

Legitimising children's evidence: Inclusive participatory research with children with disability

*Erin Wilson, Robert Campain, Elena Jenkin, Kevin Murfitt
and Matthew Clarke, Deakin University*

Introduction

Achieving human rights is at the core of development outcomes, and the achievement of positive development outcomes increasingly relies on evidence-based policy and practice. However, people with disability have been routinely excluded from research evidence and knowledge production, both due to a lack of interest in their issues (Yeo and Moore, 2003) and through an over-reliance on research design that does not address barriers to their participation as research respondents (Wilson et al. 2013). Children with disability are even more marginalised from participation in knowledge production processes and have been passively subjected to research being conducted on or about them, rather than with them (Gray and Winter 2011a). This exclusion is even more evident in developing countries of the global south though with some rare exceptions (Kembhavi and Wirz, 2009; Singal, 2010; Wickenden and Kembhavi-Tam, 2014; Don et al, 2015; Nguyen et al, 2015). This paper reports on the 'Voices of Pacific Children with Disability' project (hereafter referred to as the *Voices* project) which, drawing on the broader field of child participatory research, developed a method for children with disability to competently provide evidence about their needs, aspirations and human rights priorities. Eighty-nine children with disability living in rural and urban areas of Vanuatu and Papua New Guinea (PNG) participated, using a suite of data collection 'tools' designed to support children to express their life priorities and human rights' needs. In this paper we examine a sub-set of this data related to children's future priorities, the primary one being employment, and explore the utility of such evidence for governments, NGOs and other stakeholders, in shaping policy and service delivery in line with the rights of children with disability. Such data is important when working in an evidence informed way as often these organisations have limited data on the needs and values of the groups they serve.

Exclusion of people with disability from evidence production

The exclusion of evidence from and about people with disability in international development is a significant issue (Yeo and Moore 2003; Groce et al. 2011). Despite increased attention to this area, partly due to the ratification of the Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006), there remains a need for a larger evidence base, including 'both quantitative surveys and in-depth ethnographic interviews' with people with disability to explore experiences and meanings of key issues 'at the level of the individual, the household, the community and broader society' (Groce et al. 2011:1509). Kroll argues that 'if people are systematically excluded from participation in

research their needs, experiences, perspectives are rendered invisible' which skews the evidence base affecting evidence-based practice (Kroll 2011:67). This 'may bias the choice of outcomes, ... and ultimately the adoption of "best practices" and intervention guidelines' (Kroll 2011:67). Similarly, Groce et al. (2011) make a case for the importance of disability-inclusive evidence to effective intervention in international development contexts arguing that without such evidence, researchers, service providers and governments remain uninformed about the complex factors affecting the experience of disability. Without opportunities to provide evidence, people with disability remain disenfranchised and their rights under the CRPD in jeopardy.

A core element of disability-inclusive evidence is the opportunity for people with disability to self-report, or communicate directly, about their own views and this is the assertion (now endorsed in the CRPD) that experiences. Underpinning perspectives of people with a disability, including those with cognitive impairments, are 'credible and valuable' (Mactavish, Mahon and Lutfiyya 2000:217). There is a growing body of literature that reports on barriers to self-reporting for people with a disability as well as the research design strategies that can be employed to overcome these issues. Common barriers for people with intellectual or cognitive disabilities are reported to be cognitive issues such as lack of a concrete frame of reference, difficulty with abstract concepts, difficulty with temporal concepts, limited literacy and vocabulary, communication barriers including unresponsiveness and inarticulateness, limited attention span, and fatigue (see Wilson et al. 2013). Equally, people with a broad range of physical, sensory and motor impairments may be excluded from research through a variety of mechanisms including the data collection methods (such as the use of various instruments) that may be inaccessible for people with these disabilities (Kroll 2011). Overall, researchers argue that the research design must be based on a clear understanding of the preferred communicative modes and optimal participation environments of respondents (Owens 2007). Failure to implement strategies to overcome exclusions, can be understood as a breach of human research ethics as well as a breach of human rights (Office of the Commissioner for Human Rights 2010).

