



## Ethical issues and lessons in the Voices of Pacific Children with Disability project

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### 1. SUMMARY OF RESEARCH AND PARTNERS

Knowledge of the needs and experiences of children with disability living in Vanuatu and Papua New Guinea (PNG) is limited and that which does exist, does not focus on data collected directly from children themselves. This project aims to establish a method of data collection to determine the self-reported needs and priorities of children living with disability in Vanuatu and PNG. The project involves a multi-staged capacity building approach between two Disabled People's Organisations (DPOs): PNG Assembly of Disabled Persons (PNGADP) and the Disability Promotion and Advocacy Association Vanuatu (DPA); and Save the Children and Deakin University. The research is funded by an Australian Development Research Award and is being undertaken between 2013 and 2015. The research will collect data from up to 50 children with disability aged between 5 and 18 years in each country.

### 2. RATIONALE AND PURPOSE

The voice of children with disability in the Pacific is largely missing in the development agenda. To date, no research has directly captured these Pacific children's concerns and aspirations and linked them to human rights priorities. Frequently, research activities (even in developed countries) do not seek to collect data directly from people with disability or, if they do, tend to utilise research methods that do not enable the self-reporting of people with diverse disabilities. In this context, this project sought to develop a method of data collection that enabled children with diverse disabilities (intellectual disability, vision or hearing impairment, physical disabilities, etc.) to report on their life needs and aspirations. This data was later analysed in terms of human rights implications. The research design commenced with a literature review of research methods involving the self-reporting of children and of people with disability. A series of potential data collection methods were identified and developed, with training/resource materials developed about their use. The methods were further adapted and translated in each country with the active involvement of DPO members and Save the Children personnel. Local in-country researchers (including people with disability) from both agencies were employed to interview up to 50 children with disability in each country and trial the methods, collecting data from children as well as evaluative data in relation to the effectiveness of each method.

### 3. ETHICAL CHALLENGE

The project required full ethical review from the Deakin University Human Research Ethics Committee as it dealt with a vulnerable population (children, people with disability including cognitive disability, developing countries). Ethical issues that needed particular consideration were:

- a. Recruitment
- b. Consent/assent
- c. Safety and anonymity.

All of these required explicit strategies and some posed continuing complexities throughout the research.





#### 4. RESPONSE AND APPROACH

The overarching methodological and ethical response was to design and utilise data collection methods that enabled children with diverse disabilities to participate, so as not to exclude children with particular disabilities (e.g. those who were hearing or vision impaired). This required significant work to identify accessible methods for all stages of recruitment, consent, and data collection, suitable to a diversity of disabilities as well as appropriate to the local culture. A range of data collection methods was developed utilising visual, aural and activity prompts relevant to different communication modes and impairments. The involvement of DPO members with disability in the adaptation and design of methods was particularly important in this regard. At the commencement of the research, a one-week training workshop was run in each country that involved all stakeholders and aimed to finalise the recruitment, consent and data collection methods to be used. This workshop was well attended by DPO members from both Vanuatu and Papua New Guinea who provided advice on the appropriateness of methods. For example, one significant input was in regard to translations of disability vocabulary such as appropriate terminology for vision impairment, physical disability and intellectual disability. This process identified that non-disabled local researchers in-country did not always share the same understanding about appropriate disability terminology as DPO members, and this was an important capacity building moment.

While the overarching research design set the scene for accessibility and ethical participation, a number of specific ethical issues needed to be addressed. These are discussed below.

##### **Recruitment strategies**

On commencement, the research team was mindful of possible stigma and discrimination in relation to disability in the focus countries. Researchers therefore needed to consider the potential negative implications of recruitment, where approaching potential participants (families and children) could identify them as having a disability where this may not be publicly known, or where identifying or recording a type or level of disability as part of data collection may further stigmatise children. It is important to note that almost all children recruited had not been formally diagnosed as having a disability, so this required sensitivities and added complexities to the process. Discussion with DPOs and Save the Children during initial training identified the need to promote positive messages regarding disability and raise awareness generally in communities. In some instances, a DPO member facilitated introduction to communities or attended initial meetings. DPO involvement in the initial training also assisted in developing suitable recruitment 'scripts' in local languages for researchers to use in order to introduce the purpose of the research, affirm positive messages about disability, and fully explain the implications of participation. Recruitment was undertaken as a multi-staged process, firstly introducing the research and messages about disability to community heads; secondly, with their permission, returning and speaking to community members; and thirdly, returning to speak to interested families; and fourthly, undertaking consent and data collection processes.

Anticipating potential difficulties in locating children with disability, time was built into the design to enable researchers to build relationships with communities, families and children. This emphasis on following customary protocol, building relationships and valuing children with disability for their capacities was the key to building trust in communities, amongst families and, most fundamentally, with the child participants. This focus has been vital to high recruitment and retention amongst participants.





## Consent and assent

Three main issues are present in designing and implementing consent processes in this context.

