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The human rights needs and priorities of children with disability in Papua New Guinea

A final report from the 'Voices of Pacific children with disability: Identifying the needs and priorities of children with disability in Vanuatu and Papua New Guinea' research project.

Defining the problem

According to the *World Report on Disability*, children with disability experience significant disadvantage. These children are less likely to start school than children without disability; have lower rates of retention and advancement in school; are less likely to gain employment; earn less when they are employed; are likely to live in households experiencing greater poverty and material hardship; and have inadequate access to health care.ⁱ These conditions mean that children with disability are frequently denied their human rights mandated in the Convention on the Rights of Persons with Disabilities (CRPD) (2006), and the Convention on the Rights of the Child (CRC) (1989).

Despite Papua New Guinea (PNG) being a signatory to both the CRPD and the CRC, the government has not yet domesticated the CRPD into national lawsⁱⁱ. Little is known about the human rights situation of children with a disability in PNGⁱⁱⁱ. The precise number of children with disability in PNG has not been established but, using the World Bank and WHO estimate of 15% of world population with disability^{iv}, there are estimated to be more than 408,000 children with disability under 15 years^v. Estimates suggest only 2% of people with disability receive services^{vi} with the Government of PNG confirming that people with disability 'have no or limited access to support services'^{vii}. Service provision is even more diminished in rural areas where access to even the most basic health services is unavailable^{viii}. Many children have disabilities that could be 'remedied or alleviated with early screening, intervention and treatment' and 'neglect of many common, treatable health problems causes serious disability'^{ix}. There is also an acute lack of assistive devices available to people with disability, with only three providers in Papua New Guinea^x. In 2003, the United Nations noted that both abuse and negative attitudes remain major barriers to inclusion, with children with disability often experiencing child abuse, taunts and discrimination, as well as seclusion and segregation^{xi}. A high level of gender-based violence adds a further dimension to this, and females also experience more limited access to health and education than males generally^{xii}. In 2005, the Government of PNG stated that people with disability were 'totally invisible in all areas and at all levels of the development processes of this country' and described them as 'the most discriminated group of the marginalised sector of our population'^{xiii}.

To combat the significant disadvantage experienced by adults and children with disability, the region has adopted a *Pacific Regional Strategy on Disability 2010 – 2015* that aims to protect and promote the rights of persons with disability and provide guidelines to support national efforts to advance disability issues^{xiv}. In PNG, this was foreshadowed in the National Disability Policy which outlines the Government's strategies and commitment to people with disability. Despite this, the National Disability Research and Advocacy Centre argues that there remains 'a distinct lack of knowledge and resources for managing disabilities' and people with disabilities remain 'unable to join community life, go to school or work'^{xv}.

In addition to the ongoing barriers to human rights attainment for children with disability in Papua New Guinea, their voices are largely missing in the development agenda which means that their needs and priorities are not adequately addressed in service delivery and policy design. To date, no research has directly captured Pacific children with disability's concerns and aspirations and linked them to human rights priorities.

The project

This research was funded through an Australian Development Research Award. The project aimed to: develop a method of data collection / communication with children with diverse disabilities to enable them to 'speak' for themselves; identify the human rights priorities of children with disability in PNG and Vanuatu; and analyse these in relation to the CRPD. The research was undertaken between 2013 and 2015 by Deakin University in partnership with Save the Children, the PNG Assembly of Disabled Persons and the Vanuatu Disability Promotion and Advocacy Association. In Papua New Guinea, researchers collected data from 46 children with disability aged between 5 and 18 years living in both urban and rural areas. Of these, 52% of

children had a communication disability, 50% had a physical disability, 50% had a cognitive disability, 26% had a hearing disability and 17% had a vision disability^{xvi}. Of the 46 children, 72% had multiple disabilities and 72% had a severe disability (with 35% having more than one severe disability)^{xvii}.

