

*Proposed Eligibility Criteria for the Issuance of the PWD ID
As presented in the Public Hearing on 27 November 2014*

FEEDBACK & RECOMMENDATIONS

A submission from the Philippine Alliance on Persons with Chronic Illness

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This document represents views by the following DPOs convened for an FGD on 10 Dec 2014 at the Dept of Health:

- Psoriasis Philippines
- Rheumatology Education Foundation
- People Empowerment for Arthritis & Rheumatology Lupus
- Breast Cancer Survivor Network
- Cancer Warriors Foundation
- Alyansa ng May Kapansanang Pinoy /AKAP Pinoy

SUMMARY OF RECOMMENDATIONS

Definitions / perspectives of disability

1. Formulate a general unified definition that is compliant with the U.N. Convention on the Rights of Persons with Disabilities.
2. On proposed seven categories of disability (psychosoc / behavioral; learning, intellectual, visual, physical, hearing, speech)
 - Add an eighth category: Chronic Illness / Multiple / Other; sub-category for Children with Chronic Illness / Multiple / Other Disabilities
 - Use all of these categories only as initial guide, and NOT as closed categories

PWD ID Card

3. Separate Disability Identification from Disability Discount Entitlement (design separately on front / back of Card?)
 - Person with Disability Identification (/ Child with Disability) [front of card]
 - Disability Discount Eligibility [back of card]
4. The card will not specify the category of impairment, but may indicate extent.

Disability Discount

Determination of eligibility for Discount

5. Use WHODAS 12item+24 version for Screening, Assessment to generate equal weighted Disability Scores for :
 - functional limitations
 - participation barriers
6. Pilot WHODAS across different impairments and document validity / reliability.

Disability Discount

7. Explore increase of discount to a range (see Options paper recommendation):
 - current 20% for services: increase to 20-50%
 - current 5% for basic commodities: increase to 5-20%

Disability Discount program in Social Protection framework

8. Mandate shared oversight of design and implementation of the Disability Identification / Discount Card between the NCDA/ DSWD, with DOH, NAPC, NEDA
9. Conduct impact assessment of the range of discounts piloted in #7 on:
 - poverty level of persons with different impairments (/households with children with disabilities)
 - addressing disability-related costs across the different impairments, and among households with children with disabilities
10. Do a comprehensive review of social protection for persons with disabilities, and specifically for women/ girls, and children with disabilities for the Disability Discount as one among many mechanisms, and its overall impact and contribution to poverty reduction.

Other Concerns

- How many Filipinos with Chronic Illness have been issued PWD ID cards? With changes, how many potentially may be delisted?
- If there are changes in the eligibility criteria, shall these individuals have to go through re-registration / assessment; or would just have to update their records (still maintain their PWD status)?
- With possible delisting, what are the grievance mechanisms for requesting review or reconsideration for these individuals?

RATIONALE FOR RECOMMENDATIONS

Recommendation #1

Formulate a general unified definition that is compliant with the U.N. Convention on the Rights of Persons with Disabilities.

Current definitions of what disability is, and who persons with disabilities are, vary across executive agencies and government owned-/controlled- corporations (GOCCs). Several of these adopt a purely functional perspective of disability, based on the 1992 RA 7277 (Magna Carta for Disabled Persons),

which has not been harmonized with the ratified U.N. Convention on the Rights of Persons with Disabilities (2008). For the benefits provided by social insurance GOCCs (ex. SSS, GSIS, PVAO, ECC, OWWA, etc.) the criteria are employment dependent (currently-, or previously employed), excluding the many persons with disabilities.

It is possible however, that a particular agency, for instance the DepEd, DOH, DSWD, DOLE, etc. shall further fine-tune the definition or categorization of disability according to their particular agency mandates. But all of these must still be consistent with the general unified definition applied nationwide.

*Note the proposed 7 categories arbitrarily interchange the terms *impairment* and *disability*. This is not consistent with the CRPD perspective. We recommend that all use the term impairment consistently.

Recommendation #2

On proposed seven categories of disability (psychosoc / behavioral; learning, intellectual, visual, physical, hearing, speech)

- Add an eighth category: **Chronic Illness / Multiple / Other; sub-category for Children with Chronic Illness / Multiple / Other Disabilities**
- Use all of these categories only as initial guide, and NOT as closed categories

The CRPD perspective of disability as restricted participation resulting from the interaction of barriers with longterm physical, mental, intellectual and sensory impairments, is notably NOT a definition (and does not limit only to specific impairments). Rather, CRPD Art. 1 is an open classification that presents an evolving concept of disability. Such a perspective allows the greatest inclusiveness to encompass the diversity of impairments traditionally, or currently recognized, and continuing into the future.

