: Identifying the needs and priorities of children with disability in Vanuatu and Papua New Guinea’ research project had a number of aims including the development of a method of data collection/communication with children with diverse disabilities to enable them to ‘speak’ for themselves. The research was undertaken between 2013 and 2015 by Deakin University in partnership with Save the Children, the Vanuatu Disability Promotion and Advocacy Association (DPA) and the PNG Assembly of Disabled Persons (PNG ADP). Researchers collected data from 89 children with disability aged between 5 and 18 years living in both urban and rural areas in Vanuatu and Papua New Guinea (PNG).

As part of the research, local researchers (including people with disability) were trained and a range of inclusive ‘tools’ for communicating with children with diverse disabilities were developed or adapted from existing tools. Tools included audio recordings of local sounds, a photo library of local images, the use of a camera by participating children, a walking tour of the community, drawing and dolls – all acting as prompts to help children express their views about their lives. These tools are made available in this guide to assist the identification of the views of children with disability in a wide range of settings.

This guide provides a discussion about the key principles and ethics that need to be considered when conducting research with children with disability and introduces the tools and method for their use. The guide draws on both academic literature and the experiences of researchers in the above mentioned rights-based participatory research project.

The guide is divided into two main sections. The first summarises what is known about the methods of researching with children and those with disabilities, and examines the principles and ethics of this work. The second section presents short guides to each tool and provides some general advice for their use. As the guide is intended for use primarily in field settings, each section and guide to each tool is succinct and practical in orientation. Throughout both sections, short practice examples are provided to illustrate the application of ideas in practice. Practice examples are drawn from ‘The Voices of Pacific Children With Disability’ project, and based on the reflections and comments of local in-country researchers. All participants’ names have been changed in line with ethical practices.

It is anticipated that the guide will inform researchers and those working with children with disability in a wide variety of circumstances. The language of the guide often refers to research but this should not limit consideration of the tools and principles to this task only. While the tools outlined here were used in a specific context to address specific questions, the tools essentially act as prompts for communication and can therefore be adapted for use in a variety of contexts. Tools could be used as a method of consultation with children, needs analysis for service development and planning, monitoring and evaluation, research, and in any other situation that requires aids for communication with children with disability. As the tools were developed and adapted for use in developing countries where English is not the main language, the explicit focus has been on tools that do not require literacy. In this manner the tools have universal application and can be used for children with a range of impairments.

Given that the use of participatory methods with children with disability is in its infancy, it is hoped that the guide will encourage those working with children with disability to directly seek their views and opinions and to understand their experiences, as well as stimulate further development of practice to ultimately advance the human rights of children with disability.

SECTION ONE

Research involving children

Methods for engaging with and listening to children as to what is important to them continue to develop within social research, with a range of tools and techniques for collecting data being explored. There are a range of issues that need to be examined when researching with children including processes of engaging with children, the use and effectiveness of various tools, as well as principles and ethics that need to permeate the work. Many of these issues apply to all children while some are specific to those with disability. The focus of this guide is on children with disability though some of the literature drawn on refers more broadly to children in general or adults with disability.

Listening to children and directly seeking from them an understanding of their experience and knowledge is a challenge to well established methods - we have traditionally learnt about children from adults who have conducted research on children rather than with children.^{1 2 3 4} The shift in paradigm for studying children reflects a move to seeing children as actors in their own right rather than as passive recipients of adult socialisation. A focus on conducting research with children, rather than just on them with no attention given to their unique viewpoint, requires consideration of an appropriate methodology.⁵ Participatory research provides a methodology that acknowledges children's agency and recognises children for their abilities to competently report on their own experiences.^{6 7} This recognition legitimises and values the experiences and thoughts held by children⁸ giving children greater power in 'defining their own situation and ideas'.⁹ This can provide an invaluable insight into children's lives which increases the chances of being able to support children's wellbeing.¹⁰

In general, children and young people should be regarded as having capacities and skills to offer throughout a research process, challenging perceptions that children are vulnerable and with limited capacity to offer ideas, insights or feedback.¹¹ Children's ability to express their views is regarded as a human right and affirmed by the United Nations Convention on the Rights of the Child (CRC) (1989).¹² Many research projects^{13 14} highlight the mandate for child agency and participatory rights of Article 12, which declares that:

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.¹⁵

Further, Article 13 declares, in part, that '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...'.¹⁶ The participation of children in research provides a means of fulfilling this human right to self-expression.

As well as providing a means of exercising the right to freedom of expression and enabling further knowledge to improve the lives of children, there are other benefits to the participation of children in research. Children can become empowered in the research process through increased awareness and development of personal skills to become active agents in their own lives.¹⁷ Other benefits can include an increase in self-esteem,¹⁸ along with the formation of closer bonds between children and their families through improved communication, as well as children feeling valued and proud of their contribution to the research process.¹⁹

These benefits for children in general apply equally to those with disability. Often, family members and stakeholders are reported to be resistant to children with disability participating in research, citing children's incapacity to engage or stay engaged in the research. The same stakeholders are often surprised and overwhelmed by an observation of children with disability's capacity to actively engage in research.^{20 21} This revelation can lead to a greater awareness and respect for children with disability's capabilities for participation.²²

Ultimately, the key purpose of engaging children in research is to provide them a means of sharing their understandings and viewpoints, and to add to the body of knowledge regarding children's lived experiences, thoughts, priorities and concerns. Researching with children enables them to have a voice that is not often heard due to the unequal power differences between adults and children that privileges the adults and may silence children. Hearing children's voices and capturing what is important to them, fills in knowledge gaps, often contradicts adults' understanding of children, and enables society to better respond to children whether that be within families, communities, organisations or government.²³

Research involving children with disability

Just as children have a fundamental right to express their views, so too do people with disability have the same rights mandated within the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006).²⁴ This Convention affirms the entitlement of people with disability's right to enjoy 'full and effective participation in society on an equal basis with others'.²⁵ Further, a person with disability also has the right 'to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice'.²⁶ Such rights have clear implications for research as well as the involvement of people with disability in all forms of public consultation, planning and evaluation.

Historically, research exploring the experience of people with disability – including children – has largely been undertaken without their involvement. Yet there are shifts towards greater empowerment of people with disability in the research process. The emerging 'socio-political interpretation of disability' in the 1970s and 1980s, led to a new emancipatory approach to disability research.²⁷ Within this approach, people with disability are seen as researchers and experts of their experience in contrast to 'the power of the researcher-expert ... [with] control over the design, implementation, analysis and dissemination of research findings' that is traditionally held by researchers without disability.²⁸ More recently, consideration has been given to methods to include the active participation of people with cognitive impairments. This has been identified as an 'inclusive' research method which involves the importance of making research participation accessible to those with a variety of impairments including cognitive impairment.²⁹

In order to achieve an accessible and inclusive research method in which children with disability can participate, researchers need to focus on the design of the research project to achieve this. In particular, this includes alternative and diverse methods of respondent recruitment as well as adaptations and supports in data collection procedures that enable children with diverse disabilities to self-report, or communicate directly, about their own views and experience. Customising recruitment and data collection processes to each individual's communication and support needs is a key strategy, along with allowing additional time (including multiple episodes of data collection) in the data collection process to enable children with disability to participate at their own pace and utilise their own mode of communication.

There is now a growing body of literature that reports on barriers to self-reporting for people with a disability as well as research design strategies that can be employed to overcome these issues.^{30 31} Barriers and strategies to address these are summarised in Table 1 on the following page.

Overall, the central message is to plan to adapt research methods and offer alternative modes of asking and answering questions, customising the process to the preferred communication mode of the person with disability and providing the supports necessary to enable participation. This guide offers some tools and guidance to achieve the inclusion of children with disability in research. It is far from encompassing and seeks not to be overly prescriptive (especially when using the tools) but aims to assist and encourage those who wish to engage with children with disability and to equip them with principles and techniques to do so.

Table 1: Barriers to and strategies for research participation in relation to broad impairment groups

Impairment	Resulting issues/barriers	Strategies (examples)
Vision	<ul style="list-style-type: none"> • May not be able to see/read text (or smaller font text). • May be unable to see visual prompts including photos and pictures. 	<ul style="list-style-type: none"> • Offer tactile and aural prompts, such as opportunity to hear questions or to feel objects associated with question/answer. • Use large font and high contrast in text and pictures. • Offer a Braille translation of questions if person uses Braille, and opportunity to respond in Braille. • Offer opportunity to audio tape answers to questions, and listen back over their answer to check this.
Hearing	<ul style="list-style-type: none"> • May be unable to hear or have difficulty hearing instructions/questions that are spoken. • May not have developed a spoken language (or have limited spoken language). • May not have had opportunity to learn a sign language (or have limited or very localised sign system). • Vocabulary/concepts of the research may not translate into sign language easily. • Literacy may be limited. 	<ul style="list-style-type: none"> • Use visual prompts (text, pictures, symbols). • May require interpreter for communication (check with interpreter that there is an appropriate sign translation for your questions and topics). • Use text (written instructions and questions) rather than verbal instructions. • Use basic concepts and/or key images for those who lack vocabulary. • Use telephone typewriter or relevant text system if person uses such systems (though length of text restricts long questions and answers so these need to be broken up into smaller chunks).
Cognitive/ intellectual	<ul style="list-style-type: none"> • May not understand abstract ideas, concept of time. • May have limited or no language development. • May communicate through vocalisations, gestures, movement etc. that are not widely understood except by people who commonly communicate with the person. • May have limited literacy and vocabulary. • May have limited attention span. • May not be able to reflect on emotional states. 	<ul style="list-style-type: none"> • Use simple language with concrete supports, such as visuals or audio support (for example, use photos or images to supplement text or verbal instructions, visual cue cards etc.). • Carefully construct the question format to make simple and concrete/specific. • Ask about one element/topic at a time. • Provide time to answer, and/or repeat question. • Use simple answer choices (e.g. 2 point scale). • Design method for the preferred communication mode of the person – recognise the use of facial expressions, gesture and behaviours. • Prepare for diversity of methods to support diverse needs of people with cognitive impairment. • Do preparatory work with the person prior to data collection to help them understand the concepts/topic.