As part of the research, local researchers (including people with disability) were trained and assisted to develop a range of inclusive 'tools' for communicating with children with diverse disabilities. Tools included audio recordings of local sounds, a photo library of local images, the use of a camera by participating children, walking tour of the community, drawing and dolls – all acting as prompts to help children express their views about their lives. These tools are now available to government and service providers to assist the identification of the needs and priorities of children in order to aid service design and policy development. A number of capacity building activities were undertaken throughout the project including several workshops which involved Deakin University, Save the Children and the PNG Assembly of Disabled Persons.

The human rights priorities of children with disability in Papua New Guinea

Children were asked two questions about the important elements in their lives now and their aspirations for the future. Their responses are translated and presented below.

Priorities of children with disability in their lives now

Having an adequate standard of living (a human right area mandated in Article 28 of the CRPD) is a key priority for children with disability in PNG, as directly identified by 37% of children. Discussion focused on having adequate food, housing and warmth, with many children talking about being hungry.

Food is important in my life...I don't like to feel hungry, I need to have plenty of fresh food. (Semu is 12 years old and has hearing and vision disabilities. Semu communicated by signing, and drew a picture of a pumpkin and a pineapple.)

Recreation, leisure and cultural life (a human right area mandated in Article 30 of the CRPD) are also important to children with disability in PNG (discussed by 37% of children). Children with diverse and multiple disabilities talked about the importance of being included in recreational activities (music, singing, sports), and church ceremonies, as well as playing with friends which was one of the most common themes for children. For many children, these were rare but treasured events.

I love children being around me. When children play around me, they make me feel happy and not worried, they make me laugh and take away thought of being lonely. (Tabitha is 16 years old with physical and cognitive disabilities. Tabitha stays at home as her parents have stopped her going to school due to their fears about her disabilities.)

Luke was shouting and pointing in the direction the music was played. His parents said he likes music since he is always left alone at the house with nobody to talk with. Music is the only thing that makes him feel somebody is around. (Luke is 6 years old with physical and communication disabilities. Luke is kept at home alone all day while his parents work, he is often hungry and lonely.)

Home and family life (Article 23) were also top priorities for children with disability (mentioned by 35%). Children talked frequently about the importance of their parents, grandparents and siblings in their lives. Children recognized the importance of family to their current and future security, and some talked about the importance of getting married and starting their own family.

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 ... because I feel insecure living with impairments, given that my grandparents will not always be alive to protect and support me. (Fran is 18 years old and has a physical disability.)

My mother is the most important person in my life, because I love her so much. She cares for, and supports me. (Jimson is 14 years old and has a vision disability and lives with his mother who is a single parent.)

The hopes and dreams of children with disability

When asked about their hopes for the future, the majority of children dreamt of working and earning money (a human right mandated in Article 27 of the CRPD). Twenty-five children (54%) with diverse disabilities (hearing, vision, physical and cognitive) aspired to an equally diverse 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 from home working like my brother, earning money and then be able to go for an operation. (Kat is 18 years old 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.)

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.)

Children with disability also hoped to engage in recreation and leisure activities, including travel (as mandated in Article 30). Many children dreamt of being able to drive themselves to visit different places, or to travel by plane.

I hope and dream of owning a car in the future...I want to drive and visit places. (Manu is 14 years old with physical and hearing disabilities.)

Max loves listening to music and hopes that one day he would become a musician, he loves fiddling with guitar strings and moving his body to the sound of the guitar. (Max is 14 years old with physical, cognitive and communication disabilities. He communicates by gestures and vocalisations that are understood by his family who interpret for him.)

Children also aspired to engage in or complete their education. For many, participation in school had been denied them due to their disability, so their dream was simply to attend school. Many saw education as the pathway to gain employment. Some children and families talked about how this aspiration was at risk, with no resources (such as teacher's aides or assistive technology) to support the child's needs in a school setting.

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.)

