



## Cross-cultural Understanding of Health Assessments for People with Intellectual Disability: an Australian resource in the Philippines

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## Abstract

The Convention on the Rights of Persons with Disabilities has resulted in the involvement of high income countries in international development assistance to people with disabilities in low and middle income countries. Healthcare tools designed in high income countries and delivered in low and middle income countries may not be appropriate to the context of the lives of people with disabilities. We undertook a short qualitative study of participants' views of an Australian-designed comprehensive health assessment tool, with participation from a WHO-Collaborating non-government organisation in regional Philippines. We also examined the participants' perceptions of the barriers to healthcare for Filipinos with intellectual disabilities. Responses to the comprehensive health assessment tool were positive although participants agreed that both linguistic and cultural translation would enhance wider use of the tool. The barriers identified included poverty, family isolation, stigma and communication issues as preventing appropriate healthcare delivery to Filipinos with intellectual disability. Consideration must be given to the complexities of transference of healthcare resources to a low and middle income country context, as well as the systemic and cultural barriers to appropriate healthcare provision to people with disabilities.

**Keywords:** *Health assessment; cross-cultural; Australia; Philippines; intellectual disability*

# Cross-cultural Understanding of Health Assessments for People with Intellectual Disability: an Australian resource in the Philippines

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## I. Introduction

Eighty per cent of the 600 million people with disabilities live in low and middle income countries (World Health Organization, 2011), representing the “biggest definable disadvantaged group on the planet” (Mercer & MacDonald, 2007). Disability is a neglected development issue (Officer & Groce, 2009). The entry into force on 3 May 2008 of the UN Convention on the Rights of Persons with Disabilities (CRPD) is, however, a pivotal advancement (United Nations, 2008). Specifically, Article 25 requires states to provide health services needed by persons with disabilities because of their disabilities, as well as ensures the right of people with disabilities to equally access “the highest attainable standard of health without discrimination on the basis of disability”. Without equal access to healthcare, “people with disabilities are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation” (Stein, Stein, Weiss, & Lang, 2009).

In response to the CRPD, high income countries such as Australia are designing and delivering international development assistance to ensure that people with disability are included throughout and benefit equally with others (AusAID, 2011; Lord et al., 2010). While such programmes are significant steps, it is of particular importance that the health rights of people with intellectual disability in low and middle income countries are the focus of both national and international efforts, resource, policy and partnership.

The dearth in the literature on people with intellectual disability in low and middle income countries perpetuates this populace’s invisibility (World Health Organization, 2007), while intellectual disability in general has been a marginal area for healthcare and health research (Salvador-Carulla & Saxena, 2009). The prevalence of severe intellectual disability in low and middle income countries is at least double that of high income countries (Durkin, 2002), attributable to preventable causes, such as lead poisoning, malnutrition, birth trauma and iodine deficiency (Salvador-Carulla & Saxena, 2009). The requirements for adequate healthcare and good health are distinct needs which should be recognized and met (Cooper, Melville, & Morrison, 2004). It is incredible to consider the imbalance between the sheer size of the developing world population, how little is known about intellectual disability, and disability in general (Fujiura, Park, & Rutkowski-Kmitta, 2005), and the fact that the largest body of knowledge on intellectual disability is based on research in developed countries, “while people with intellectual disabilities in developing countries face the same or even greater health problems” (van Schrojenstein Lantman De Valk, 2005).

The Republic of the Philippines has committed to uphold the health rights of its citizens with intellectual disability through its ratification of the CRPD on 15 April 2008 (United Nations Enable). While this is positive, the World Health Organization (WHO) (2007) reports a lack of research presence on intellectual disability in this middle income nation. Indeed, there is a void in the literature on the health experiences of Filipinos with intellectual disability. The most recent disability study in the Philippines has indicated that 6% of people who experience disability experience an intellectual disability (Japan International Cooperation Agency, 2002).

In response, in July 2010, we conducted a small qualitative study with twenty one professionals and community based rehabilitation volunteers from the Filipino island of Negros Occidental who work with people with intellectual disability in challenging urban and rural settings. Our aim was to develop insight into the barriers to healthcare and good health for this populace. Our research was in the context of exploring whether the Australian designed Comprehensive Health Assessment Programme (or CHAP), a primary health care tool for people with intellectual disability, could be adapted and transferred into a low and middle income country environment to support and promote the health rights of disadvantaged people with intellectual disability.