Impairment	Resulting issues/barriers	Strategies (examples)
Cognitive/ intellectual (continued)		<ul style="list-style-type: none"> • Recognise and allow the role of communication partners (i.e. someone who knows the person and how they communicate) to assist the person to understand the questions and communicate or translate/interpret their answers.
Communication	<ul style="list-style-type: none"> • May have little or no speech or speech that is hard to understand. • May use communication systems (such as movement, gesture, pointing, eye gaze) that are not widely understood except by people who commonly communicate with the person. • May have other impairments (such as physical, vision, cognitive etc.) that affects how the person communicates. 	<ul style="list-style-type: none"> • Identify the preferred communication mode of the person and design the process around this. • Provide time to answer question (as different communication modes can take extra time). • Use communication supports (including augmentative or alternative communication supports), which may also require alternative seating or lighting to assist use of this mode. • Provide alternate communication modes, such as written and video recorded answers. • Recognise and allow the role of communication partners (i.e. someone who knows the person and how they communicate) to assist the person to communicate or translate/interpret their communication. • Customise your communication to incorporate the facial expressions, gestures, signs, symbols, and personalised vocabulary used by the person.
Physical	<ul style="list-style-type: none"> • May not be able to get to/attend the place of data collection. • May not be able to easily mobilise and participate in some methods (e.g. guided tour). • May not be able to hold a pencil etc. or undertake activities associated with the research. 	<ul style="list-style-type: none"> • Identify if carer support will be needed during the interview and provide this. • Meet in a venue that is easily accessible to the person (including transport to and from venue). • Provide alternatives to writing/drawing (requiring hand dexterity), and other research activities. • Be prepared to accommodate the seating/lying position of the person by moving data collection tools into the viewing range of the person. • Provide a scribe to write down answers if the person requires, or an opportunity to audio or video record answers.
Psychosocial	<ul style="list-style-type: none"> • May have lack of focus or limited attention span. • May have behavioural issues that affect their interaction. • May be more likely to experience distress or upset during research processes and interactions. 	<ul style="list-style-type: none"> • Have a support person available to provide comfort and support should the person become distressed or aggravated. • Strategies for other impairment groups may be useful.

Principles of inclusive research with children with disability

Research projects are guided by explicit research methodologies adopted by researchers. Research with children with disability encompasses many topics, methodologies and methods, but we suggest that in order to be consistent with children’s rights, research should be based on the following principles.

Table 2: Principles of inclusive research with children with disability

Respect	<p>We will value the inherent dignity and autonomy of the individual.</p> <p>We will be honest, ethical and accountable in our work.</p> <p>We will respect the views and experiences of children and take these seriously.</p>
Trust, relationships and time	<p>We recognise that children might be distrustful of us and will need time to get to know us.</p> <p>We will allow time to build trust and rapport between researchers, children, families and communities.</p> <p>We will ensure ongoing, informative communication with all participants.</p>
Strengths	<p>We recognise that all children have strengths and we focus on these.</p> <p>We value children’s capacities, ideas and experiences.</p> <p>We recognise that all children, regardless of how they communicate or their disability, have something valuable to communicate.</p>
Inclusive of diversity	<p>We believe everyone should have an equal opportunity to be involved.</p> <p>We will work in inclusive ways to enable the participation of children with vision, hearing, intellectual/cognitive, physical, communication, mental health and multiple impairments.</p> <p>We will adapt the way we work to cater for differences in age, language, personality, gender and cultures.</p>
Listening	<p>We will listen to children with disability as a priority and value their ideas, views and opinions.</p> <p>We will listen in diverse ways including paying attention to facial expressions, bodily gesture and movement, vocalisations and other signals.</p>
Choice and comfort	<p>We will support children to decide the degree of participation they are comfortable with.</p> <p>We will offer locations and ways to participate that are relevant, comfortable and appropriate to each child.</p>

Respect

Children must be respected at all times during the research process. Article 3 of the Convention on the Rights of Persons with Disabilities highlights the principles of respect for inherent dignity and individual autonomy including the freedom to make one's own choices, along with respect for the evolving capacities of children with disabilities.³² Respect also requires researchers to have consideration for the 'welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective, of those involved in research'.³³ This also means that any specific agreements made with the participants or the community should be fulfilled.

In effect, respect for the child in research is an overarching principle that underpins all principles and ethics of research with children (both with and without disability). It places accountability on the researcher to ensure that their work and engagement with children is honest and ethical, and that principles and ethics such as those outlined in this guide are central to all aspects of the researcher's activities. It may not always be clear how to apply the ethics and principles in a given situation and there may be conflicting opinions on what is right or wrong. In such circumstances it is important that all those involved in research bring a keen ethical awareness to their thinking and decision-making³⁴ with respect for the inherent dignity of the child at the forefront. Principles and ethical guidelines are not simply a set of rules. They require deliberation on the values and principles, exercise of judgement, and an appreciation of context.

Listening to and valuing what children have to say is central to respect for children. Researchers from an Australian research project noted that young people identified the importance of respect and reported that 'participation should be respectful, that their views should be taken seriously and that recognition is most deeply experienced when they are invited to talk directly with decision-makers'.³⁵

Practice example

Loto is eight years old and has a physical disability that affects his arms and legs. Loto's native language is Bislama so the research aims and processes, consent procedure and the research questions, were all explained in Bislama to Loto. He had some difficulty in understanding them so his father assisted with translation. Loto understood once they were explained by his father who also assisted researchers with questions that Loto had for them. Loto understood but took time to comprehend and to respond, requiring us – as researchers – to not rush the process but to respect Loto and the pace and rhythm he was comfortable with. We needed to take our time with the questions and allow time for responses. Questions needed to be repeated and explained a few times, being careful that the meaning was precise and clear. We were aware of the need to ensure Loto was comfortable both physically and emotionally throughout our time with him, having respect for his wellbeing while he participated.

Trust, relationships and time

Trust between children, researchers and families is central to the research process. Trust cannot be built overnight; time is required to build relationships with children and their families and allows for the experience of mutual exchange as children get to know researchers and vice versa.^{36 37} The building of trust requires ongoing planning, reflection and negotiation, with time built in to the research process to allow for activities to build rapport with participants and to negotiate community support for the research.³⁸ Ongoing communication must ensure that all participants are fully informed about the study and their rights in relation to the research.

Positive, respectful relationships facilitate the development of trust. Given children with disability often experience being devalued or discriminated against, children could potentially be distrustful of others and so respect for the individual is essential to the process of building rapport and trust. The success of children's participation very much depends on the level of trust they feel which must be built over time through reciprocal relationships.^{39 40}

Practice example

Airine is a 12-year-old girl with physical and cognitive disabilities. We met Airine and her parents at their home and explained the research to them, answering their questions and gaining their consent. In all we visited five times, getting to know Airine and her family, often telling stories together as well as explaining the research further. We found that by visiting a number of times we were able to build a relationship with Airine who became more comfortable and open with us.

Strengths

A focus on a child's strengths means not regarding children in terms of deficits but seeing them in terms of their unique individuality and their assets. A strengths perspective values the positive characteristics, knowledge, skills, assets and resources of an individual.⁴¹ A focus on strengths shifts from seeing children with disability as incapable, to valuing the unique contribution they can make to any endeavor – including research. Children with disability must be appreciated for their capacities, ideas and their experiences, rather than viewed for their lack of life experience or impairments.^{42 43 44} Research must take the starting assumption that 'all children and young people – whatever their communication and/or cognitive impairment – have something to communicate. It is up to us to find ways of understanding their views and experiences'.⁴⁵ In this context, the focus is on potential not limitations, where capacity is seen as evolving and growing for all individuals.⁴⁶

Valuing children for their strengths and ability to self-report, rather than deficiencies, enables greater personal interest in the research with closer involvement and power in the process.⁴⁷

Practice example

Marietta has disabilities that affect her physically. She finds walking difficult and has breathing problems. Her father was pleased Marietta was included in the research as he said no one has ever asked her what she thinks or what she believes would help improve her life. We (the researchers) soon learnt that she liked to draw and color, and that this activity helped her to tell stories, which she also liked doing.

We spent a lot of time during visits and did activities that Marietta enjoyed and felt good at, so we all gained mutual trust. Engaging in stories and spending time with Marietta gave her the confidence to talk with us and tell us about herself. She was thoughtful and intelligent with her responses to the questions, though if we had rushed the process with Marietta it would not have been so successful. We let Marietta take the lead and determine the tools/activities to engage in. At first Marietta was shy and looked to her father to answer the questions but we asked him to encourage her to speak for herself. As her confidence and trust grew over a couple of her favourite activities (drawing and colouring), Marietta spoke to us more openly.