His father said that he hoped that Willy would learn to talk again ... that he will go to school, get an education and lead a normal life. (Willy is 5 years old and has hearing, cognitive and communication disabilities. He can speak some words, and uses gesture to communicate which those around him interpret.)

Factors that would make life better for children with disability in Papua New Guinea

Children were also asked a third question about what would make their lives better. These responses are presented below, incorporating other relevant data from the project.

Despite their clear aspirations to be productive members of their families and communities, children with disability in PNG face many barriers to attaining their basic human rights. Children and families identified a range of things that would improve their situation.

A job for a secure future

Children saw work and employment (Article 27) as a means of meeting their needs for future security and an adequate standard of living both for themselves and for their families. Many children saw education as being the path to getting a job in the future.

I want to go to school and read books, so that I will become a teacher and earn money for my parents. (Mellisah is 5 years old and has hearing and cognitive disabilities.)

In the future I will be able to sell things at the market and get money to support my family. (Fran is 18 years old and has a physical disability. She stopped attending school after completing primary school as there was no money for school fees.)

I want to become a cook in a hotel and earn money for my living in the future. (Swando is 5 years old and has hearing and physical disabilities. He does not go to school due to his disability and poor health.)

Food, income and appropriate care

Children with disabilities desired to see changes in the area of basic standard of living for them and their family (related to their human rights under Article 28 of the CRPD). The living situation for many children was difficult. Many were experiencing hunger and neglect, with several instances of children begging in the street. Fourteen children discussed their need for adequate food, money, housing and household items.

Food is important and will make my life better. (Hensley is 7 years old and has a physical disability.)

Money would make my life better and happier. Money will change my life. I could build my own house and pay people who will help me make my garden. (Furimo is 14 years old with a physical disability and drew a picture of 20 toia and 10 toia coins to help explain his answer. Furimo had to stop going to primary school due to discrimination and taunts from others.)

In some cases, children and their parents could anticipate improvements resulting from the provision of a range of very basic items that addressed the fear and loneliness of the child with a disability.

The only thing to make my life better and happier is to have a light since I do not like to stay in the dark. (Kat is 18 years old and has physical, cognitive and communication disabilities. Kat is often teased by local children about her disability as she gets around by crawling and has difficulty talking.)

Families were sometimes unable to adequately care for their child, and in some cases children were relinquished to the care of other relatives where parents had separated or were unable to cope. Multiple instances of child neglect and lack of care were observed, with children with disability being left alone with little or no support (and sometimes no food), with inadequate attention to hygiene, social and intellectual stimulation. In many instances, this was due to family members needing to work or attend to the garden for food.

Accessible, affordable and inclusive education

Throughout data collection with children and families, education was a constant theme, including a desire by children to remain at or go to school and the need for necessary education supports to enable this. A majority of children were not attending school, with some having attended previously but ceased due to a range of issues. Barriers to attending school were identified as lack of money or resources; negative treatment at school by fellow students; parental fears about inappropriateness of school for the child because of their disability or fear of the child becoming ill at school; and the inability of some children with disability to attain similar levels of learning as other students. Despite these barriers, both children and parents saw education as the key change factor toward a productive and independent life.

Going to school will make my life better and happier ... I will complete school and be able to find a job to take care of myself in the future. (Luther is 12 years old and has a physical disability. He hops to and from school every day.)

Parents often asked about 'special' schools suited to their child's disability, referring to the additional supports required to offer effective education to overcome the barriers of the child's impairments.

Health interventions, rehabilitation and assistive technology

Parents identified the need for medical intervention as a way of improving the life opportunities of their child with disability. Desired interventions included eye treatment, surgery, brain scan and general medical advice and treatment. Some parents also discussed their previous contact with health services which appeared to be fleeting and often unhelpful. In several cases, while treatment or an intervention was proposed, it was not provided due to lack of follow up by health personnel.