The CHAP is a 25-page booklet developed to be attractive and easy to use. The first part is completed by the care provider and covers the person's socio-medical history. The second part is completed by the general medical practitioner (GP) and includes a review, a guided physical examination and health action plan. It also lists commonly unrecognized health conditions in this population and charts syndrome-specific co-morbidities to inform the GP. The CHAP underwent a randomised controlled trial in Australia in 2001-2002 in which it was found the tool increases health promotion, disease prevention and case-finding activity in adults with intellectual disability living in the community and in less formal settings (N. Lennox et al., 2007; N. Lennox et al., 2010; N. G. Lennox, Ware, Bain, Taylor Gomez, & Cooper, 2011). The CHAP is also currently utilized in all Australian states, with versions in New Zealand, the United Kingdom, and Canada.

## II. Methodology

The Philippines was chosen for our exploratory study due to its middle income country status, geographic proximity to Australia, and a link between the Queensland Centre for Intellectual and Developmental Disability (QCIDD, The University of Queensland, Australia) and a WHO collaborating non-government organization (NGO) in Bacolod City in Negros Occidental, a one-hour flight south of Manila.

A questionnaire was developed by researchers from the School of Public Health (The University of Queensland) and the Queensland Centre for Intellectual and Developmental Disability (QCIDD) (MRI-UQ) for health professionals and others working or volunteering with Filipinos with intellectual disability. The collaborating NGO provided input on the questionnaire content, as did a Brisbane (Australia) based Social Worker of Filipino background. The questionnaire featured both short answer and open ended questions on what were the perceived problems to healthcare and good health for people with intellectual disability in the Philippines. Twenty one respondents took part in the interviews, recruited by the NGO. An Ilongo interpreter was utilized by the interviewer and a stipend was paid to respondents to cover their time, transport and other administrative costs. The participants were asked for their views on whether the health of people with intellectual disability is better, worse or the same as the general population (and why), what are the key problems to healthcare and good health for people with intellectual disability and, significantly, provide suggestions on how these challenges can be overcome to advance the health rights of this population. All participants were asked in open-ended questions about their views of the CHAP and its useability in the Philippines. The shortest interview was 25 minutes, and the longest interview was one hour and 15 minutes; average interview time was 52 minutes. Responses were thematically coded by two independent researchers for inter-rata reliability. Consent was obtained from each of the participants and from the NGO prior to the researcher's arrival. Ethics approval was provided by the Behavioural and Social Sciences Review Committee, The University of Queensland.

### III. Findings

Table 1 outlines the occupation of the 21 respondents who participated in our study, which consisted of three men and 18 women. One third of respondents were Community Based Rehabilitation (CBR) volunteers, who are managed by the collaborating NGO. Anecdotally the interviewer was informed the CBR volunteers enjoy a degree of status in their villages and barangays due to their voluntary activities working with people with disability, which includes performing social work, basic physiotherapy (trained and overseen by the NGO's two physiotherapists), and advocacy to local authorities for individual funding and support.

Community Based Rehabilitation Volunteer	n=7
Special Education Teacher	n=4
Physiotherapist	n=3
Social Worker	n=3
Doctor	n=2
Occupational Therapist	n=1
Community Public Health Nurse	n=1
<b>Total:</b>	<b>n=21</b>

**Table 1:** Occupation of 21 Respondents

Table 2 highlights how long respondents have worked or volunteered with people with intellectual disability. The average length of time is more than eight years, with nine respondents having more than 10 years' experience. The respondents are therefore relatively skilled and knowledgeable in working or volunteering with this populace.

4 Respondents:	>20 years
2 Respondents:	>15 years
3 Respondents:	>10 years
7 Respondents:	>5 years
3 Respondents:	>3 years
2 Respondents:	>1 year

**Table 2:** Respondent's Time Working/Volunteering with People with Intellectual Disability

The majority of respondents (n=16, 76%) reported that the health of people with intellectual disability in the Philippines was worse than that of the general population. Two respondents stated it was slightly worse, one stated it was the same, and two reported that it depended on the status of the individual and their family:

It's okay if you are wealthy, but if poor, it is the worst condition.  
 Sometimes better. Depends on status if rich or poor because if rich have caregivers or parents to help do things or do things to perform. Worse for those who are poor because no assistance from their parents, especially financial appeal.

The respondents gave a variety of responses as to why they thought the health of people with intellectual disability was better, worse, or the same as the general population (see Table 3).