Inclusive of diversity

Researchers need to work in inclusive ways to facilitate participation of children with vision, hearing, communication, cognitive, physical, mental health and multiple impairments. Researchers must consider methods and children's specific impairments carefully so that they can offer a variety of tools to try, and therefore ensure that children are able to genuinely participate and share their experiences. Previous research notes that 'unless there is a specific focus on including children and young people with significant communication and/or cognitive impairments, they will inevitably be excluded'.⁴⁸ An important part of this focus must be adapting the research tools⁴⁹ and using ones chosen by the child and that they are comfortable in using. Such adaptations provide the opportunity for children to exercise their capacities while ensuring that their impairment does not impede their right to participate.

Research projects are generally found to be successful when they adapt and cater to the diversity of children such as their age, language, personality and gender, along with different cultural interpretations, research contexts and individual interests.⁵⁰ Researchers need to acknowledge that the level of participation will vary according to a child's age, impairment, interest, personality, comfort, setting, and level of trust with the researchers,⁵¹ while striving to ensure that children aren't excluded because of a lack of accommodation on behalf of the researchers.

Methods require careful consideration for cultural relevance, with a research approach that is flexible enough to respond to ensure that methods are used in a way that reflect children's rights to express their views in a way of their choosing. For example; despite common assumptions, some children in a Fiji study felt uncomfortable drawing: 'Some were self-conscious, while others felt that it was a test to determine whether or not they could draw the correct image.'⁵² In this instance, a tool considered appropriate proved not to be so. The methodology allowed the researchers to decide not to use that tool, or to amend it. Whilst some methods can be pre-empted as culturally inappropriate or irrelevant prior to use, researchers also need to carefully observe how children respond and feel when using certain tools. Providing children with a choice of tools increases the chance of children participating using methods that are appropriate for them and that they feel comfortable with.⁵³

Practice example

Jayz is ten years old and has had chronic ear infections since birth. The infections have caused damage to Jayz's hearing and that makes it difficult for him to communicate. We used a combination of drawing and story-telling as these seemed to suit his interests and worked best to suit his communication needs. It was important not to rush him and take our time. Asking the questions in Bislama (his native language), and explaining the questions clearly, worked really well. We let Jayz take the lead with the conversation so he thought he was conducting the 'interview'. Plenty of time must be spent with children like Jayz as he wants to understand and likes to really think about things. He liked participating in the research with the help of his mother and not alone.

Listening

An emphasis on the 'voice' of children as integral to the research process has meant that researchers need to critically consider how to facilitate children to express their views, giving primacy to children rather than adults as has traditionally been the case. This applies equally to children with disability. Often children are silenced and deemed too young to express their voice, or deemed to be incompetent, and that it is adults that have to act on their behalf. The recognition of the rights of children challenges this perception. The role of the researcher using a rights-based approach is to value what children have to say by 'listening to, interpreting and acting upon'⁵⁴ what children tell the researcher. Parents and caregivers may provide additional information to add context to children's stories or they may assist with communication, acting as an interpreter of the child's mode of communication. This role is an important aspect of this approach, and differs from the role of 'proxy' where an adult is asked to give their own view of what they think the child wants or needs. As a communication partner/interpreter, the other person is someone who knows the child well and can accurately interpret their communication so that the child is able to be heard.

The listening role is not just about hearing the child's actual voice but includes 'using all the senses and emotions' as children's communication includes more than speech.⁵⁵ When listening to children with disability, 'it is necessary to look to their body language, different tonal patterns, facial expressions and bodily movements. These signals help build a picture of what life is like in the setting for these children, what their preferences are and how competent and confident they feel'.⁵⁶ Listening can surprise researchers' assumptions and challenge practice, raising expectations about what children can contribute. 'Seeing and hearing children express their interests and priorities can provide unexpected insights into their capabilities'.⁵⁷

Practice example

Rozario uses verbal speech in his mother tongue. He is eight years old and has had a hearing impairment since he was born. To communicate with Rozario, you have to get very close to him so that he can read your lips and look at your eyes and facial expressions. If you don't engage with him directly, he can't hear you and loses interest. We became aware from changes in his posture and face when he was frustrated with us. When listening to Rozario, we also had to focus on his lips and listen carefully to what he had to say. It is important to explain things clearly and not rush him, but provide him with time to think before responding. He wanted his mother to be with him throughout our time together. However, while she was on hand to assist in the dialogue between us, we found that taking our time and being focused on Rozario allowed us to have direct conversation with him.

Choice and comfort

The research setting can influence how children participate in the research.⁵⁸ Children interact with adults differently depending on the setting. Consideration needs to be given to the context and environment in which research is conducted with children and in which conversations take place. The location and the power differences present in a particular location, such as a school, will impact how comfortable a child will feel.⁵⁹ Conducting research interviews in the home can also be problematic depending on the context. Children may feel more comfortable at home so may be more likely to participate in that setting, however, older children may feel uncomfortable discussing topics that their family are unaware of or that involves their family and are of a sensitive nature.^{60 61} Given this diversity, the right of the child to choose where the research is conducted is paramount to enabling maximum participation and child comfort.

In addition to setting, children also need to be comfortable with the methods of research. Children need to be provided with an array of methods or tools that they can choose from according to their comfort.⁶² The variety of methods provided to children needs to be sensitive to age, development and capacity.⁶³ Given this, offering a variety of tools is thought to be a more inclusive approach that caters to a diverse range of children including children with disability.⁶⁴ Relying solely on one method can lead to exclusion. For example, relying on verbal communication only is found to limit children's ability to participate. A song or verbal story telling tool may suit a child with a vision impairment whereas visual tools such as pictures and drawing, or story telling in sign language, may benefit a child who is deaf.⁶⁵

In general, researchers are encouraged to draw upon a range of tools⁶⁶ and playful activities that provide children with choice and flexibility.^{67 68}

Practice example

Olima is seven years old and lives with his parents and siblings. He has speech and hearing impairments and attends the local elementary school. Unfortunately, we could not use sign language in Olima's preferred language but we were able to rely on the family – especially his father – to assist us to communicate directly with Olima. This was a great help. However, we had to balance this assistance with the fact that Olima likes to be alone when he draws and doesn't like to be watched by others. We provided him with paper and pencils and let him work alone and at his own pace. Once he finished, we were able to discuss the drawings in relation to the questions with assistance from the family. We emphasised that it was Olima's ideas and opinions that were important.

Ethics of research with children with disability

To engage directly with children and seek their unique perspective of their experiences and world-view raises a number of ethical considerations. An ethical approach is based upon ethical protocol and concerned with upholding and protecting the rights of children that are participating in the research. Ethical guidelines relating to the conduct of human research require researchers to take account of the special needs of vulnerable groups.^{69 70} The following ethical principles for research with children with disability need to be considered.

Table 3: Ethics of research with children with disability

<p>Informed assent and consent</p>	<p>We will make sure both the child and their parent or responsible adult understand the research.</p> <p>We will make sure that children’s participation is voluntary.</p> <p>We will respect the child’s right to agree to participate or to decide not to participate at any stage.</p> <p>We will keep checking at each stage of the research to see if the child still agrees to participate.</p> <p>We will respect the parent or responsible adult’s right to agree for their child to participate or to decide they cannot participate.</p>
<p>Balancing privacy and support</p>	<p>We will respect the child’s right to give information in private if they wish to.</p> <p>We will ensure children are safe and protected when giving information in private.</p> <p>Children can choose to participate in private or with their parents or responsible adult present.</p>
<p>Confidentiality</p>	<p>Individual children will not be identified in our research. We will report information that the child tells us only in ways that maintain the anonymity of the child.</p> <p>We will keep all information confidential, except where there is a risk to the child if we do so.</p> <p>We will explain to the child and the parent at the beginning of the research, about when we will need to breach confidentiality and pass on information in order to protect the child.</p>
<p>Safety, protection and safeguards</p>	<p>We will work in ways that promote the safety and protection of children.</p> <p>We will have clear rules about who can be researchers and their behaviour so as to protect children.</p> <p>We will always try and reduce any discomfort or distress that children might experience by participating in the research.</p> <p>We will have supports in place for the child if they feel upset or distressed.</p> <p>Children can choose what information they feel safe to share with us.</p>

Informed assent and consent

The terms ‘assent’ and ‘consent’ are often used interchangeably in child research literature. In general, ‘consent’ relates to agreement from someone who has the legal authority to agree to the child participating in the research, usually the child’s parent or responsible adult. A large proportion of child research requires consent processes, with parents or responsible adult to authorise their child to participate in the research. However, for some research projects, older children can provide their own consent, depending on their maturity and the legal and ethical tests of competence that apply in that jurisdiction.⁷¹ In addition to consent to participate, research that adopts a participatory rights agenda must also seek children’s assent or agreement to participate in the research.⁷² In short, children have to want to/agree to participate (assent) and their parents or responsible adult has to approve or authorise their participation (consent).