His mother said that if he could have his sight restored, he could go to school and have a good life (... he needs an operation which needs to be done overseas). (Jimson is 14 years old and has a vision disability. He was born with blindness in one eye and at the age of 12 lost his sight in the remaining eye due to being hit in the eye while playing. His single mother does not have the resources to access health services or education for her son.)

I want to become a policeman and get money to help my parents look for somebody who can make me walk (Rudol is 8 years old and has a physical disability for which he has had no treatment or equipment.)

A few children had assistive devices (such as wheelchairs), but aids were also very rudimentary (e.g. rubber tied to the foot of a child to stop it rubbing on the ground; or handle of umbrella instead of a white cane for a child who is blind). Other children needed assistive technology to mediate their disability, and many were isolated and immobile due to a lack of mobility equipment. Assistive technology was especially necessary to assist carers who themselves were elderly or unwell, and where the child was totally dependent on a carer to move them around the house or environment.

Her grandmother said that Elsie would really benefit from a wheelchair so that her old grandmother can take her out of the house and introduce her to the world. (Elsie is 12 years old and has physical, cognitive and communication disabilities. Elsie is unable to sit up without support and cannot walk. She now lives with her grandmother because her mother could not care for her.)

Several parents identified the need for rehabilitation for their child, seeing this as a means to regain function (such as walking and talking), strength, independence, and to avoid the 'negative perception' of disability in the community. In some instances, the child was required to live with extended family members in a main centre in order to access rehabilitation, while their parents and siblings lived elsewhere.

The parents said that they would like Benoni to attend somewhere where he can access rehabilitation to increase his strength and become more independent. They said this is important because they won't always be around to support him. (Benoni is 13 years old and has physical, cognitive and communication disabilities. He has not attended school though he wants to and he enjoys playing with his friends.)

Changing attitudes to disability

Many children and their families reported teasing and abuse in relation to the child's disability from other children, and discrimination from schools and services.

At first the school that Lilla is currently in didn't allow the child to do studies because of her condition. Lilla's father was so disappointed and didn't agree about the decision made by the school. Lilla's father told the school that every child has the right to go to school... it was really a challenge but he had to break down barriers to overcome that challenge. (Lilla is 8 years old and has a vision disability.)

The prevailing desire of children with disability was to be included in the everyday activities of childhood and adolescence, especially in friendship groups with other children. Many children talked of wanting to be 'like' other children, or seen as 'special' just like other children, and to be a respected and valued member of the community.

The important sound I heard (from the sound library) is the singing in the church and school children in class... churches help us to respect other people just as they are (Noah is 18 years old and has a visual impairment.)

Policy and program recommendations

The *Papua New Guinea National Policy on Disability* states ‘that people with disabilities should be empowered, their rights recognised and that they should be included in the mainstream of social and economic life in Papua New Guinea’^{xviii}. While a range of policy documents including the *PNG Development Strategy 2010-2030*, *Papua New Guinea United Nations Development Assistance Framework (UNDAF) 2012-2015*; *Papua New Guinea Child Health Policy and Plan 2009-2020* and the *Papua New Guinea National Policy on Disability*, identify the significant needs of people with disability, little or no specific attention is given to children with disability, and where strategies addressing disability are identified, they offer little specific detail as to programmatic and funding actions that flow from these. Based on the needs identified in this research, significant funding, policy, program and attitudinal change needs to take place for the vision of disability policy to be realized for children with disability in PNG.

Provision of financial, social protection and other supports to families of children with disability

The *Papua New Guinea National Policy on Disability* recognizes families as the ‘first level of support for people with disabilities’^{xix}. This research also demonstrates that families are the main support for children with disability, providing direct care as well as acting as a substitute for mainstream services such as communication support and education when these are not available. Families are experiencing significant hardship and poverty, which directly flows on to children and can result in neglect. Additional costs are incurred by families in relation to meeting their child with disability’s needs, and often crucial supports (such as health care, education, aids and equipment) are not affordable by families. As the main provider of support to children with disability, families need an increased focus from government in terms of social care and protection, and poverty alleviation policy (e.g. via direct financial supports, school subsidies or free education as predicted in national policy), as well as in relation to direct service provision and support by service providers. In addition, a central and proven element of family support is the facilitation of peer support networks among families with disabilities. However, little exists in this regard beyond limited and largely un-resourced activity by local branches of Disabled People’s Organisations (DPOs). DPOs require funding if they are to act as a central resource for children with disability and their families.