Hearing children's voices as a human right

Children's right to communicate their views and make decisions is affirmed by the United Nations Convention on the Rights of the Child (CRC) and the CRPD. A current body of child research is focused on participatory methods that allow children to self-report, however, commentators have noted the absence of children with disability's voices in research and program design and have argued that 'to

avoid or to neglect listening to the voice of disabled children is to discriminate and to disempower them' (Carpenter and McConkey 2012:258). Mitchell (2010) and Wright (2008) note that children with intellectual disability and/or complex communication needs are the most marginalised within the disability population. As a result they are the least researched, most vulnerable and excluded. Additionally, children with disability living in the global south 'are arguably more excluded and disadvantaged' (Wickenden and Kembhavi-Tam 2014:403) and remain hidden and 'simply forgotten' (Wickenden and Kembhavi-Tam 2014: 403), further compounding their significant and continuing disadvantage in all areas of life (World Health Organization 2011).

To achieve inclusion of children with disability in research, a range of barriers need to be overcome including assumptions from parents, carers, and teachers of a child's incapacity to participate (Wickenden and Kembhavi-Tam 2014); barriers to participation related to particular impairments and environments; and passive or tokenistic participation opportunities (Gray and Winter 2011b). To this end, a significant focus of inclusive child-participatory approaches is the development of 'child-friendly' methods or tools of engagement to enable children with disability to self-report in ways suitable to their interests, knowledge and abilities (see Jenkin et al. 2015).

The research approach of the 'Voices' project

The above considerations informed the research design of the *Voices* project, undertaken between 2013–15 by Deakin University in partnership with Save the Children, the PNG Assembly of Disabled Persons and the Vanuatu Disability Promotion and Advocacy Association. A suite of data collection tools was designed to enable children with disability in PNG and Vanuatu to self-report their human rights priorities. These tools offered alternative modes of communicating via visual, audio and tactile means. The explicit focus was on tools that did not require literacy given the low percentage of children with disability who attend school in developing countries (see Jenkin et al. 2015 for full explanation of tools). We adopted a participatory focus through involvement of local adults with disability who undertook roles as consultants and researchers on the project, assisting in the development of tools, undertaking data collection and dissemination of results in their respective countries, as well as through maximising the active participation of children with disability.

Children were asked three questions about the important elements in their lives now and their aspirations for the future:

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?

Data was analysed against Articles 5-30 of the CRPD, with the identification of sub themes in relation to relevant Articles.

Eighty-nine children with diverse disabilities aged 5–18 years living in rural and urban areas participated (43 in

Vanuatu, 46 in PNG). Recruitment processes of children and families relied upon the local DPOs who ensured local researchers used community protocols to access children and their families who were then introduced to the local researchers by a trusted and known person within the community. In order to be consistent with children's rights, the recruitment strategy and data collection were also underpinned by a clear set of ethical protocols and inclusive research principles for researching with children with disability (see Jenkin et al., 2015). Ethical approval was sought and provided by Deakin University's Human Research Ethics Committee.

Disability categories were identified by parents using an adapted version of the Short Set of Questions on Disability (Washington Group 2010). In Papua New Guinea, the most predominant impairment types were communication (52 per cent), physical (50 per cent) and cognitive (50 per cent) with 72 per cent of children with multiple impairments and 72 per cent with a severe impairment and 35 per cent having more than one severe disability. In Vanuatu, the most predominant impairment types were cognitive (58 per cent), physical (47 per cent) and communication (44 per cent), with 58 per cent of children with multiple disabilities, 88 per cent with a severe disability and 44 per cent having more than one severe disability.

Table 1: Disability type for children with disability¹

	Cognitive	Communication	Physical	Hearing	Vision	Multiple	Severe disability
PNG 46 children	23 (50%)	24 (52%)	23 (50%)	12 (26%)	8 (17%)	33 (72%)	33 (72%)
Vanuatu 43 children	25 (58%)	19 (44%)	20 (47%)	15 (35%)	16 (37%)	25 (58%)	38 (88%)
Total 89 children	48 (54%)	43 (48%)	43 (48%)	27 (30%)	24 (27%)	58 (65%)	71 (80%)

Evidence from children with disability: An example

Data analysis of these answers to the second question on hopes and dreams for the future revealed results relevant to policy direction in relation to children with disability and international development, in particular evidencing an overwhelming concern with employment in both the informal and formal sectors (related to Article 27 Work and Employment of the CRPD). This is an area that is currently underdeveloped within policy or aid planning for children with disability. The results are summarised briefly below.