Family poverty:	19%
Neglect:	17%
Poor hygiene and self-care of people with intellectual disability:	16%
Person's inability to communicate health concerns:	16%
Lack of family awareness of diagnosis and (medical) interventions:	10%
Lack of medical investigation (early intervention):	5%
Lack of knowledge or time by family physician:	5%
Poor maternal health:	2%
Lack of hospitals with facilities:	2%
Inadequate diagnostic tools to assess intellectual disability:	2%
Stigma/labelling:	2%
People with intellectual disability experience rights deprivations:	2%
Nil response:	2%

**Table 3:** Why respondents consider the health of people with intellectual disability is better, worse or the same as the general population Summary

From analysing the responses, it became evident that the themes of family poverty, neglect, and poor self-care were interlinked. The following quotes from various respondents exemplify this point:

Because if there is no one to take care of them, so they cannot eat and if they do not eat they do not sleep, they just roam around. Families sometimes cannot take care of them, the family is harmless but sometimes they cannot afford to feed them so therefore they roam around and ask for food from the people. Some of the families work on sugar cane fields and have no time to feed the children.

Because poverty. Could you imagine how the family can survive with 50 peso [approximately USD\$1.12] salary per day on the farm, and having a large family?

Families lack drive to help and to care and give attention to people with intellectual disability. Attention is the big factor I think [Why?] Financial, busy look for money. Financial need; they don't have somebody to take care of them, except well off families, even middle class families cannot afford help. Because some of the family members abandon them or just ignore the patient. The patient also lacks self hygiene and poor self care.

Participants also were asked to comment on the barriers to healthcare and good health for people with intellectual disabilities in the Philippines (see Table 4). Unsurprisingly, there is some overlap with responses reported in Table 3. The reported problems were mainly structural.

Family Poverty:	26%
Lack of parental education on Intellectual Disability and health services:	16%
Lack of specialist health professionals and services:	16%
Healthcare costs:	13%
Neglectful family attitude/devaluing individual:	8%
Lack of government prioritisation/commitment for PWID:	6%
PWID lacks individual supports:	5%
Lack of baseline data:	3%
PWID People With Intellectual Disability:	3%
Poor maternal health:	2%
Lack of community consultation by government:	2%

**Table 4:** Respondents' view of barriers to healthcare and good health for people with intellectual disabilities in the Philippines – Summary

The respondents again gave a multitude of responses on how the problems to healthcare and good health for people with intellectual disabilities in the Philippines may be overcome. These are presented in Table 5.

Filipino government prioritization, commitment & resourcing:	23%
Health Promotion - family education on intellectual disability & health needs:	17%
Unsure:	11%
Funding and support of Disability Support Services (NGOs):	9%
Preventative: improvements in infant and maternal health:	7%
Whole community support & valuing people with intellectual disability:	7%
Advocacy efforts to Filipino government:	7%
Financial assistance to access health care:	7%
More volunteers and workers to support individuals/families:	4%
Encourage students to work as health professionals with PWID:	4%
Data collection on prevalence and needs of PWID:	2%
International donor aid to support health care access:	2%

**Table 5:** Worker and Volunteers' Views on Overcoming the Barriers

Participants were also asked about the CHAP and its useability in the Philippines in open-ended questions. All responded that the CHAP was a useful tool, and would be very useable in the region if it were translated into Ilongo. For some respondents, the CHAP confirmed that their practice was sound: I am already asking all of these questions. For others, its simplicity was seen as a substantial advantage for families and practitioners alike:

These types of questions can be understood by the people. It is not medically difficult.  
It makes the work of the doctors easier.  
The questions are basic. The family can understand it.  
It's easy, simple and very useful.

When asked how the CHAP translated culturally, the respondents were very clear that generally the CHAP translated well into Filipino culture. However, many expressed concerns about the limits of the CHAP's questions with respect to sexual and reproductive health.

I am unsure to ask if a person is sexually active, depends on the family, if they'll answer this.  
It's a sensitive question. Me personally [doctor], I can ask it directly but I wouldn't ask it of the opposite sex because of our values.

Several participants emphasizes that explicit discussion of sexual relations and sexual health were not generally acceptable in Filipino culture. If their matter were to be raised, participants advised caution in how questions were phrased.

It won't be offensive to ask the question but 80% will give a no answer, especially in rural areas.  
Even though we're 'modern' in some areas, virginity is still highly prized so admitting sexual activity is a blight on your family name.

Some participants also specifically mentioned the stigma of being asked about psychiatric issues due to cultural sensitivities:

There's a big stigma when talking about psychiatric illness. Stigma about even seeing a psychiatrist as going to see one most people would assume you are "buang" (Ilongo), crazy. So awareness about other illnesses like depression, anxiety is not very high. Only when behaviour creates a lot of disturbance that family members bring the patient to see me, otherwise if it is depression or anxiety, they will let it go, they won't bother to bring to me or they bring patient first to folk healers.