Making mainstream services accessible to children with disability

An overarching policy approach to addressing the needs of people with disability within PNG is the integration of people with disabilities into mainstream services. Mainstream services highlighted by children, young people and families are: pre-school, primary and secondary education; technical, vocational and tertiary education; health and rehabilitation services; and transport. However, there is little clear direction and absent resourcing of services related to the needs of children with disability. For example, the *National Child Health Policy and Plan 2009-2020* mentions children with disability but provides no identified health or rehabilitation services to address their needs. Policy and direct programming that focuses on both capacity building and resourcing of these service portfolios is urgently needed. Children in rural areas are particularly disadvantaged with little access to these services. Donors should provide additional funding and resources to overcome the individual and systemic barriers to the inclusion of children with disability in mainstream programs and services.

Provision of disability-specific supports

At present, there is a limited policy focus on prevention and early intervention in relation to children with disability, focused on children 0-4 years. Internationally, early intervention and community based rehabilitation regarding disability are established best practice and cost effective mechanisms to alleviate exclusion and disadvantage. This encompasses children with disability throughout their development, often with a special focus on children from birth to entry into school (around 6 years), with additional supports during school years and transition into employment. This broader focus is urgently required in PNG to support children of all ages who often lack diagnosis and treatment in the early years, and remain in need of specialist interventions including community based rehabilitation. Specific resources are needed to target the needs of children with

disability from 0-14 years, particularly in the areas of communication (including sign language and communication aids); medical and health interventions; and assistive technology. The provision and maintenance of assistive technology (including communication aids) for use in all spheres of life including home life, mobility, education and employment is an urgent priority which has the potential to significantly increase inclusion for children with disability. Whilst the *Papua New Guinea Medium Term Development Plan 2011-2015* recommends a target of 10% increase in service providers for vulnerable groups^{xx}, this is inadequate when the needs of children with disability remain in many cases totally unmet.

An explicit and holistic approach to supporting the inclusion of children with disability

At present, the needs of, and services for, children with disability (aged 0-14 years) and young people with disability (15-24 years) are virtually invisible in donor strategies and government disability policy in PNG. Government policy to date has identified prevention and early intervention strategies for children 0-4 years, along with an emerging focus on education. Donors and child focused international development organisations tend to prioritise education for children with disability as a major priority of inclusion reform. While this remains an important and central strut of inclusion and human rights outcomes for children with disability, these findings indicate that a holistic approach is needed to ensure that the needs and priorities of children with disability across a wide range of life domains are not neglected. Alongside education, children with disabilities need support in regard to their family life, social networks (friendships), recreational and cultural life, standard of living, health and employment needs. Government and service provider strategy must go beyond a focus on inclusive education, and explicitly identify actions across the breadth of human rights areas prioritized by children with disability. Further, in planning and reviewing services, organisations (including evaluators) should seek the views of children with disability and their families (drawing on inclusive tools to support communication). Donors should provide funding specifically to address the holistic needs of this group, and government should require all policy portfolio areas to demonstrate explicit inclusion of children with disability as a specific area of accountability.

Focus on the employment future of children and young people with disability

Children with disability have clear goals about becoming productive adults who are meaningfully employed and able to support their families and communities. Children and young people with disability do not have an explicit presence in employment and economic development strategies of donors or government, with the exception of limited reference to the need to increase people with disabilities in vocational training. In particular, transition from education to employment for children and young people with disability is a missing element of donor, government and service provider strategy. Given the importance of economic development to poverty alleviation, this area requires a major focus from all development partners and the PNG government.