This additional 8th category allows for flexibility in including individuals with impairments which do not easily fit into the other categories such as: deaf blind individuals, persons living with HIV/AIDS, chronic conditions such as rare diseases (orphan disorders), cancers, psoriasis, epilepsy, Hansen's Disease, and so on.

For children with chronic illness, the social protection framework of UNICEF should be adopted.

An example of this ongoing global discussion relating chronic conditions to disability is shown below:

HIV and Definitions of Disability under International and National Laws

The Convention on the Rights of Persons with Disabilities states that:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1)

The Convention does not explicitly refer to HIV or AIDS in the definition of disability. However, States are required to recognize that where persons living with HIV (asymptomatic or symptomatic) have impairments which, in interaction with the environment, results in stigma, discrimination or other barriers to their participation, they can fall under the protection of the Convention.

States parties to the Convention are required to ensure that national legislation complies with this understanding of disability. Some countries have accorded protection to people living with HIV under national disability legislation. Other countries have adopted antidiscrimination laws that either explicitly include discrimination on the basis of HIV status or can be interpreted to do so. Such laws offer a means of redress against HIV-related discrimination in a number of areas, such as employment or education.

OHCHR / WHO / UNAIDS. 2009. Disability and HIV Policy Brief.

Recommendation #3

Separate Disability Identification from Disability Discount Entitlement (design separately on front / back of Card?)

Person with Disability Identification (/ Child with Disability) [front of card]

Disability Discount Eligibility [back of card]

Identification by the State that one is a Person with a Disability recognizes the bearer's rights and fundamental freedoms. This serves a *legal* function which may be useful in: referrals for assistance or other services (such as rehabilitation, educational arrangements, acquisition of assistive devices or technology, etc.), use of priority lanes, or as basis for grievance and litigation (invoking protection from the CRPD).

The entitlement to a discount however serves a *social protection* function. This is necessary because of the economic marginalization and poverty associated with disability. Thus, depending on the design, and efficiency of implementation of this mechanism, it may contribute to poverty reduction, or at least offset to some extent the economic burden of disability-related costs to the individual or her family.

Possible scenarios of an individual being recognized as having a disability but not being entitled to a discount include the ff:

- the individual waives her entitlement to the discount (for personal reasons such as fear of discrimination upon disclosure of personal info when availing of a discount, inconvenience in claiming discount, feels she does not need the discount, etc.);
- if means-tested: establishing a minimum threshold relative to costing of this person's disability related need; for instance: a wealthy, employed person with a disability may or may not be entitled to a discount. But if her/ his chronic condition requires for ex., antiretroviral drugs (for Persons living with HIV), steroids (for Psoriasis and other auto-immune conditions), chemotherapy drugs (specially for aggressive forms of gender-associated cancers such as testicular, prostatic, breast, etc.) - these total to hundreds of thousands of pesos needed weekly / monthly which can impoverish even individuals who are in higher socio-economic brackets; [this scenario requires further study, and formulation of guidelines which would be responsive]
- the individual is aged 60 and above and opts to avail of her Senior Citizen discount instead

This separation of objectives simplifies the issuance process, making it more responsive as well as efficient.

Recommendation #4

The card will not specify the category of impairment, but may indicate extent.

The necessity of disclosing that one has a disability may result in embarrassment, stigma or outright discrimination. There have been numerous experiences on the ground when availing of the Discount in purchasing medicines from Mercury Drug, or labs and other medical services in hospitals or health facilities, for air travel and other public transportation, etc. This has to do with stereotypes of the public-at-large. Negative remarks such as "*hindi ka naman mukhang disabled..*", "*sayang, ...maganda /guapo / cute (for children) ka / siya pa naman...*", "*ay.. akala ko normal ka / siya (for children)..*", etc.

Referrals for the kind of services needed may be indicated on the card, but NOT the impairment.

