THE HUMAN RIGHTS NEEDS AND PRIORITIES OF CHILDREN WITH DISABILITY IN VANUATU

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

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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. 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 Vanuatu being a signatory to both the CRPD and the CRC, the government has not yet domesticated the CRPD into national laws. Little is known about the human rights situation of children with a disability in Vanuatu. The precise number of children with disability in Vanuatu is not known but, using the World Bank and WHO estimate of 15% of world population with disability, there are estimated to be more than 13,000 children with disability under 15 years. A recent analysis of population data identifies that children with a disability are more likely to experience violent parental discipline than non-disabled children. Similarly, a 2005 report by the Government of Vanuatu and UNICEF observes that children with disability appear to be more at risk of abuse, whether physical, emotional or sexual abuse, and neglect. The incidence of child abuse against children and women in Vanuatu is high compared to world standards, with instances of commercial exploitation of children. Despite passing an Education Act in 2001, making discrimination against children with disability in school illegal, the percentage of children with disability attending primary, secondary and senior secondary schools is only 9% of the school population (including only 5% of the senior school population) and is decreasing. Barriers for children with disability accessing pre-school education have been identified as limited knowledge and understanding of disability amongst teachers, community leaders and parents; negative attitudes towards disability inclusion; the prohibitive cost of schooling; limited access to assistive devices; and inadequate transport options and disability accessible facilities. Similarly, limited resources impact negatively on the reach and quality of primary health care services, with spending on the health system lower per capita than most Pacific neighbours.

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. In Vanuatu, this is echoed in the National Disability Policy and Plan of Action 2008-2015 which prohibits disability discrimination and outlines the Government’s strategies and commitment to people with disability.
However, the voices of children with disability in Vanuatu are largely missing in the development agenda. This means that, in addition to the ongoing barriers to human rights attainment for children with disability, 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 and communication with children with diverse disabilities to enable them to ‘speak’ for themselves; identify the human rights priorities of children with disability in Vanuatu and PNG; 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 Vanuatu Disability Promotion and Advocacy Association and the PNG Assembly of Disabled Persons. In Vanuatu, researchers collected data from 43 children with disability aged between 5 and 18 years living in both urban and rural areas. Of these, 56% of children had a cognitive disability, 44% had a physical disability, 44% had communication impairments, 37% had a vision impairment, and 35% had a hearing impairment. Of the 43 children, 63% had multiple disabilities and 86% had a severe disability (with 51% having more than one severe disability).

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. 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 Vanuatu Disability Promotion and Advocacy Association.

The human rights priorities of children with disability in Vanuatu

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

Recreation, leisure and cultural life (a human right area mandated in Article 30 of the CRPD) are key priorities for children with disability in Vanuatu (mentioned by 56% of children). Children with diverse and multiple disabilities talked about the importance of being included in recreational activities (music, singing, sports), custom and church ceremonies, as well as playing with friends. Children had frequently found ways to participate in these activities despite their disabilities, though sometimes they faced difficulties in being included.
I like playing soccer with my three brothers and sisters after class and on another day I like to join a football club in our community

(Mark is 8 years old and has cognitive, communication and hearing disabilities).

Daniel is demonstrating his love of ‘music’ by beating sticks on the table. He is happy as he beats a tune and then stops to see if everybody is taking notice. His mother says that these loud noises are important to him because he thinks he is beating a drum. He likes the guitar … and has learned to play the strings more gently rather than just banging it.

Education (Article 24) was also an important priority for children with disability (44%), with several calling it ‘one of the most important things in life’. Children talked about how school was also a place to meet, spend time with and ‘do the same things as’ other children. School was frequently seen as important to getting a job in later life.

School is very important in my life. If I continue to work hard at school I will be really privileged to achieve my goals and get whatever job I want to do in the future. My parents support me a lot in whatever difficulties I have at home. They always make sure that I go to school. They understand that it is one of the most important things in my life.

(Tua is 8 years old and has a physical disability).

Some children experienced abuse or discrimination at school and others did not attend school due to a range of barriers. These children also talked about a love of learning from parents or others, and often still aspired to go to school.

Even though my teacher hurt me, I would like to go to school.

(Rosario is 14 years old and has hearing, cognitive and communication disabilities. Rosaria only went to school for a short time and has not returned since her teacher hurt her).