A number of strategies have been noted in child research literature to ensure that the consent and assent process is not tokenistic or passive, but meaningful and facilitative to enable children to exercise their rights and make informed decisions.^{73 74} Accessible consent, assent and dissent strategies involve the development of child-friendly information about the consent process, the research purpose, relevance of the research to the child and the value of participation to other children like them.^{75 76} Information about the research may be provided in different formats and may include photos of the researchers,⁷⁷ simple language, pictures and symbols, information provided in sign language,⁷⁸ use of a doll that children can communicate with, stickers indicating thumbs up and down, pictures of facial expressions, cameras, tape recorders and drawing.⁷⁹ Observing children’s facial expressions and body language can be valuable for researchers to ascertain assent or dissent.⁸⁰

Obtaining assent is viewed as a continual process throughout the research project.⁸¹ This might involve describing each new stage of the research as it occurs and then re-gaining assent.⁸² For example, each interview might commence with re-visiting assent, including explanations about the research, the privacy of information provided, and re-assurances about safety.⁸³

Respecting children’s ability to indicate signs of interest and engagement in research also requires respect for their right to dissent. Just as with assent, checking for dissent is an ongoing process throughout the research.⁸⁴ Dissent occurs when a child is asked whether they wish to participate in research and indicates ‘no’ verbally or non-verbally. Dissent gives recognition to a child’s objections and to the desire to refuse to engage in or – just as importantly – withdraw from research. A child might not make an explicit request to withdraw from research but researchers need to be aware of verbal and behavioural signs that indicate when a child does not want to continue. Researchers have noted that such behavioural indicators include: passivity, lack of cooperation, fussiness, silence, crying or puckering, constant looks towards the door, lack of eye contact with the researcher, and/or signs of boredom such as multiple yawns. Verbal indicators may be explicit but may also include more indirect indicators of not wanting to continue such as: ‘I want to go to the toilet’, ‘I’m tired’, ‘When will I be done?’ and/or responding repeatedly to direct and age-appropriate questions with ‘I don’t know’.⁸⁵

All of these strategies to facilitate consent and assent, and to check for dissent, require time, resources and above all, genuine intentions. Whilst some children may not understand consent/assent or the concept of research, most will be able to gain a basic appreciation and make informed decisions ‘so long as the information is presented in an accessible manner and there is time to fully explain and answer questions if necessary’.⁸⁶

No participant should ever be coerced to take part in research, which should always be chosen voluntarily after being fully informed about the key aspects of the project.

Practice example

We met with Toni (13 years of age) and his mother in the kitchen of their home. After introducing ourselves we explained more about the project. Toni's uncle (who is his mentor) explained that Toni needs plenty of encouragement. He had experienced plenty of 'cheeking' (teasing) at school because of his physical disability that affected his walking. Now he mostly just stayed at home or walked to the shop to talk with friends. Consent was obtained from Toni, his uncle and parents.

On our next visit, Toni was waiting for us but he was disappointed because his mother had agreed to the appointment and instead had gone out to the garden. We talked with Toni again about the project and asked him if he wanted to continue and he agreed. Toni was happy to walk with us and to show us through his village and talk about what he did during his day. We asked Toni if he would like to take some photos of things he likes while walking. He was interested in how the camera worked. He then guided us through his village as he took photos of the things that interested him, including his house, his younger brother and some flowers. After a short time Toni was only interested in returning to his friends. He no longer wanted to answer any questions or be involved in story-telling. When we asked him if he was tired of the questions, Toni did not answer. He asked us if we could come back on Saturday when his mother would not be at the garden.

When we arrived on Saturday, Toni was sitting in one of the community meeting areas with his teenage friends. He did not show any real interest in us being there but took us to meet with his mother. His mother was not receptive and did not show any greetings or interest as demonstrated at our previous meetings. We talked about the research again and asked if she still wanted Toni to be involved. She did not respond to questions and became less interested as we tried to engage her in conversation. Toni displayed the same dissent so we stopped questioning and gently explained there was no obligation for Toni or the family to continue in the research. We also explained they have the option to reconsider if they wished to be involved and could contact us if they wanted to do so.

Balancing privacy and support

Careful planning is required to assist researchers to anticipate the sensitive and complex dimensions the notion of privacy entails. In this instance, privacy refers to the issue of whether or not a child participates without a parent/guardian present when working with a researcher.

Parents (or families, guardians) may regard their children as needing extra protection in research contexts due to the potential for exploitation of the power imbalance given adult authority in relation to children, who may respond in ways they think are expected from them.⁸⁷ However, parents – and researchers – need to appreciate that children have a right to privacy and this may involve participating in research without their parents or other people present.^{88 89} This maintains the child's right to not have the information they give to researchers shared with others. The dialogue with children and parents needs to include an explanation as to why privacy is important to consider, as well as considering the impact of parents being or not being present

during the interview and the impact on the child of being alone with the researchers given power differentials. The characteristics of the child and their circumstances need to be understood by researchers when considering eliciting information from a child. This includes the age of the child, the comfort and safety of children participating, their ability to communicate with or without the support of a family member and the nature of information being sought.⁹⁰

In order to respect children's rights to privacy along with choice and comfort, children should be offered a choice to participate in private or with a family member present and that choice be respected during the research process. This issue is particularly pertinent for adolescents where they may wish to disclose information that is unknown to their parents but are unable to in the presence of a parent.⁹¹ It could also be argued that young children, without the company of their parents, may feel uncomfortable participating in research and communicating their thoughts and ideas. For safety reasons parents may also be uncomfortable with their children participating without parental presence.^{92 93} These conflicting requirements and concerns need to be weighed up by researchers who need to be mindful of the concerns of parents while respecting the choices of children.

Researchers also need to consider that different results can emerge when interviewing children alone or with their parents or others⁹⁴ and therefore researchers need to assess the consequences of this when considering research results.

Practice example

Farah really enjoys drawing and colouring. He is eight years old and has a physical disability. It took a couple of sessions to get to know him and for Farah to begin responding to the questions. Trying to question him in his own community was unsuccessful because he was distracted by the people and what was going on around him. We asked Farah if he would like to move somewhere quiet. He was happy for himself and his mother to move away from the distractions, so we moved to a space Farah was comfortable in. We set up the drawing activity, leaving him alone with his mother and one researcher he was friendly with. Farah was happy for his mother to be with him while we chatted. Being away though from other people worked successfully. Farah was at ease and the questions were answered over two sessions.

Confidentiality

Where privacy relates to the research participant's direct disclosure to the researcher, confidentiality relates to the extent to which the researcher protects the participant's private information once it has been obtained. Enabling children to confide in researchers and keeping their information private is integral to the respect researchers have for children. The information children provide can only be used for the purposes they have agreed to as part of the research project, and only the researchers involved can have access to information about who has participated and the details of what they have shared. Children's names or faces must not be identifiable and children may have a choice to develop their own pseudonym for use in the research.⁹⁵ There are occasions when children specifically ask for their information to be identifiable and this may or may not meet ethics requirements.⁹⁶ This tension between the need to ensure a child is not put at risk through being identified in a research process and a child's right to decide that they wish to be identified is complex. Even where researchers are not prevented from identifying children by ethics guidelines or child protection policies, discussion is needed between researchers, children and responsible adults as to the risks and benefits of this identification.

Children may disclose information that is concerning and places them at risk. Information may involve disclosure of abuse or neglect, exposure to – or participation in – at-risk activities, self-harm, or life threatening situations. Various researchers have developed different approaches to manage situations where they feel the need to breach confidentiality and disclose children’s information in order to protect the children’s safety and wellbeing. Coined as ‘limited confidentiality’, researchers are encouraged to discuss with children and families (prior to the commencement of the research) how confidentiality will be respected and when it will be breached for children’s safety.⁹⁷ In such cases, researchers require clear protocols for the passing on of information to relevant bodies whose role it is to protect children.

Family members who may be present in their child’s participation may not fully understand the concept of confidentiality and it may be culturally unfamiliar to them. Whilst privacy and confidentiality are concepts understood in western societies, they will need to be carefully discussed and planned for in developing contexts and utilised in a way that simultaneously respects local cultural norms. It is important to support family members to understand the ‘importance of preserving their child’s right to confidentiality – particularly if they are present during the sessions’.⁹⁸

Practice example

Luke is six years old and has multiple disabilities – he cannot walk without support, and cannot speak clearly. He is always left alone and locked up at the house whenever his parents need to go gardening or go somewhere else. When I (the researcher) go and see him, he is always locked up in the house and is alone with no food. When he hears me talking outside the house saying hello to him, he cries in hunger. I am concerned, as a researcher, about his welfare. I have reported his situation to the child protection officer at our organisation.

Safety, protection and safeguards

The comfort and safety of children must be of paramount concern to researchers during the research process.⁹⁹ This requires researchers to be sensitive to participant concerns throughout the research.¹⁰⁰ When children are asked to share experiences in their life, there may be experiences that cause them pain and anxiety. Researchers have the responsibility to minimise any distress children may experience.¹⁰¹ One way of doing this is to ensure there are steps in place to ensure the protection of children. This could involve telling children that as researchers we don’t want them to feel upset or unsafe at any time during the process and that any given research activity would stop if a child felt distressed.¹⁰² Another strategy is the use of tools or activities that support children to feel positive after a period of sharing experiences that leave them feeling sad or vulnerable.¹⁰³

Children must be continuously advised that they have a choice not to participate at any given time and that research activities can be stopped if the child chooses. Children should also be advised that they have a choice to participate but not to disclose information that they feel unsafe to share.¹⁰⁴

Embedding safety mechanisms into child research will assist in the prevention of harm to children and ensure comfort in the research process. Safety mechanisms include:

- Police and reference checks of researchers where possible.^{105 106}
- Clear rules within the research process that direct the behaviour of researchers (for example, no inappropriate touching of children). Researchers should not be alone with a child; a third person must always be present, such as a family member or second researcher, as a method to eliminate opportunity for harm to children.^{107 108}
- Supervision of researchers to ensure researchers are abiding by ethical processes and research principles that aim to maintain children's safety at all times.^{109 110}
- Reflective practice to monitor risks and improve the practice of engaging with children throughout the research process.¹¹¹ This involves careful consideration and includes regularly checking in with children, how they participate, the benefits, risks or limits of participation, relationship development and elements required for children 'to remain engaged and committed'.¹¹²
- Discussing support options for children such as linking children to other people in their community that can provide support.