Children with diverse disabilities (hearing, vision, physical and cognitive) in both Vanuatu and PNG aspired to a diverse range of jobs spread across the formal and informal sectors. In Vanuatu, this included forklift driver, teacher, scientist, pilot, doctor, carpenter, policeman, office worker, plumber, house-girl, sports-person and having their own business (sewing, beading, trucking, farmer, gato). Thirty-one children (72 per cent) with a disability in Vanuatu indicated a desire to work in the future:

I really want to be a teacher because I want to help other children. I want to have a job so I can help my parents and so when my parents are not able to look after me I can survive on my own. (Ioane is 9 years old and has physical, hearing and communication disabilities.)

I want to own my own truck business one day so that I can help my family and my community. I really think that if I earn money my family will be happy and that their lives will be easier. (Erika is 9 years old and has hearing, physical and cognitive disabilities.)

Similarly, twenty-five children (54 per cent) with diverse disabilities (hearing, vision, physical and cognitive) in PNG aspired to a similar range of jobs including policeman, bus or truck driver, pilot, coffee plantation owner, cook, restaurant owner, store worker, plumber, teacher, doctor and musician.

I want to become a PTC [PNG Telecom and Communications] worker like my elder brother. I want to stay away then be able to go for an operation. (Kat is 18 years old from home working like my brother, earning money and has physical, cognitive and communication disabilities.)

I want to have a coffee plantation like my father. I want to harvest the coffee beans, sell them, and build a big house for my parents and me. (Mellisah is 5 years old and has hearing and cognitive disabilities.)

Children's data emphasised the importance of education to employment outcomes, with 28 per cent in Vanuatu and 19 per cent in PNG rating completing education as a priority. Children identified their view of education as a means to employment, income generation and independence. On one level, this affirms inclusive education as a significant focus for government and aid policy, where much attention is directed towards the adequacy of resourcing, accessible infrastructure, teaching training and increasing rates of enrolment of children with disability. While this focus is warranted, little focus is given to the 'ends' of inclusive education, i.e. preparation for employment, as opposed to the 'means' of implementing inclusive education. Comments from two PNG children, below, explore this theme:

I want to go to school, read as many books as I can and I will go to higher school. From there I will become a policeman to control the bigheaded people in...town. (Rudol is 8 years old and has a physical disability. Rudol does not go to school as he cannot walk there due to his disability, nor sit or hold things for long periods. Rudol does not have any equipment to support his needs.)

I would like to complete school and work in a store as I have seen a young girl with a hearing aid working in a store serving ice cream. (Dee is 6 years old and has hearing and communication disabilities. Dee signs to communicate.)

Similar views of the relationship between education and employment were expressed by children in Vanuatu:

I want to become a scientist so I am studying hard especially in science and mathematics so that I can fulfil the dream for my successful future. (Katherine is 16 years old and had a physical disability.)

Children strongly identified that employment was critical to financial security, for both them and their family. Children articulated their aspiration to support and contribute to their family and community, providing benefits through employment and income generation. Contribution was a strong theme across both countries, as exemplified by one girl's comment from Vanuatu:

I really want to be a primary school teacher because my parents are making so much effort to make sure I have a good education. If I become a teacher I can earn a living and help my parents and support them financially and also I can help my community to become well educated in the future. I want to finish my education. (Vailea is 8 years old and has cognitive and communication disabilities. Her parents are worried about Vailea's safety attending school when she doesn't understand all the instructions.)

As these examples show for many children, an additional goal related to employment was to hold a valued role in their community through which they could work to benefit their community more broadly. Another child from Vanuatu expressed this as follows:

My dream is to become a driver of heavy machines that repair roads, so that one day I can help to fix the roads from south Santo to Luganville because some people have to travel on those rough roads from work and reach home very late at night and then early in the morning they will go back on that same road to town. (Samson is 9 years old and has an intellectual disability.)

Employment is the primary means by which to contribute to both family and community, and children evidenced clear and, for the most part, reasonable goals in terms of their job or income-earning aspirations. However, these aspirations remained challenged by a range of barriers identified by children and their families including barriers to education, lack of communication supports, lack of assistive technology and health care, and discrimination and stigma.

The utility of data from children with disability for policy

Data from children with disability, such as the short example provided provides both a direction for policy as well as a way to concretise policy intentions into relevant program planning. Such data, despite its small sample size, has utility in a range of ways, for existing Australian aid policy frameworks.

