

Children with neuro – development impairment

Neuro development impairment in Papua New Guinea is one of those classes of disability that is rarely spoken of or heard of.

I as a parent of a child with multiple disabilities for whom I have nursed for over 24 years [that being my child's age today] through lived experience I believe this is because of the **severity of the nature of this disability and the very high support needs it requires**. Due to its cognitive dis-function children with this impairment are disorientated, slow to respond, have difficulty in speech, have mobility issues [being or not being able to coordinate motion], are hyper-active, have difficulty in sleeping, having the tendency of wandering off, not being able to recognize the surroundings outside of their comfort zone. Children with very extreme conditions are those that have underlying medical issues – in most cases this would be epilepsy. These epileptic seizures place a lot of risk upon their lives falling upon the impact would cause injury or even death. They are also entirely dependent upon their carers and cannot do anything for themselves. They cannot feed, bathe, cloth nor use the toilet though in some cases the person may have mobility. Persons in this criteria are extremely difficult to care off and require intensive care. It is a strenuous exercise each day to provide this care, this is even more difficult when the child is an adult.

Disability in PNG is more family-based. The care-giving is provided by the family rather than others. For persons with neuro development impairment it is the nuclear family that is the focal point where care-giving is provided and basically not the extended family. As the first-hand responder and a full-time care-giver and a parent to my child – I know my child better than anyone else, I know his weaknesses and strengths I can speak his language and this is why as parents and care-givers we cannot trust anyone but ourselves to provide that care.

The fragility of the nature of the impairment and other factors such as stigma, discomfort in the exposure of privacy, difficulty of the magnitude in the kind of care given are some reasons that validate for this situation not receiving much attention by the government and other actors in this space. It is one seen by the care-givers and families that no one can do anything about it. It is seen as the responsibility of the family alone.

Based up on my experiences and of 3 other children with neuro development impairments who were present at the consultation meeting these are our findings as per the interview.

Challenges	What can be done
<p>1. Education -Non- completion of education due to stigmatization and age difference -Learning tools not accessible -Teachers not trained</p>	<ol style="list-style-type: none"> 1. The need for trained professionals 2. Provide capacity building training for staffs 3. Make education accessible -design suitable learning programs. Eg, home based schooling if need be -contextualize learning materials 4. Train parents and care-givers on methods of educating

2. Adverse impact on family/care-givers	
<p>Normality in the family is unstable, as a result, there is child negligence:</p> <ul style="list-style-type: none"> • Education is disrupted • Older siblings take up responsibility of parents, • The risks involved with children increases. • The able children/siblings stand in provide the care in the absence of both parents • Parental attention is divided. More attention is given to the child with the impairment rather than to the other children. This leaves the able child to be more self-reliant doing things on their own rather than needing assistance from their parents 	<ol style="list-style-type: none"> 1. Create alternate care options. Institutionalize the care-giving 2. Create a job description for care-givers/relief staff. Provide training. 3. Provide assistance to heavily impacted families. 4. Create a reliable data-base
<p>- Financial inequality One parent works while the other stays at home to provide the care. The intended level of sustainability is not in par.</p>	.
<p>-Limited restriction of movement There is an imbalance in the full and meaningful participation in society.</p>	
<p>3. Inaccessibility in live-in surroundings Children with severe conditions need safe and clear surfaces to move around.</p>	<ol style="list-style-type: none"> 1. Provide an enclosure with an open clear surface. This enclosure can be a relief for the care-giver. It may act as barricade to keep the child from wandering off. It may prevent a casualty during an epileptic seizure.

Prepared by: **Sandra Gambro (Parent of a child with multiple disabilities)**
Program Coordinator for Parents of Children with Disabilities
National Capital District Diff-Abilities Advocacy Agency
Kunai Street, Hohola, Port Moresby, PNG
Office Landline No. 342-1079
Office Email: admin@ncddaa.org.pg