Conclusion

The principles and ethics outlined above apply to all children both with and without disability. Children with disability will most likely require accommodations to be made by researchers to ensure that they can be fully included in any research and that all communication with them is done in a way that is applicable to their preferred manner of communicating. Children with disability may be more vulnerable to risk and harm than those without, and this will require additional planning to ensure their protection while enabling their full participation. There is no pro forma to ensure a research project is ethical and has minimised risks. However, research will be aided by a combination of factors including ethical protocols by research institutions, as well as the 'context of the particular study taking place, the care and protection laws under which the researcher may have to abide by, and the views and opinions of all the research stakeholders and participants'.¹¹³ Above all, researchers need to be thoughtful and respectful of children – with and without disability – and their human rights. Researchers need to reflect critically on their practice and to heed the warnings of previous researchers who assert that children's involvement is often 'tokenistic, unrepresentative in membership, adult-led in process and ineffective in acting upon what children want'.¹¹⁴

Listening to and involving children with disability, their families and stakeholders throughout the course of the research, and ensuring that children have as much control as possible over the research process, will promote respect for children along with their safety and comfort, fostering greater participation while enhancing the benefits of the research for children with disability.

SECTION TWO

Introduction

This section presents ‘how to’ guides to each inclusive tool. These are designed to guide practice in the field and to identify key considerations in using each tool. However, the selection and use of tools is part of a process which aims to be flexible and adaptive to meet the needs of children with disability involved. Therefore this section starts out with a brief discussion of underpinning approaches when using any inclusive tool with children with disability.

General tips in using inclusive tools

Rationale and process for the development of inclusive tools

The development of these research tools was based on a literature review of other participatory tools used with children, particularly with disabilities. We took note of what tools experienced researchers observed to work well with children with disability and in what context. In addition, we spoke to service providers and resource centers about particular tools and suitability for children with particular impairments. Prior to the research commencing, we tested the tools with a range of adults and researchers with disabilities and refined them further. Finally, the tools were trialed with 43 children in Vanuatu and 46 children in Papua New Guinea. All of the child participants had a range of different impairments and, often, multiple impairments. At the completion of the research process, the child participants and their families gave feedback on what they thought of the tools. Finally, the researchers from both countries reflected on the use of the tools throughout the process and these findings were collated, analysed and included in the refinement of the tools.

As our research was based in developing countries, we know that many children with disability in such contexts are not able to access education. Therefore, literacy-based tools were avoided. Most of the tools included in this guide have either a visual, audio or tactile element to them. Whilst they are designed to be inclusive tools, they can be used by children with and without disabilities in research inquiry.

In the ‘Voices of Pacific children with disability’ project, our overall research question was: What are the human rights needs and priorities of children with disability in Vanuatu and Papua New Guinea? We decided to ask children with disability three questions to help answer this:

1. What is important to you in your life?
2. What are your hopes and dreams?
3. What would make your life better or happier?

We oriented each tool around these three research questions (and our overall research question). For example, in the case of the Photo Library, we deliberately collected photos that represented a range of human rights areas using the Convention on the Rights of Persons with Disabilities (CRPD)¹¹⁵ to ensure that children had a diverse array of photos (that represented a full range of life areas) to select from when answering the research questions.

When using these tools in other research projects, they can be adapted to suit the research topic and question/s in each new context, as well as the specific needs and interests of children who are participating.

It's about the conversation

Any inclusive tool or method of eliciting the views of children with disability is, at its simplest, a prompt or facilitator to support the child to participate in the research and provide answers to research questions. Interviews or conversation without the use of tools can feel contrived and unnatural for many children. Tools are a means to generate communication and conversation in a more playful and supported way.¹¹⁶ In this way, the focus is on what is communicated both through using the tools AND through the conversation that occurs around this. Given that children are at ease with objects or activities that they can play, interact and have fun with, tools can also be a means of maintaining enjoyment and engagement, while the child answers questions. That is, the child may be happy to play with the tools or do another activity (such as kicking a ball) while answering questions. Tools can also be a distraction from children's shyness, a vehicle to maintain interest and comfort while answers are elicited. In this way, tools can function in many ways within a research context and ultimately are to be used as a vehicle to support the child to communicate and converse about the research topic in whatever way works best for them.

Offering a range of tools that are accessible

To ensure accessibility in research for children with disability, it is important to think about what tools will be suitable to children with particular impairments. This also involves consideration about what tools may be suitable for children with two or more impairments.

The following table outlines a basic guide to tool selection according to impairment type – keeping in mind that every child has diverse needs and interests, and that impairments vary. There is no set rule.

Table 4: Guide to tool selection according to impairment type

Tools	Physical impairment	Blindness and low vision	Deaf and hearing impairment	Cognitive impairment	Comment
Photo Library	✓	✗ Not suitable for children who are blind. ✓ May suit some children with low vision.	✓	✓	Especially useful for children who are deaf or hearing impaired, and very young children.
Story in a Bag	✓	✓	✓	✓	
Sound Library	✓	✓	✗	✓	Originally designed for children who are blind or have vision impairments but is enjoyed by children with diverse disabilities.
Doll	✓	✓	✓	✓	May not be appropriate for older children.
Drawing	✓	✗ Not suitable for children who are blind. ✓ May suit some children with low vision.	✓	✓	May suit children who are familiar with drawing and enjoy the activity. Research has found some children do not enjoy it. ¹¹⁷
Camera	✓ Some children may require assistance to take photos of their choice.	✗ Not suitable for children who are blind. ✓ May suit some children with low vision.	✓	✓ Some children may require assistance to take photos of their choice.	
Walkabout, guided tour	✓ May require assistance with mobility.	✓	✓	✓	
Story telling	✓	✓	✓ In sign language for deaf children.	✓	
Feeling 'OK' tool	✓	✓ Aural description may suit children who are blind or have low vision.	✓	✓	Can be pictorial rather than word based.

Adapt the tools and environment

Research in the area of disability inclusion and child participation identifies that a key element of any approach is adapting it to suit the context and characteristics of the child, including gender, age, disability, interest, culture, language and other contextual characteristics. Our researchers developed a list of recommendations for using and adapting tools or methods used:

- Ensure the environment is appropriate to the child's needs and is conducive to participation. For example, consider choosing a place that does not have distractions such as noise, community members, other children etc. Some children will need a more private or quieter environment than others, which may assist them to concentrate, hear, or help the researchers hear the child's form of communication.
- Make sure there is enough space for the child to engage in the research activity (for example, laying out the photos, or drawing a picture).
- Use the local language used by the child. This may mean researchers need to work with translators or through family members, who can ask questions and interpret answers.
- When asking questions or communicating with the child, use appropriate tone of voice and eye contact. Avoiding eye contact with the child may be appropriate in some contexts, and assist in making the child feel comfortable.
- Pay attention to the preferences of the child. Some children may prefer to work on the tool (such as drawing) alone, and at their own pace. Some children may express a preference for tactile rather than visual or aural tools.
- Recognise the broader context and its effect on what is suitable or interesting to the child at the time. For example, if the child has recently been introduced to photos at school, this may have added meaning and value to them at this time.
- Allow time for the child to participate. Many children may want additional time to think through answers or to become familiar with the tools. Some children with communication and/or intellectual impairments require additional time for communicating their responses using a variety of communication methods. Researchers may need to slow down and/or repeat questions and explanations.
- Tools need to be adapted to the characteristics of the child, for example adapting the gender of dolls to suit the child.
- Tools can be used in combination (for example, photos and doll) to suit the preferences of the child.
- Children can be offered a choice of tools, if it is thought that this is not confusing or overwhelming.

Build relationships

A key enabler of child participation is the relationship and rapport built between the researcher and the child, and their family and community. Rapport takes time to establish, and many visits (for example 2–5 visits) will be needed to establish a sense of trust and to build skills in understanding the child's communication mode. Knowing the child better also aids in better understanding their meaning when they provide answers to research questions. Engaging in free play and interacting with the tools together will assist the child and researcher to develop a trusting relationship.

Manage the role of parents and carers

Parents and carers are important supports for children. It is important to affirm their role in supporting the communication of children, especially those with communication impairments. Often it is only through the role of this 'interpreter' who knows the communication mode of the child, that children can voice their views. When parents or carers take this role, it is important to view this as the child 'speaking' through their interpreter. However, parents and carers, and other community members can also dominate and answer 'for' the child, without representing the child's views. This can mean that the child is not able to speak for themselves. Such situations need careful management. Researchers can remind the parent/carer of the need to let the child 'speak' for themselves, or seek a space to have a more private conversation with the child (with the consent of parents and child).

The tool guides

Prior to using the tools, we recommend researchers read the guides on 'Communicating with children with disability' and 'Getting to know the child – fun activity'. Both of these guides are essential prior to collecting data from children. Collection of data really depends on a sound relationship between child and researcher and an established communication mode between both parties.

Each tool has a brief description and some basic tips about how each tool could be used. Our researchers were able to draw on these quick guides when needed, to refresh their memory or help them think of different ideas. The tips have been refined by the researchers that have used them. When reading the guides, please remember that they are just guides. It's important to think about how you may use particular tools to answer specific research questions, which will differ from project to project. Tools will need to be tailored to match the research questions of each project.

Communicating with children with disability

Summary

The core of any research or consultation with children is building good communication between researcher and child. The following is a set of basic communication tips for working with children with disability.