A snapshot of policy related to this area, particularly to PNG, Vanuatu and Australia's role in international development in these countries, provides an example of policy focus which does not fully encompass the articulated needs of children with disability. Australia's *Development for All 2015–2020: Strategy for strengthening disability-inclusive development in Australia's aid program* (Commonwealth of Australia 2015) provides a strategic framework of policy intention in relation to disability-inclusive development. In relation to employment, the document broadly identifies the need for increased employment of people with disability, linking this to both accessible infrastructure and inclusive

education. The focus on employment is via ‘skills development ... responding to work force demands and linking to industry’ (p.21). This focus on skills development for the formal sector is echoed at a country level in the Department of Foreign Affairs and Trade aid investment plans for both PNG and Vanuatu (Commonwealth of Australia, n.d. a and b). Both plans place emphasis on vocational training ‘responding to businesses’ and government’s need for more skilled employees’ (Commonwealth of Australia n.d b: 6) along with a focus on working with the private sector to increase employment opportunities. Overall, there is minimal to no policy attention on employment in the informal sector, supports for this, or on the specific supports required for people with disability to overcome barriers to employment in the formal sector.

The data offers utility to policy in several ways. First it requires a sharpening of attention on the employment futures of children with disability. These children aspire to jobs and income generation activities through involvement in the informal sector, and have clearly named these occupations. This sharpening of focus places attention on self-employment, micro enterprises and small business as employers, providing a necessary additional layer to the dominant policy focus on large scale industry and trade development which is likely to continue to exclude people with disability if implemented without attention to other strategies. Primary data of this sort enables triangulation with other research evidence. Such data confirms that the ‘vast majority’ of people with disability in developing countries are self-employed (Groce et al. 2011:1505) and that economic policy continues to overlook the dominance of the informal sector in most developing countries (Gilbert 2013). This evidence then opens up links to broader research knowledge, namely how best to support people with disability into employment via micro finance and other strategies (Groce et al. 2011; ILO n.d.), including via innovative uses of technical vocational education and training (TVET) (Gilbert 2013). Connecting this research evidence offers an immediate sharpening of strategy towards actions that are more likely to be relevant and effective.

Secondly, the data places a firm focus on readying children for employment and self-employment at both the level of primary and secondary education, as well as via TVET. Given that many children with disability do not complete secondary school, and children as young as five are identifying their employment aspirations, the focus for their employment futures needs to be more strongly included in primary and early secondary education, as well as alternative forms and stages of TVET offered, building on innovative models such as that operating for people with disability in Vanuatu (Gilbert 2013). Thirdly, the data makes clear that children with disability are actively considering their employment futures and require a range of targeted and early supports in this process including suitable assistive technology, community education, financial and other supports for participation in the formal and informal sectors. The example of two older children highlights this focus. The barrier preventing employment for one female teenager was the lack of finances to purchase a sewing machine, and in the second case, the ongoing barrier

remained the need for occasional physical support to undertake the work task (i.e. pick up or pass beads where the child could not physically do so). A ‘skills development’ focus of policy will not address these employment barriers, and needs to be paired with concrete support provision.

Conclusion

Given the increasing focus on evidence-based policy and practice advocated by governments, donors and NGOs, it is imperative that such evidence includes hearing from those who are the intended beneficiaries. Children with disability are frequently excluded from research which means that their voices do not contribute to evidence—a denial of their human rights. The *Voices* project provides an example of a research method that enables children with disability to provide evidence of value to international development. Through examining a small sub-set of data related to children’s self-report aspirations around employment, it is apparent that such evidence offers valuable direction and detail to aid policy and programming. This evidence suggests a greater focus on preparation for employment in the informal sector, along with increased attention to employment related skills development at all educational levels. Children with disability clearly see themselves as productive and valuable members of families and communities, and stronger policy and programming efforts are required to enable them to achieve this goal and their related human rights. This example exemplifies how evidence generated through inclusive research design has significant utility as an essential mechanism by which to further target policy and to concretise it into detailed, relevant and more effective program actions.

Note

- ¹ Impairment type (Table 1) was identified by using an amended version of the Washington Group ‘Short Set of Questions on Disability’ (Washington Group 2010) ascertaining disability according to function and level of difficulty. Researchers at Deakin University interpreted these questions into impairment categories—intellectual, communication, physical, hearing, vision—and also determined those experiencing ‘severe’ functional limitation related to their impairment.

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