This kind of stigma associated with disability identification and disclosure is not unique to the Philippines, and is documented in other countries. Two examples below from Peru, and the U.K.:

Human Rights Watch. 2011. I Want to be a Citizen Just like Any Other: Barriers to Political Participation for People with Disabilities in Peru. www.hrw.org/sites/default/files/related/peru0512_accessible.doc. Accessed 310115.

“Peru’s law permits the inclusion on the identity card, on a voluntary basis, of information that a person has a permanent disability.¹ Many people with disabilities choose not to include this information, out of concern that doing so will subject them to discrimination based on their disability...”

“For example, the identity card of some people with hearing impairments lists the term “deaf” under the observations without their consent. People within the deaf community questioned: “Why should my identity card have this? Why should it have a tag with my disability there?”² The advocate also explained how in her experience she has met several people with intellectual or psychosocial disabilities and their families who reported limitations to the exercise of other rights such as the right to own property or open a bank account.³”

“ Note: The context of this study is about a national ID Card (and not a PWD ID Card), but it still reflects experiences on sensitivities when disability is disclosed. See Annex A for longer excerpt

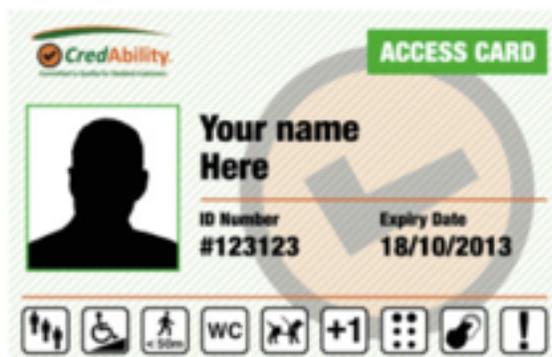
Access Card. credability.uk.com/access-card/
Accessed 310115.

*“The Access Card is a card like no other, we translate your disability / impairment into symbols which highlight the barriers you face and the reasonable adjustments you might need. This then informs providers quickly and **discreetly** about the support you need and may gain you access to things like concessionary ticket prices and complex reasonable adjustments **without having to go into loads of personal detail**. Its all based on your rights under the Equality Act and providers responsibilities....”*

Testimonials:

“... My disability is not always visible so I have to go through the embarrassment of explaining my personal health problems to complete strangers who sometimes don't even believe me...”

“... The card would be a useful tool, to save me the time and humiliation of having to explain everything – often to people who don't have time, or are in a noisy environment so I have to shout!”



*Note: This is a card issued by a private service provider.

Of course, information about the impairment is kept in the government database.

The rights of children with disabilities should also be considered, and Identification should be compliant with international standards of the CRPD and the Convention on the Rights of the Child, and other domestic laws.

In other countries such as Nepal, a color-coded scheme of the disability identification card indicates extent of impairment only (not kind of impairment) which provides basis for range of disability benefits (see Annex B).

Recommendation #5

Use WHODAS 12item+24 version for Screening, Assessment to generate equal weighted Disability Scores for :

- **functional limitations**
- **participation barriers**

The DOH is already using the WHODAS2 tool to “identify those with functional difficulties and rehabilitation needs so that interventions can be done accordingly...”:

“... This is the tool we have started to train health care providers in the primary health care facilities (RHUs, Barangay Health Stations) to use already to all patients they meet in their facilities. As we have started already to train primary health care providers on this, and since the tool is sensitive in identifying levels of difficulties in functioning, we thought, it might be helpful to also use it for purposes of the PWD ID card....since it is our intention to identify difficulty in functioning in all patients seeking health/medical attention in primary health care facilities so we can intervene accordingly, if found with moderate to severe difficulty they are considered PWD and therefore eligible for an ID..., this would also help MHOs to have basis in issuing a medical certificate particularly for those with non-apparent disabilities. Yes, BHWs/Midwives or whoever sees patient first will use the first 5 screening question to determine further assessment by MHOs.”

[P.Cuevas email communication, 15Dec 2014]

However, we recommend a modification in the interpretation of the Disability Score to adapt it to the objective of assessing for discount eligibility (this would differ from the initial use of DOH of WHODAS for generating a basis for referral for other services). This modification has to do with mathematically transforming the raw scores from the administration of the tool into *equal-weighted points for functional limitations and participation barriers*.

This we believe, is a CRPD compliant procedure for assessing disability-related needs by adopting the view:

impairment + barriers = restricted participation => Disability.

The equal weight of participation to functional limitation avoids the traditional practice of equating disability *only* with functionality (limitations from the impairment).