Technical issues were discussed with regard to particular healthcare actions. In the Philippines, immunisations against Hepatitis A and B, and measles are available to the general population but influenza and cervical cancer are not. Similarly, thyroid function and vitamin D tests are not available. Mammograms are very expensive and not available to most Filipinos. If during a vision and hearing examination, glasses, surgery or hearing aids are recommended, these are generally beyond the financial reach of Filipinos with disabilities. Generally, the term 'desensitisation' was not recognised by participants.

The CHAP was well received and considered useable if translated into Ilongo with some cross-cultural considerations.

## IV. Discussion

Providing healthcare and other support services to people with intellectual disability and other people with disabilities in low and middle income countries, by virtue of the poor economic status of those countries, is no easy task. The World Health Organisation recognised this in 1976 and thus promoted rehabilitation programs worldwide in order to provide cost-effective, community based, volunteer driven supports to people with disabilities in low and middle income countries (Helander, Mendis, & Nelson, 1980; Helander, Mendis, Nelson, & Goerdts, 1989). While CBR programs are not without their practical and evidential limitations (Finkenflugel, Wolffers, & Huijsman, 2005), the literature indicates some success in implementation of CBR programs in the Philippines (Lagerkvist, 1992; Valdez & Mitchell, 1999). However, there appears limited focus in discussion or evaluation of Philippines based CBR services on the specific health needs and healthcare experiences of people with intellectual disability. Therefore, affirmative research and action specifically focusing on the health rights of Filipinos with intellectual disability is needed.

With over 92 million people living in the Philippines and around 33% of those living below the national poverty line (Asia Development Bank, 2010), it is unsurprising that the respondents in our study raised family poverty as the major barrier to healthcare and good health for Filipinos with intellectual disability. Most people with disabilities in the Philippines live in poverty (Japan International Cooperation Agency, 2002). Whilst poverty is a key feature of people's lives, it is of interest that respondents focused on government support to this specific population as being of utmost importance in overcoming barriers. While the National Council for the Welfare of Disabled Persons (NCWDP) is the national coordinator for Philippine disability support activities, it is not clear from the grey literature whether the Council has implemented specific policy and programmatic commitment to people with intellectual disability and improving their health. Such affirmative action would be consistent with the Philippines' Article 25 (right to health) commitment as per its ratification of the CRPD.

A lack of research presence on this populace in the Philippines certainly reinforces the invisibility of their healthcare needs to the national government (WHO, 2007). This is arguably an important indirect feature of our present study; facilitating an advocacy voice for experienced Filipino grassroots workers and volunteers to impress on their government the need for greater focus on Filipinos with intellectual disability. In fact some respondents identified that overcoming barriers to healthcare and good health for people with intellectual disability indeed depended on advocacy efforts to government. Fujiura et al (2005) promote that advocacy around disability policy agendas is significant in

low and middle income country contexts. Such efforts for people with intellectual disability may be enhanced by collaboration with public health supporters which are based internationally. Public health practitioners have been called to take a leadership role in advancing health equity and the health and well-being of minority and disadvantaged populations (Bassett, 2011). By working with internationally based health and human rights advocates for people with intellectual disability, in-country workers may obtain greater success in advocating not only to national governments, but to donor states, agencies and international aid assistance programs. For example, international lobbying to the Philippines government might assist in its acknowledgement of the issues and commitment to funding better supports for this specific populace. In fact the fourth major theme in overcoming the barriers was the need to resource non-government organisations involved in supporting people with intellectual disability. Collaborative national and international advocacy efforts may be more opportune in securing funding for health rights projects for people with intellectual disability in NGOs operating in low and middle income countries. Collaboration may also be particularly meritorious in view of the recent and ongoing global financial crisis; fewer resources call for even more robust, strategic and collaborative advocacy efforts.

Education of Filipino families on intellectual disability and their specific health needs was considered of further import to respondents in overcoming barriers. A minor interlinked theme that emerged was also the need for whole community support and valuing of people with intellectual disability. The latter can presumably be achieved through education efforts as well.

## V. Conclusion

In low and middle income countries, there is little known about intellectual disability in the healthcare system. If healthcare tools from high income countries with coherent healthcare systems are to be successfully adapted for use in low and middle income countries, we must understand what the perceptions of healthcare and understand the barriers. Whilst this paper looks at the barriers to healthcare for people with intellectual disability in the Philippines, it acknowledges that policy makers need to listen to grassroots workers about how to improve the health and wellbeing of Filipinos with intellectual disability. Persons with intellectual disability and their families also need to be heard by policy makers.

As part of exploring the potential trial of the CHAP in a country such as the Philippines, it was important to gain insight into the structural and critical factors that shape the health rights and needs of people with intellectual disability.

The findings will inform any consideration of the transference of healthcare resources to a low and middle income country context.

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