1. Conducting research in communities who have little experience of research poses consent issues as potential participants have little understanding of the risks of participation, and how the research will be used. Additionally, participants may have limited or no literacy and may not understand some of the concepts of research (e.g. anonymity or publication). In this project, Plain Language statements and consent forms were simplified and translated into local languages.
2. Research involving children requires the consent of the responsible adult (usually a parent or carer), as well as assent from the child (that is, the child needs to be willing to participate). Guidance on these dual processes is available in the literature (Gray & Winter, 2011; Noble-Carr, 2007; Harcourt & Sargeant, 2009). In this project there was a two-stage process of explanation (informing) and consent/assent from both the carer or parent and child. Two separate consent forms (one for adults and one for children) were used, with suitable translations and 'easy' terminology. These were verbally explained by researchers, and consent/assent marked on the forms. It was especially important to pay attention to the assent (or refusal) from children, even when parents had provided consent. Equally, it was important to re-check both consent and assent at each stage of the research (i.e. on every visit with the participant, and at every point of the data collection). Participants expressed consent/assent (or refusal) at different times throughout the data collection, and by using different forms of communication and behaviours to which researchers needed to be attentive. Initial consent by parents and assent from children did not always result in ongoing consent for data collection. In some instances, parents and children simply were not available or present for planned data collection activities on a continuing basis. In some cases, this form of indirect dissent appeared to constitute withdrawal of consent. In other instances, children appeared to lose interest in the data collection activity, and researchers elected to finish the session and return at a later date, repeating the process of consent/assent at that point, and continuing only if it was re-gained. Throughout the data collection, researchers continued to read children's body language as an important indicator of assent or dissent.
3. Consent and assent processes needed to be designed to be accessible for children with diverse disabilities (for example, children with hearing or vision impairments, children with intellectual disability). This required thinking through how to explain the requirements of research participation, its benefits and risks, and the use of a range of communication modes such as visual prompts, written translated texts, etc.

## Safety of the child and anonymity

Child protection policies were a key ethical consideration. Ensuring child safety when participating in research required both male and female researchers to be trained in relevant child protection policies and processes, and be present together during data collection with the child. This project encouraged the parent or carer to be present throughout the data collection with the child, both as an added protective factor for the child, and as a communication aid where the child used a method of communication not familiar to researchers. Additionally, the partnership with Save the Children enabled researchers to be linked into child protection reporting processes should any concerns become evident during the research.





Anonymity of participants and processes for de-identifying data are common requirements in many research projects as part of compliance with the National Statement on Ethical Conduct in Human Research and its values of 'respect' and 'beneficence' (NHMRC, ARC & AVCC, 2007). Two complexities in this regard were present during this project.

**First, while it was planned to collect data from children with only their parent or carer present, cultural norms led to a range of community members being present and observing data collection which potentially presented issues of privacy and anonymity of response.** This meant that participation was rarely anonymous in the true sense of the word, as community members knew who participated and sometimes also witnessed what was said. The research team addressed this by ensuring that participants understood that their information was given in front of others, and consented to this. In addition, where possible, some research team members took on a role to communicate with attending community members, acting as a buffer while two other team members (one male and female) attended to data collection with the child and parent/carer. This created as much 'private' space as possible and often assisted in providing a quieter and more focused data collection environment for the child. This approach emphasised the advantage of drawing on in-country researchers who are able to respectfully work with communities, acknowledge cultural norms and understandings, and maintain ethical requirements.

**Second, the project was subject to three levels of requirement to ensure that the child could not be identified in subsequent publications:** the funder (Australian Government Department of Foreign Affairs and Trade, DFAT); Save the Children Australia; and the Deakin University Human Research Ethics Committee. Such requirements are common where personal information is collected about vulnerable individuals, and important as a child protection measure. Acceptance of the research funds entailed an agreement to comply with the DFAT Child Protection policy, which stipulated that 'file labels, meta data or text descriptions do not reveal identifying information about a child when sending images electronically or publishing images in any form' (AusAID, 2013, p.13). Advice from the DFAT Child Protection section confirmed that identifiable images of children should not be published in any form given the potential to link these images to other descriptive text publications about the project and participants. This is consistent with the requirements of Save the Children and Deakin University. The research project addressed this issue by planning to photograph children's art work, or selected objects of importance in their lives, rather than identifiable images of children. This was, however, a contentious issue in Vanuatu, as one partner organisation identified that participating children and families were requesting that their photos be taken and published and that to deny this was undermining their autonomy and human rights. Despite evidence to suggest that many participants did indeed feel proud of their participation and wished to be fully identified in the project, further discussion with DFAT and the Deakin University ethics committee confirmed that child participants could not be identified in images in this way, even with their assent and the consent of parents/carers. This remains a complex and sensitive area.

## 5. OUTCOMES AND ONGOING CONSIDERATIONS

Undertaking research with any vulnerable population poses particular challenges, which are increased in contexts where there is limited shared understanding of the concept of research, research ethics and risks. These are made more complex when the focus is on children and those with disability who are often denied participation in research due to inflexible research design and inaccessible research methods.

These issues were addressed by designing a research process that was appropriate to the context and focused on maximising access and participation by children with a diverse range of disabilities. This







process relied on a strong working partnership between research academics, an International Non-government Organisation and DPOs in two countries. Together, this partnership established a shared (and translated) set of research principles for working with children with disability, a clear process of recruitment gaining informed consent and assent, and practices for safeguarding children. Key to this was the recruitment of local researchers who held responsibility for recruitment, seeking consent and assent, and data collection.

Frequently, ethics complexities occur at the moment of practice, particularly in the practices of recruitment and data collection, and this is where significant communication with supervision and capacity building of in-country research personnel is necessary (but often absent as people are scattered in the field). One strength of this project was the partnership between groups which meant that, in most sites, in-country research personnel had on-the-ground supervision and support provided by their host employer. However, a focus for the future would be to build the capacity of in-country hosting organisations in terms of managing research and understanding ethical issues and responses in a research context.

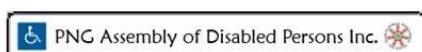
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