Children’s family and home life (Article 23) were also very important to them, with many children (42%) acknowledging the importance of family relationships and activities. Children’s description of their families, and the sacrifices that families often made for them, show that families are the key resources and supports for children with disability in Vanuatu, though some struggle to fulfil this role due to poverty and other hardships (such as having multiple children with disability in the family).
Family members provide personal care (e.g. helping the child toilet, bathe and eat), as well as teach language and other skills, including those useful for work.

_The most important things in my life are my mother, father, brother and sister ... They are really important because I need help moving, going to the toilet and some other activities. If I can’t do something – like reach my beads, I call out to one of my family or friends and they come and help._

(Amira is 13 years old and has a physical disability).

Some children attribute their own successes and achievements as solely dependent on the support and teaching of family members. Some children with disability also found company and friendship in animals around the family home.

**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). Children with diverse disabilities (hearing, vision, physical and cognitive) aspired to an equally diverse range of jobs including 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%) indicated a desire to one day work so that they could help support their families and themselves and to contribute to their communities.

_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).

Children also aspired to engage in or complete their education (28% mentioned this), and many saw this 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 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).

Work and education were linked with the desire to be financially secure and have an adequate standard of living (Article 28).

I want to have a good house because I am sleeping in a natangura (bush) house. When I grow older I want to have a proper permanent house.

(Mark also drew a picture of the house he wants to live in. He is 8 years old and has hearing, cognitive and communication disabilities).

Factors that would make life better for children with disability in Vanuatu

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 Vanuatu face many barriers to attaining their basic human rights. When asked what would improve their lives, children’s parents were sometimes more able to identify clear strategies than were children. These included communication supports; health interventions; and assistive technology (aids and equipment). Children themselves identified the need for income and financial security for themselves and their families, and also described their concern with the negative effects on the health of their parents when caring for a child with disability.

Communication supports

Several parents described the significant communication deprivation of their children, a denial of their human rights under Article 21 of the CRPD. A range of disabilities, including physical, hearing and cognitive disabilities, affected different children’s communication and development. Children were largely found to be lacking in communication supports, other than those devised by the family, such as simple sign and gestural communication systems. The lack of shared communication systems had a significant negative impact on many facets of children’s lives including education, social life and employment.
Rosario’s mother and grandmother told us that if Rosario could learn sign language it would be so much easier for her to communicate and that would make her life happier and so much better. With additional communication skills, Rosario will be able to learn sewing and can make her own life in the future.

(Rosario is 14 years old and has hearing, cognitive and communication disabilities. She communicates using gestures and facial expressions. She attended a disability centre for a short time where she learnt some sign language, but her family did not learn with her so many signs have been lost. Rosaria tries to speak but has no formal support to learn this).

His father says that Ser’s’ life would be so much happier and better if he can communicate because he shows signs that he understands. If he is happy he smiles and his eyes are bright. If he is not happy he frowns and closes his eyes. But all of this requires a lot of effort. If Ser had another way of communicating, his life would be easier.

(Ser is 10 years old and has physical, vision, cognitive and communication disabilities. Ser was born with disabilities which delayed his learning to talk till he was four. He became very ill around this time with malaria and epilepsy and now cannot speak).

His mother says that if Toni could understand what people were asking him to do or when he is being given instructions it would make his life better because at the moment he doesn’t understand things that are not good for him.

(Toni is 7 years old and has vision, hearing and cognitive disabilities affecting his communication. Toni can sing simple words but not talk, and has not been to school to learn as he can’t walk the distance – 1 hour – to school).

Health interventions

Around one third of families provided information about their history of access to necessary health and medical treatment for their child with a disability. While some positive interventions were mentioned, the overall tenor of discussion regarding doctors and hospitals suggests minimal treatment/intervention when the disability was first suspected and little or no follow up thereafter. In several cases, while treatment or an intervention was proposed by the health personnel, it was not
provided due to lack of family finances or lack of prescription and follow up by health personnel. Parents identified the need for medical intervention as a way of improving the life opportunities of their child with disability, with interventions including eye treatment, shunt insertion, and other surgical procedures. These needs relate to Article 25 of the CRPD.

Michelle’s mother thinks that if she could stand up and walk, she will be able to take part in every activity around the house and in the community. She could also go to school.

(Michelle is 5 years old and has hydrocephalus. Though she has been fitted with a shunt – in Australia – when she was very young, there has been no medical follow up since. Michelle can’t walk due to her condition and does not attend school, though she loves to spend time with people).