Process

When communicating with children with disability, consider the following points:

1. It takes two people to have a conversation.
2. Think about the child's age, level of understanding and communication method.
3. Be a good listener. This involves being observant, supportive and understanding.
4. Lots of communication happens without talking. Think about the child and your:
 - Tone of voice
 - Jokes and laughter
 - Eye contact
 - Gesture and other non-verbal communication
 - Where you both sit.¹¹⁸
5. When you talk together, remember to:
 - Ask open questions (however sometimes closed questions may be necessary for some children)
 - Ask one question at a time
 - Use simple language
 - Check the child understands you
 - Communicate in the child's first language
 - Don't panic; slow down and wait
 - Don't feel the need to fill the gaps in conversation
 - Look at the child rather than their interpreter or communication aid
 - Think about your own body language and tone of voice
 - Observe what is happening around you. Is there a lot of noise creating a distracting environment? Are there too many people in the room for the child to comfortably communicate?¹¹⁹

Practice examples

1. Aime is a 12-year-old girl with a physical disability and lives in PNG. She cannot speak nor use sign language, but communicates using her body. She can smile and giggle when she is happy. She can cry out when she is unhappy, or uncomfortable. With the assistance of Aime's grandmother, who knew her well and understood how Aime communicated, we were able to determine answers to questions. She is not comfortable making eye contact so we were careful to avoid looking directly at her in a way that would make Aime uncomfortable. Spending time with Aime helped us to understand how she communicated and for everyone to feel comfortable together.
2. The researcher asked Toimpa what his hopes and dreams are. Toimpa gave the sound and action of a car. When asked why, he gave the action of driving a vehicle. Toimpa is 13 years old and has a physical disability as well as limited verbal communication. His speech is unclear and he can only say a couple of words at a time. Time spent with Toimpa and speaking with his parents made us aware how his displayed emotions demonstrate how he feels about things, with clear indications of happiness and approval, and sadness/upset and disapproval. His happiness around cars – both real and with the toys he chose – demonstrated his love for them. From this we would conclude that having some involvement with cars, and even driving a car, is one of Toimpa's hopes for the future. His parents laughed and confirmed that this was true.

Getting to know the child – fun activity

Summary

This activity is a way of spending time with the child to help them feel comfortable with the researcher.¹²⁰ The researcher can also learn more about the child, their life and their preferred communication. This may help the researcher suggest the best tool to try (photo, doll etc.) when they next meet to ask the child the research questions.

Activity suggestions

Child makes or does something that identifies something about them such as craft or a picture book that they can keep. Researchers can refer to the item to start conversations with the child when they visit in future.

Different activities may include:

- pottery, making a mask or sculpture that identifies them (e.g. painting a mask)
- painting or drawing a picture
- story book about themselves – ‘My name is ... I am X years old, I live with ... I like ... , I don’t like ... ’, may include photo of themselves
- walking tour: the child leads the researcher on a tour of their house/area/village, and talks about what they do each day, what they like. You might get the child to collect objects (shells, etc.) which they can keep and that you can talk about later. Or you might ask the child if they want you to take a photo of these places or the things that they have collected.
- read, sing, make music together
- play the child’s favourite game
- play with a favourite toy or a toy provided by the researcher
- use or play with an everyday item such as fishing line.

Preparation and activity

1. Allow 1–2 hours
2. Make sure you take materials such as:
 - paints
 - crayons, textas, pencils
 - paper, cardboard
 - mask
 - camera
 - toys
 - everyday items (e.g. fishing line).
3. Explain your ideas to the child about what you might do together. Think about adapting the options and activities to suit the child’s strengths and communication style.
4. Take audio recorder, camera, notepaper to make your own notes and observations.

Photo Library

Summary

In this process, the child selects photos from the Photo Library to help them show and explain their answers to the research questions.

Also known as the picture library, this tool has been used in previous research with people that have cognitive disabilities.¹²¹ It's a useful tool to prompt children and adults, including those with cognitive disabilities or limited life experiences, about aspects of their lives, including those that they have not yet experienced (or may desire to experience) or may have difficulty articulating.

The photos are just a prompt to help the child talk or communicate about the research questions. There is no one right way to do this process, you can be creative. Choosing the photos can lead to other activities that might be useful such as:

- Taking photos of things the child wants to include
- The child drawing or writing more about the topics of the photos.

Making a Photo Library

1. Think about all the areas of a child's life that are relevant to the research question. This may include health, housing, play, social life (friends), family life, food and drink, education, safety, transport, holidays, work, communicating, culture, spiritual life and religion, money, animals, law and order, future aspirations, etc.
2. Travel around the local area and take clear and colourful photos that relate to the research question (considering a broad range of answers and areas of the child's life). Children may be recruited here to assist with taking photos of their world.
3. Laminate the printed photos.
4. Make a list of all the photos in order. Give each photo an identification number and a title (e.g. 1. Cooking at home).

Process

1. Explain that you are going to ask some questions and that the child might like to use the photos to help answer them.
2. Ask the research question/s
 - The child can answer this in any way they want, including telling you the answer. Offer the photos as an option to help them answer. Explain that the child might want to choose some photos that are relevant to them.
 - Lay out the photos in front of the child slowly, let the child touch, hold, look at the photos.
 - Give the child time to look carefully at each photo.
 - Tell the child they can choose as many photos as they like.
 - Lay each of the photos chosen aside into a separate collection – laid out so the child can still see them. The child can arrange them into groups or patterns if they want to.
 - Either while the child is choosing, or after the child has finished choosing, ask them to tell you about each photo they have chosen. Ask what it means to them, and why they have chosen it.
 - Use other prompts to expand their initial answers.

- Take notes of everything they tell you.
- Take a photo of the collection of photos and note the identification number of photos they have chosen.
- Be positive about the child's choices and what they are telling you.

Considerations

1. Photos need to be very specific to the local context and culture – generic photos will not be as successful or meaningful.
2. Having too many photos to choose from can overwhelm the child. In these instances, researchers can reduce the number of photos to be used by leaving out photos that represent similar ideas. Try to maintain as much breadth of topics as possible.
3. The child can be influenced by conversations and commentary of nearby adults – so you may need to keep adults at a distance (unless they are needed to assist the child to communicate, or support the child).
4. Photos can raise the child's expectations and so it needs to be made clear from the onset that children aren't choosing photos of things they would like, but things that are relevant to the research question being asked.
5. Photos are less suitable for those with vision impairment.

Skills of the researcher

1. The researcher must have patience as this activity can take some time.
2. Use open ended questions to prompt discussion of the photo. (Not all children understand the question 'why', e.g. 'why is this important', so other questions and discussion are needed to prompt around this).

Practice example

Sena is 18, has completed primary school and lives at home with her grandparents. The Photo Library gave us a shared task, helped put Sena at ease and opened up our conversation. Sena told us, 'I picked the picture of a young couple with a baby on the left [chosen photo shown below]. I want to have a partner. That's the only important thing in my life. The important part of my life is how I will look after myself in the future as a person with disability without depending on my parents.'

I am a grown up and need a partner. Getting married will make my life better and happier. The person I marry will help me to care for myself and support my family'.



Story in a Bag¹²²

Summary

In this process we use a bag filled with a selection of familiar objects to help the child communicate answers to the research questions. The child removes objects from the bag, identifies them and selects any that help them answer the research questions.

There is no one right way to do this process, you can be creative. The objects in the bag are just a prompt to help the child talk or communicate about the questions. Handling the objects can lead to other activities that might be useful such as:

- Collecting objects the child wants to include or talk about,
- The child drawing or writing more about the objects or the ideas they represent to that child.

Making a Story in a Bag

1. Think about all the areas of a child's life that are relevant to the research question. For example, consider: health, housing, play, social life (friends), family life, food and drink, education, safety, transport, animals, law and order, holidays, work, communicating, culture, spiritual life and religion, money etc. You might also want to look at the Photo Library and think about what objects represent each picture. Objects in the bag may be different in rural and urban areas and will vary according to the child's age.
2. Travel around the local area and collect objects that relate to the research question, (considering a broad range of answers and areas of the child's life), and that are likely to be familiar to the child. Usually these will be everyday objects like a piece of fruit, a drinking cup, a toy or ball, and objects that represent other things, for example, a pen and book, which might mean 'school' or education to the child.
3. Find or make a bag to put the objects in and place the objects in the bag.
4. Make a list of all the objects. Give each object a number and a title (e.g. 1. Pen).
5. Include around 10–15 items for each exercise, taking care to consider the age, circumstances and abilities of the child to be interviewed. (NB. some children have tactile sensitivities, so items selected should not aggravate these difficulties.)

Process

1. Explain that you are going to ask some questions and that the child might like to use the objects in the bag to help answer them.
2. Explain that to help the child, you have a bag with a number of familiar things in it, such as a coconut.
3. Explain that the child can explore the bag, pull out the objects and feel them, and talk about them if they help them answer the questions.
4. Explain that the bag has only nice/safe things in it, and you think exploring the bag and the things in it will be fun.