Including children with disability in decision-making process

With the development of methods to enable children with diverse disabilities to communicate their views, it is possible to now include them in decision-making processes concerning the identification, planning, implementation and evaluation of programs affecting their well-being. A wider dissemination of these methods and associated tools will allow key stakeholders (including community leaders, Disabled People's Organisations, national and international NGOs, and provincial and national government authorities) to actively consult with children with disability. Children with disability have voices that should be heard and it is incumbent upon those working with these children to listen to what they are saying.

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ⁱ World Health Organisation 2011, *World Report on Disability*, WHO Press, Geneva.

ⁱⁱ Office of the High Commissioner for Human Rights, Regional Office for the Pacific 2012, *Human Rights in the Pacific – Country Outlines*, United Nations, Human Rights, Office of the High Commissioner, Fiji.

ⁱⁱⁱ Evidence consists mainly of reports by international agencies; including the United Nations, the World Bank and the World Health Organisation, local groups such as the Pacific Disability Forum (the umbrella body for Pacific Disabled People’s Organisations established in 2002), and situational reports by international non-governmental organisations.

^{iv} World Health Organization 2011, *Op. cit.*

^v UNdata, Country Profile – Papua New Guinea, <https://data.un.org/CountryProfile.aspx?crName=Papua%20New%20Guinea>

^{vi} National Disability Resource and Advocacy Centre n.d., *Disability in Papua New Guinea*, <http://ndrac.weebly.com/disability-in-png.html> (accessed May 29, 2014).

^{vii} Department for Community Development 2005, *Papua New Guinea National Policy on Disability*, Author, Port Moresby, p.14

^{viii} United Nations Committee on the Rights of the Child, (2003) *UN Committee on the Rights of the Child: State Party Report: Papua New Guinea*, UN Committee on the Rights of the Child (CRC), <http://www.refworld.org/docid/3f8d18e74.html> [accessed July 9 2014]

^{ix} *Ibid.*

^x Walji, F & Palmer, M 2012, *Improving access to and provision of disability services and facilities for people with disabilities in the Pacific: Disability service and human resource mapping*, CBM Australia – Nossal Institute Partnership for Disability Inclusive Development, Melbourne.

^{xi} United Nations Committee on the Rights of the Child 2003, *Op. cit.*

^{xii} Government of Papua New Guinea and United Nations 2011, *Papua New Guinea United Nations Development Assistance Framework (UNDAF) 2012-2015*. Government of Papua New Guinea, Port Moresby.

^{xiii} Department for Community Development 2005, *Op. cit.*, p.5

^{xiv} Pacific Disability Forum Secretariat 2009, *Forum Disability Ministers’ Meeting, Session Nine, Pacific Regional Strategy on Disability 2010-2015*, <http://aid.dfat.gov.au/countries/pacific/rp/Pages/initiative-pacific-regional-strategy-disability.aspx> (accessed July 21 2014).

^{xv} National Disability Resource and Advocacy Centre n.d., *Op. cit.*

^{xvi} All disability types were based on reports by parents and not formal diagnoses, which were frequently absent. For the purposes of this report, functional indicators were categorised in relation to disability classifications such as vision, hearing, cognitive, and physical.

^{xvii} Severity provides a measure of the extent of functional limitation resulting from the impairment. In this instance, ‘severe’ disability was equated with answers that identified that the function could occur with ‘a lot of difficulty’ or ‘cannot do at all’ as recorded on a Disability Identification instrument based on the Washington Group on Disability Statistics ‘Short Set of Questions on Disability’ http://www.cdc.gov/nchs/washington_group/wg_questions.htm.

^{xviii} Department for Community Development 2005, *Op Cit.*, p.7

^{xix} *Ibid.*, p.19.

^{xx} Department of National Planning and Monitoring 2010, *Papua New Guinea Medium Term Development Plan 2011-2015*, Author, Port Moresby, p.102



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