Assistive technology

Overall, children lacked necessary aids and equipment (related to their rights under Articles 4, 9 and 20 of the CRPD). Parents and children recognised the value of equipment such as wheelchairs, prams, scooters, trolleys and eye glasses to support their life activities such as visiting friends, attending school and other activities. In some cases, equipment had been donated but later became unusable with no parts available to mend it. Lack of equipment negatively affected both the child and family members.

I would like to have a new pram because my old pram is broken. If I have a new pram I can walk everywhere.

(Fred is 8 years old with a physical and cognitive disability. Fred cannot move around himself and needs to be carried. He has been given a pram and a wheelchair by the Vanuatu Society for Disabled People (VSDP) but these need repair).

Her mother says that if Mary had a pusher it will be better and will make life a lot easier not just for her but for the rest of the family who find it difficult to carry Mary. If she had her own comfortable pusher/stroller she could interact more (rather than lying on the mat).

(Mary is 15 years old and has multiple disabilities including physical, cognitive and hearing impairments affecting her communication. A donated wheelchair is too difficult for the family to use because the wheels don’t roll easily over the rough ground and it is very heavy).
Income, standard of living, supports for families

Children most desired to see changes in the area of increased income and resources to support the standard of living of their family (related to their human rights under Articles 28 and 23 of the CRPD). In many instances, children with disability saw themselves as having a key role in making these changes and being responsible for getting work and bringing in extra income to contribute to the care of the family.

My family needs more money because they struggle to meet all their costs – school fees and other expenses. I know that if I become a policeman I will make life better for my family and my community through helping with money and stopping crime.

( Jonas is 13 years old and has a vision and cognitive disability).

Having a garden that always provides food for me will make life happier because without food nobody can carry out their daily activities. If I have enough food I know that my life will be happy.

( Jean has a cognitive disability and is 9 years old).

My life and life for my family would be better if my father had a truck. I worry about my father’s health because he carries me to school on his shoulders. I worry that he is very tired and he has to work in the garden as well. If dad had a truck he can also drive all the other children (4 who have disabilities) to school and they will be safe. I want the truck to help my community.

( Jasmin is 9 years old and has physical, cognitive and hearing disabilities. Jasmin’s father takes Jasmin to school by alternately carrying her and pulling her in a cart along a dirt road and across a river. This is a 2 hour return trip twice a day, and reduces the amount of time he can spend working to gain an income).

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. Barriers to attending school were identified as the long distance to school (often made worse by the nature of the child’s disability, lack of mobility equipment or transport, and difficult terrain); negative
treatment at school by the teacher or fellow students; the school not accepting the enrolment of the child with disability; lack of appropriate supports and strategies to assist the child at school (including teacher’s aide); and inability to pay school fees and associated costs (such as transport).

I really want to go to school

(Joshua is 8 years old, and has a hearing and communication disability after being very ill when he was 1 year old, at which time he was refused medical attention. The local school refused to accept Joshua so he has been undertaking activities at VSDP twice a week for the past two years but is becoming bored).

Policy and program recommendations

The findings of this research project directly relate to policy targets in the National Disability Policy and Plan of Action 2008-2015. Based on the needs identified in this research, significant funding, policy, program and attitudinal change needs to take place for the National Disability Policy to be realised for children with disability in Vanuatu.

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 0-16 years) are virtually invisible in donor strategies and government disability policy in Vanuatu. 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 aspect 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 disability 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 prioritised by children with disability. This requires an explicit recognition of children with disability from 0-16 years across all domains of policy frameworks such as the National Disability Policy and Plan of Action. 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.
Provision of financial, social protection and other supports to families of children with disability

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, often foregoing or restricting their own work and income producing activities to care for their child/ren. 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 protection and poverty alleviation policy (e.g. via school subsidies, health insurance etc.), 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

Children with disabilities are unable to access the specific supports they require to access mainstream services as a vehicle to become productive members of their society. Mainstream services highlighted by children and families are: pre-school, primary and secondary education; technical, vocational and tertiary education; health and rehabilitation services; and transport. Policy 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. Capacity building to better inform both the design and delivery of services to better include children with diverse disabilities with diverse needs is necessary, as well as a priority evidenced by the high proportion of the population experiencing these needs (an estimated 15%). 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 Vanuatu 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 0-16
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.

Focus on the employment future of children 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 adolescents 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 with disability is a missing element of donor, government and service provider strategy. It is in society and government’s interests to foster the future economic independence of children and young people with disability, through a focus on education and training at all levels, self-employment supports, and employment equity programs.

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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Endnotes


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.


viii Ibid., p.v.


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