Thus, we envision the procedure to be as follows:

Applicant presents Medical Certificate which states which of eight categories (DOH proposed 7 categories + our proposed additional category of Chronic Illness / Multiple Disability / Other)

Step 1 Use S1-S5 as screening by Bgy Health Worker for SCREENING
=> determine if / which impairment /condition is present

Step 2 Use S6-S12 by Municipal Health Worker for ASSESSMENT
=> determine functional limitations (Cognition, Mobility, Self-care, Getting along with people, Life Activities)
=> determine participation barriers

Come up with equal weighted equal Disability Scores for :
Domains 1-5 on functional limitations
Domain 6 on participation barriers

Develop guidelines on interpretation of Disability Scores to determine eligibility for discount.

Recommendation #6

Pilot WHODAS across different impairments and document validity / reliability.

- determine if time frame of tool (30 days) is appropriate, specially for Chronic Illness (including chronic psychosocial impairments)
- evaluate its validity/reliability in urban and rural settings, across diff possible impairments, and extent of impairment
- note inclusion, exclusion errors (per impairment, urban/rural, degree of impairment); correspondingly adjust mechanics

Recommendation #7

Explore increase of discount to a range (see Options paper recommendation):

current 20% for services: increase to 20-50%
current 5% for basic commodities: increase to 5-20%

The increase is permissible under the IRR of RA 9442 (Amendments to RA 7277, Magna Carta for Persons with Disabilities) which states that the disability discount shall be *at least 20%* for:

- establishments (hotels, restaurants, Sports and Recreational Centers, Purchase of Medicine) - Rule 6.1;
- admission fees - Rule 6.2
- medical and dental privileges in government / private facilities - Rules 6.3, 6.4
- land, air and sea transportation privileges - Rules 6.5, 6.6

Recommendation #8

Mandate shared oversight of design and implementation of the Disability Identification / Discount Card between the NCDA/ DSWD, with DOH, NAPC, NEDA

The Disability Discount is primarily a *social protection* mechanism and its implementation should be overseen by the NCDA and DSWD.

Recommendation #9

Conduct impact assessment of the range of discounts piloted in #7) on:

- poverty level of persons with different impairments (/households with children with disabilities)
- addressing disability-related costs across the different impairments, and among households with children with disabilities

Recommendation #10

Do a comprehensive review of social protection for persons with disabilities, and specifically for women/ girls, and children with disabilities for the Disability Discount as one among many mechanisms, and its overall impact and contribution to poverty reduction.

OTHER CONCERNS:

1. How many Filipinos with Chronic Illness have been issued PWD ID cards? With changes, how many potentially shall be delisted?
2. If there are changes in the eligibility criteria, shall these individuals have to go through re-registration / assessment; or would just have to update their records and still be maintaining their PWD status?
3. With possible delisting, what are the grievance mechanisms for requesting review or consideration for these individuals?

ANNEX A

Stigmatization and Other Consequences of Registering Disabilities and Denying the Right to Vote

Source: Human Rights Watch. 2011. I Want to be a Citizen Just like Any Other: Barriers to Political Participation for People with Disabilities in Peru. www.hrw.org/sites/default/files/related/peru0512_accessible.doc. Accessed 310115.

Peru's law permits the inclusion on the identity card, on a voluntary basis, of information that a person has a permanent disability.⁴ Many people with disabilities choose not to include this information, out of concern that doing so will subject them to discrimination based on their disability. This choice is not always respected, however. Human Rights Watch documented at least five cases in which information about a person's disability was included on their identity cards without their authorization, in some cases despite explicit requests from parents that this information should not be displayed on the face of the identity card.⁵

⁴ Organic Law of RENIEC, art. 32(l), as amended by Law No. 29478, 2009; Human Rights Watch interview with Carlo Magno Salcedo Cuadros, deputy director, Electoral Activities, RENIEC, Lima, October 25, 2011.

⁵ Human Rights Watch interview with Mario, young man with intellectual disability, Lima, October 21, 2011; Human Rights Watch interview with Juan Roberto, a 43-year old man with intellectual disability, Lima, October 21, 2011; Human Rights Watch interview with Rubby B., 25-year old woman with an intellectual disability, and her mother, Rubby S., Lima, October 21, 2011; Human Rights Watch interview with Vanya, a young woman with Down Syndrome, Lima, October 23, 2011; Human Rights Watch interview with Juan David, a 23-year old man with autism, Lima, July 21, 2011; Human Rights Watch interview with Liliana Mayo, director, Ann Sullivan Center of Peru, Lima, July 20, 2011. In the case of Juan Roberto, the term "impedido" (or "prevented") was listed under observations.