5. Ask the research question/s

- The child can answer this in any way they want, including telling you the answer. Offer the bag full of objects as an option to help them answer. Explain that the child might want to choose some objects from the bag that help them answer the research question.
- Go through the bag slowly. Remember that the process of feeling an object takes longer than looking at an object. Allow the child to explore the bag and each object freely. For example, if there is a shoe in the bag, they might want to try it on.
- Allow the child to handle the objects one at a time and talk about each one if they wish. The child may want to identify each object (e.g. 'this is a coconut'), and you should agree and affirm this or correct them gently if they are wrong. The child might want to comment on or describe the object (e.g. 'it's hard with hair on the outside, I think this one is ripe'). You should affirm their description and perhaps add a little bit more (e.g. you might say, 'yes, I think it is a juicy one, if you shake it you can hear the coconut water inside').
- After the child has had time to identify and handle the object, ask if the object makes them think about the research question. You may need to repeat the question and ask the child if any of the objects help them answer the research question.
- Take notes of everything they tell you, including which object they are speaking about.
- Tell the child they can stop and talk about as many objects as they like.
- Ask the child if there are other objects they would like to include in the bag. For example: 'If this was a bag of things that told people what was important to you in life, what else would be in the bag?' Or 'Is anything important missing from the bag?'
- Be positive about the child's choices and what they are telling you.
- This activity is a lot of fun. Some children who were blind or vision impaired in our research really enjoyed guessing what the objects were. It's OK for the child to enjoy playing with the bag and the objects. You may want to let them play first, then go through the questions as discussed above (this may have to be at a second meeting).
- You may choose to leave the bag with the child at the end of the interview. However, some children in our research preferred the researcher to take the bag as they associated the bag with the time they spent with the researcher.

Considerations

1. The bag can be a distraction to the child prior to the Story in a Bag activity commencing. It is therefore best to keep the bag out of the child's sight until it is appropriate to introduce this to the child.
2. Child may become distracted during this activity and may wish to stop the activity to have free play with certain items from the bag.

Practice example

Toya is a 14-year-old girl with physical, intellectual and communication impairments and lives in PNG. We (the researchers) used the story in the bag and Toya liked the toy car. I asked her what she liked most and she picked the car. She was so happy playing with the car and making the sound while pretending to drive on the ground. I asked her what job she wanted to get in the future. With the help of the mother she mentioned her father and did the sound of the vehicle. I asked her if she wants to be a driver like her father and she said, 'Yes'.

Sound Library¹²³

Summary

In this process we use short audio recordings of local sounds to help the child communicate answers to our research question. The child listens to the sounds and selects sounds that help them answer the research question. This is a similar tool to the Photo Library however it provides audio prompts rather than visual prompts.

There is no one right way to do this process, you can be creative. The sounds are just a prompt to help the child talk or communicate about the questions. Choosing the sounds can lead to other activities that might be useful such as:

- Recording sounds of things the child wants to include or talk about,
- The child drawing or writing more about the topics of the sounds.

Equipment required

1. Audio recorder/player (with spare batteries)
2. Headphones.

Making a Sound Library

1. Think about all the areas of a child's life that are relevant to the research question. For example, consider: health, housing, play, social life (friends), family life, food and drink, education, safety, transport, holidays, work, communicating, culture, spiritual life and religion, money, animals, law and order, etc.
2. Travel around the local area and make short (e.g. 20–30 second recordings) of sounds that relate to the research question (considering a broad range of answers and areas of the child's life). Researchers or other children or adults with vision impairments are most useful in recording these sounds.
3. Organise the sounds onto an audio file (e.g. a CD, a digital audio file on a computer or iPad, or a tape).
4. Make a list of all the sounds in order. Give each sound a number and a title (e.g. 1. Cooking at home).
5. If possible, find sounds similar to local sounds on the internet. Usually, sounds recorded professionally and available on the internet are of a higher recording quality and have less disruptive background noise.

Process

1. Explain that you are going to ask some questions and that the child might like to listen to the sounds to help answer them.
2. Show them how the audio recorder/player works and demonstrate the headphones. Help them become comfortable with wearing headphones.
3. Practice use of the audio player and headphones with clearly recognisable sounds or music.

4. Ask the research question/s

- The child can answer this in any way they want, including telling you the answer. Offer the sounds as an option to help them answer. Explain that the child will hear some sounds which might make them think about the research question. Explain that the child can stop the sounds and talk about any that help them answer the research question. Go through the Sound Library slowly.
- Tell the child they can stop at any time and talk about as many sounds as they like.
- The child might like to listen to all the sounds first and identify them. The child might also want to comment on them (e.g. 'that sounds like my uncle's truck').
- You may need to repeat the question and ask the child if any of the sounds help them answer the research question.
- For each sound the child talks about, ask them to tell you about it, what it means to them, and why they have chosen it.
- Take notes of everything they tell you.
- Make a list of all the sound numbers (on your list for the Sound Library) they have chosen.
- Ask the child if they would like to listen to the sounds again. Repeat the process if they do.
- Be positive about the child's choices and what they are telling you.

Considerations

1. Ensure sounds are age appropriate. For example, a Sound Library for a teenager may be very different to a library for a five year old.
2. Ensure sounds reflect local context and experience of children.
3. Ensure equipment has sufficient power storage and is in working order.

Skills of the researcher

1. Be patient as there may be a repeated need to replay sounds.
2. Be comfortable with the technology (both recording sounds but also playing sounds and use of headphones).
3. If there isn't a researcher with a vision impairment as part of the team, consider engaging someone with a vision impairment to assist in thinking about and recording sounds.

Practice example

Luke is six years old with physical and communication impairments. As part of listening to the Sound Library, I played the music and Luke was so happy, smiling and shouting. I asked him what is the most important thing in his life and he was shouting and pointing in the direction the music was playing. The parents said he likes music since he is often left alone at the house and has nobody to talk with. Music is the only thing that makes him feel somebody is around. The music engaged him and we were able to ask the questions to which he could communicate his answers.

Doll¹²⁴

Summary

In this process we use a doll to help the child communicate consent and dissent or answers to our research question/s.

There is no one right way to do this process, you can be creative. Dolls have been used in research with young children with disability in a range of different ways.

Making a Doll

1. Dolls should be locally sourced and resemble dolls that children will be familiar with.
2. Dolls could be made of cloth with soft stuffing and be gender-neutral. Or dolls can be gendered (i.e. boy or girl dolls) to suit the child's preference.

Process

Here's some ways that a doll could assist children in the research:

1. To gain and re-gain consent. For example, the researcher might ask:
 - 'What if this doll wanted to talk to the researcher, could she decide 'yes' or 'no'? Well, that's the same with you, it's up to you if you decide to talk to us'.
2. To promote play. Dolls can be used in role-plays and other forms of play. Play activities are a good way for the researcher and child to get to know each other and to break down shyness of the child.
3. The researcher and the child can both use dolls to 'talk' to each other about the research topic through the dolls. Alternatively, two researchers can demonstrate how to play with the doll by interacting their dolls with each other.
4. To help children feel comfortable. Some children may be shy or wish to talk about sensitive issues. It may help to refer to the doll instead of themselves. This way, the attention is on the doll rather than them. Dolls may also help if the child wishes to share something that is difficult.
5. Ask the research question and ask for the doll to respond. The doll could be used for describing a child's day, starting with the doll being asleep and waking up. For example:
 - 'Imagine this doll is you, tell me what the doll does after breakfast'.
 - 'Imagine this doll is moving into your family and she is like you ... what do you think the doll will like about being in your family/village/house?'
 - 'If this doll had a disability like you, what do you think he would wish for to make his life better?'
6. At the end of the visit, leave the doll with the child.

Considerations

1. Dolls may not suit all genders and contexts. Researchers need to be sensitive about whether a doll would be appropriate for the child. Researchers can offer 'girl', 'boy' or gender neutral dolls.
2. Dolls may not be suitable for older children who are past the age of playing with dolls.

Skill of the researcher

1. Ability to play with child, or in front of child, without embarrassment.

Practice example

Grace is 14 years old. She does not go to school and spends her days at home with her parents, helping them with domestic chores. Her impairment affects her walking, talking and ability to understand things. The use of the doll worked well as a prompt with Grace. At times she became preoccupied with toy cars and was not interested in answering questions. The researcher then tried using the doll by asking the questions to the doll. Grace was intrigued, joined in and began answering the questions for the doll.

Drawing

Summary

In this process we invite the child to draw pictures as a way to help the child communicate answers to research questions. Drawing and art have long been used as universally acceptable tools in child research. Drawing is enjoyable to children across a variety of ages.¹²⁵

It is important that children interpret their own drawings as they can have multiple meanings.¹²⁶

There is no one right way to do this process. Allowing the child to draw pictures (and tell stories) is just a prompt to help the child talk or communicate about the questions.

Equipment required

1. Choice of equipment for drawing should reflect the circumstances of the child and be something that the child has likely used before or had exposure to within their community.
2. Examples of suitable equipment include: Paper, pencils, coloured textas/crayons, blackboard, chalk, sand and stick/finger.

Process

1. Explain that you are going to ask some questions and that the child might like to draw pictures (and tell stories about or explain the pictures) to help answer the questions.
2. Ask the research question/s
 - The child can answer this in any way they want, including telling you the answer. Explain that the child might want to draw some pictures that help them answer the research question.
 - Tell the child they can choose any of the equipment to draw a picture about something that relates to the research question.
 - Either while the child is drawing, or after the child has finished drawing, ask questions about the drawing that relate to the research question, and help the child tell the story of the drawing. Ask what it means to them, and why they have drawn it.¹²⁷
 - Use other prompts to expand their initial answers.
 - Take notes of everything they tell you.
 - The child may do one single drawing or multiple drawings.
 - 30 minutes is an ideal length of time for drawing (can be shorter depending on child's abilities and interest in drawing).
 - Take a photo of the drawings. Leave the original drawing with the child.
 - Be positive about the child's drawings and what they are telling you.

Considerations

1. Children can forget the question being asked and just want to draw what they want to draw, irrespective of the research question. If so, allow the child some time to do drawings of their own choice, then ask them if they would do a special drawing about your research question.
2. While most children enjoy drawing, some children do not have experience with 'free' drawing,¹²⁸ they find it boring or it makes them uncomfortable with negative connotations.¹²⁹ Monitor the child's comfort level and discontinue the activity if the child is not enjoying the process.