Sonia, the mother of Mario, a 24-year old man with intellectual disability, told Human Rights Watch: “I thought if it said [‘mental disability’] on the document itself, people would discriminate against him. I didn’t want to see my son being discriminated [against].”⁶ Despite their request to exclude this information, Mario’s identity card states his disability.

As one disability advocate explained, members of the disability community and families are concerned about the stigma generated from including their disability on their identity card. For example, the identity card of some people with hearing impairments lists the term “deaf” under the observations without their consent. People within the deaf community questioned: “Why should my identity card have this? Why should it have a tag with my disability there?”⁷ The advocate also explained how in her experience she has met several people with intellectual or psychosocial disabilities and their families who reported limitations to the exercise of other rights such as the right to own property or open a bank account.⁸

Roberto, a 37-year old man with mild intellectual disability, was not asked if his identity card should include an observation about his intellectual disability. His father told us: “They don’t need to mark them or wear a sign on their chest.” Roberto recounted his son’s reaction when he saw that the identity card included “mental disability” as an observation.

As soon as Roberto saw it, he threw the card.... When he showed his friends in the inclusive school that he attends, they started to laugh at him.⁹

When an identity card reveals that a person has a disability, then it may also be used to exclude individuals from exercising basic entitlements. For example, if an identity card does not have a hologram sticker, it indicates the carrier did not vote; if the card does not specify a voting group assignment it suggests that the person has been deemed incapable of doing so.¹⁰ Institutions may use this information as

⁶ Human Rights Watch interview with Sonia, mother of two young people with intellectual disabilities, Lima, October 21, 2011.

⁷ Human Rights Watch interview with Susana Stiglich, disability advocate and national technical coordinator, Social and Labor Inclusion for People with Disabilities-Peru, Foundation for the Americas, Organization of American States, Lima, October 24, 2011.

⁸ Ibid.

⁹ Human Rights Watch interview with Marcelino, father of three young men with intellectual disabilities, Lima, October 22, 2011.

¹⁰ Human Rights Watch telephone interview with Vanessa Thorsen, former legal advisor, RENIEC, January 6, 2011.

a basis to make decisions about that individual's competence to make financial and legal decisions, such as opening a bank account or getting married.¹¹

Maria S., the mother of a 22-year old man with a mild intellectual disability, told us about her son's experience at the bank, when they asked him for his identity card. "They check for the voting number and the sticker. When there is no sticker, it's like they ignore them, their capacity as an adult, as a person."¹² Human Rights Watch found similar such cases in Lima and Puno.¹³

Felipe Flores, president of the Federation of People Disabilities for Puno region, said that in one case, for example, a woman who had a speech impediment was identified as having an intellectual disability. "She had land, property that she wanted to give to her children. But since she had not voted, she could not notarize a contract, she did not exist," adding, "When we do not vote, we cannot make contracts. We cannot do anything. That's what the law says."¹⁴

¹¹ Human Rights Watch telephone interview with Vanessa Thorsen, former legal advisor, RENIEC, January 6, 2011.

¹² Human Rights Watch interview with Maria, mother of Javier, a 22-year old man with mild intellectual disability, Lima, October 22, 2011.

¹³ Human Rights Watch interview with Felipe Flores, president, Federation of Persons with Disabilities Puno (FEDDIP), Puno, October 31, 2011; Human Rights Watch interview with Marcelino, father of three young men with intellectual disabilities, Lima, October 22, 2011.

¹⁴ Ibid.

ANNEX B

Classification of Disability Identity Card (color-coded)

	Disability	Monetary Allowance	Health	Education	Transportation	Employment	Legal Allowances
R E D	Profound	Rs1000					
B L U E	Severe	Rs 300	Free health services in govt hospitals	Free education in govt schools	50% discount	Quota	Free
Y E L L O W	Moderate	Rs 300					
W H I T E	Mild	Rs 300					

Source: Giri, Nir Prakash, Nepal Mental Health Foundation. 2015. Personal communication. Kathmandu, Nepal.