Practice example

We used sign language to communicate with Konna. He attends school and enjoys drawing. He drew a different picture for each question asked. When asked, 'What are your hopes and dreams?' he drew a picture of a person fixing a pipe: 'I drew a person fixing the water pipe. I want to be a plumber so I can be able to fix water pipes'.



(Drawn by Konna, a 16 year old boy who is deaf and lives in PNG).

Camera

Summary

This is an adaptation of PhotoVoice or photo elicitation.¹³⁰ In this process the child takes photos to help answer the research questions. It has been found to be an accessible method for a range of children with diverse impairments.^{131 132 133 134}

In some PhotoVoice techniques, the child is given the camera to loan or keep for a period of time (e.g. 1–4 weeks). This provides the opportunity for the child to take photos of things relevant to the research that are not available on the day of the visit (e.g. a trip to a larger town or a cultural event).¹³⁵ Some caution is required – in some instances cameras and data have been lost, while anonymity may be compromised if children take photos of other children. Sensitivity is required when photos are taken of children at risk or of disturbing images.¹³⁶ Caution may also be required if having a camera places the child at risk of theft or violence.

There is no one right way to do this process. Allowing the child to take photos is just a prompt to help the child talk or communicate about the questions.

Equipment required

1. Sturdy digital camera suitable for environmental conditions, preferably with a screen on the back.
2. Spare batteries and memory card.

Process

1. Ask the research question/s.
2. Explain that you are going to ask the child to take photos as a way of answering the research question. The photos might be of their village, community or everyday life. You might need to re-phrase the research question into an instruction about what to take photos of (for example, 'take some photos of the things that are important in your life' or 'take some photos of your friends/what you like to learn at school/what you want to do when you leave school').
3. Show the child how to use the camera.
4. Walk with the child while they take the photos. Walk slowly from your starting point, (e.g. the child's house) and move slowly around the area, (e.g. the house and home gardens).
5. Ask questions in response to the child's explanation of what they are taking photos of. Ask follow-up questions to explore the research questions.
6. The researcher must let the child take the lead and initiate the path being taken and the destination.
7. Children can get tired quickly and so there may be a number of camera shoots over different visits. This will take patience.
8. Take notes as the child talks about the photos they are taking.
9. Keep external distraction to a minimum by having researchers and child walk by themselves (unless other people are needed to assist the child communicate, or support the child).

10. Photos should be printed and returned at the next visit. Make time to go through the photos with the child and seek clarification of what the photo is about and how it relates to the research question (remind the child of the research question). Use this time to confirm the information gathered while the photos were being taken. Depending on the research method, the child may be asked to identify which photo they feel has the most significance to the research question.
11. Be positive about the child's choices and what they are telling you.
12. At end of the visit, leave a copy of the photos with the child.

Considerations

1. The child may feel uncomfortable or lack confidence using a camera and may direct the researcher to take the photos. Due to the child's impairment, it may be difficult for the child to hold, manoeuvre or see through the camera. For these reasons, it may not be suitable, or alternatively the child may wish to continue with the activity but may require support to use the camera.¹³⁷ For example, the child can direct the researcher to take the photos as identified by the child.
2. The process can take 1 to 1.5 hours with older children as they may spend more time thinking through the choice of images.
3. There is a risk that the wider community will want to also view the photos taken. The child may come under pressure to explain the importance or meaning of the photos and this may put them in a difficult situation.

Benefits

1. Particularly good activity for older children (aged 10 years and over).
2. When other tools aren't working, then this tool might be helpful in getting the child to share information about the research question.

Skills of the researcher

1. It is important that the researcher is patient and not rush the child when taking photos.
2. The researcher will need basic skills in camera use and maintenance and be able to save, delete, download and print photographs as required.

Practice example

Max attends school where he works very hard. He prefers lip reading to using sign language. Max was intrigued by, and enjoyed using, the camera. When Max was asked what his hopes and dreams were for the future, he explained, 'I took this picture of my mother while she was standing at the front of the blackboard writing. I think that one day I will become a teacher like my mother... because I want to help other children. I think I can do this because I have high scores ... and came second out of 22 students in my class this year. I want to have a job so that I can help my parents and ... I can survive on my own'.

(Max, nine year old boy who is deaf and lives in Vanuatu).



Walkabout – Guided tour¹³⁸

Summary

This process is known by different terms such as ‘wokabot’ in Vanuatu. In this process, the child will take the researcher on a walking tour of their community to help answer the research questions.

There is no one right way to do this process. Allowing the child to conduct a walking tour is just a prompt to help the child talk or communicate about the research questions.

Process

1. Ask the research question/s.
2. Explain that you are going to ask the child to show you their village or community and tell you about the things that relate to the research question (e.g. how they get to school or what places they play in their community).
3. Ask follow-up questions to explore the research questions.
4. Walk slowly from your starting point, e.g. the child’s house and move slowly around the area – such as the house, home gardens, paths, roads, rivers.
5. Ask questions in response to the child’s explanation of what they are showing the researcher.
6. The researcher must let the child take the lead and initiate the path being taken and the destination.
7. Children may get tired quickly and so there may be a number of walkabouts over different visits. This will take patience.
8. Take notes as the child talks.
9. Keep external distraction to a minimum by having researchers and child walk by themselves (unless other people are needed to assist the child communicate, or support the child).

Considerations

1. The child may feel intimidated if too many adults participate in this activity – including adults from the community.
2. The child may be influenced by other adults discussing the path being taken by the child or the places of interest being selected by the child.

Practice example

The researcher explained that she wanted to know what was important to Hana, and what her hopes and dreams for the future were. The researcher explained that Hana might like to show the researcher her answer by taking her on a tour around where she lives.

After the researcher explained the activity, Hana guided the researcher on a tour around their yard. Hana led the researcher from the kitchen to a small shelter in the middle of the yard of her uncle's house. Hana said 'Fetching water for my mother for cooking or washing or drinking is something that is very important to me. I would like to become a house girl in the future because I do not think I will go to school. So that's why my job is fetching the water and to do all activities that relates to using the water'.



(Photo taken by Hana, 11 year old girl with a cognitive disability, Vanuatu)

Story telling

Summary

This tool has different names in different contexts. In Vanuatu, it is understood as ‘storian’. In this process, stories and discussion (‘storian’) are used to help the child communicate answers to research questions. In oral-tradition communities, this is a common way of sharing information and documenting information over time.

There is no one right way to do this process. Allowing the child to tell stories is just a prompt to help the child talk or communicate about the questions.

Equipment required

A sign language interpreter where needed.

Process

1. Explain that you are going to ask some questions and that the child might like to use stories (‘storian’) to help answer them.
2. The researcher starts by telling a story about their experience around the research issue.
3. The child and researcher talk about this story and the researcher encourages the child to ask questions about the story.
4. The researcher invites the child to tell them a story about their own experiences about the research question.
5. The researcher can use prompting questions to expand the story to collect other information.
6. Take notes of everything the child tells you. Depending on the comfort levels of the child, notes may be taken at the time or immediately after the researcher completes talking with the child.
7. Be positive about the child’s stories and what they are telling you.

Considerations

1. Children may feel embarrassed about talking in front of adults. Researchers should therefore limit those watching this activity in order to make the child feel more comfortable.
2. May be more suitable for children with high-level cognitive skills and those who are older.

Practice example

During our time with Michel we soon came to realise that he is sociable and enjoys chatting and hearing what others have to say. Story-telling worked well with Michel especially as we had good rapport and he felt comfortable with us. He is a seven year old boy with a cognitive and hearing impairment who lives with his mother and grandmother in Vanuatu. Sharing stories created an ease in asking the questions that Michel thought about at length before responding.

'Feeling OK'^{139 140}

Summary

The 'Feeling OK' tool is not a data-gathering tool but a strategy to ensure children's safety during the data collection process.

There may be times when children share something that upsets or worries them. We can tell when a child is sad or distressed by:

- Watching how they get along with others (they may hurt others or they may be afraid to play);
- The child may tell us directly;
- Their body language and expressions (for example, they may start crying or stop the conversation if it is painful);
- Physical changes. For example, the child may have nightmares, feel sick or have trouble sleeping.¹⁴¹

It is helpful for children to share their feelings. The following prompts are steps researchers can take to help the child to feel OK and to end the session with positive experiences that help to balance or neutralise the sad feelings, memories or fears.

Process

1. Take notice of the child's expressions and behaviour. If the child is becoming upset, stop the activity or discussion.
2. Ask the child to share what is upsetting them, be a good listener and take time to provide comfort. Children can feel relieved to share their feelings.
3. Do an activity with the child. The activity may be one that you know the child likes such as singing or a game, or they might make something that they can keep. An example of this comes from the 'protection tool', a tool documented by Save the Children.^{142 143} Draw a visual picture (or tell a story). Ask the child to draw (or answer) different questions such as:
 - The person I love the most is ... I am best at ...
 - I feel safe with ... My happiest memory is ...
4. Be positive! Tell the child encouraging statements like:
 - I know you are feeling sad, but it was very brave of you to tell me what made you sad.
 - I can see that you really care about your family.
 - I can see you worked really hard to make that painting.
5. Make a plan with the child. Tell the child when you are going to meet again. Tell the child it is up to them if they wish to discuss what is making them sad in a future visit.
6. Look after yourself. You may feel sad for the child. Talk to your supervisor and share your feelings.¹⁴⁴

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