

COMMENTS FROM A MIDDLE INCOME COUNTRY  
ON THE ATLAS  
AS GLOBAL RESOURCES FOR PERSONS WITH  
INTELLECTUAL DISABILITIES 2007

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It is a pleasure to represent the opinion of middle income countries regarding the Atlas. I am very glad to attend this international gathering and to meet the prominent leaders of disability movements around the World.

It is evident that the cooperation between WHO, and a known research institutions is proved to be very efficient. It produced such comprehensive database, and orientation guidebook to be used by policy makers, researchers, public sector, organizations of people with disabilities, parents groups and persons with intellectual disability around the World.

I hope that it will fulfill the contribution to Intellectual Disability across the objectives. That is identifying the gaps and needs, offering the appropriate tool – mapping questionnaire, and pave the way for networking the country respondents.

I still remember the efforts of the International Community during the last three and half decades. That was initiated by the United Nation in the IYD. UN agencies in that time presented a similar kind of mapping. It was focusing on Disability at large. The WPA was recommended to face the challenges under the main concepts Equalization and Full Participation. It was clear since then the huge gap among different World Regions. The United Nations Decade which lasts till 1993, failed to compile with the WPA. The World Regions then put another time frame – Decades for Persons with Disabilities with their own program of actions. The Inter-

Americas, the African Decade, The Asia Pacific Decade 1993-2002 then 2003-2012, the Arab Decade 2004-2013 and others are still on their ways to compile with their Regional Programs of Actions.

There another International initiatives, which were adopted by UN bodies like Health for All, Education for All, the ILO Convention, all of them were done to promote the rights of PWD. Last but not least the UN Convention which was adopted by the UN and launched on Dec.13 2006. Now more than 100 countries had ratified that starting from March 30 2007.

I was lucky enough to have role in revision of 10 Q screening tool which was established by WHO in order to help in screening people under risk of Disability in the developing World. This work was done by Bishop Baker Institute in Holland in 1998. And I had participated when WHO had started its real work on ID focusing in the area of health and aging – specially on women with ID – that was in the IASSID Round Table at WHO Headquarter in April 2000. It was very clear then the huge gap among the quality of health service programs which is provided for people with disability and it impact on the life style of PWD. It was clear that the researches being exposed during the round table were almost covering all the health conditions in developing World. Very little was focused on the health challenges for PWD in the Low Income Countries.

Now we are in front of a specific contribution from WHO and its Canadian partners where the focus is on Intellectual Disability. All we know the roles of WHO in CBR along with UNESCO, and ILO. It has successes in some areas and was not so productive in others. The PHC programs are very important being offered by WHO around the World to improve the quality of services. It was obvious the gradual shift of WHO from its old medical concept on Disability (Impairment – Disability – Handicap) to functional and socio-economic concept.

It is the first time WHO has comprehensive consideration regarding disability issue.

It is evident that the main key disability issues are being viewed from different perspectives starting from terminology, policies, legislation, protection, public awareness, financing, governmental benefits, services for children and adult, access services factors, prevention, standard of provided services, training, the role of NGO, role of International Organizations, and other issues. That was brought by certain items in the questionnaire such as Open ended comments where was revealed shocking facts in low and middle income countries. Other facts were also revealed by the questionnaire “Silent findings”. Under this heading some items were mentioned like availability of information, terminology, visibility of the issues, sources of funding, service provisions, access to services prevention, human resources, role of NGOs, gaps in resources between countries.

The way forward section contains the major actions recommended to fill the gaps. That includes changing the priorities of NGOs and governments, identify the accountable authorities, closing the gap between needs and resources, recognize the role of families, resources distribution, custodial care institutions, capacity building, making ID as public health issue, and enforce human rights and right to health.

As we can see in the current Atlas ID is viewed from much wider perspective that it was viewed earlier in the WPA. Atlas is taking in consideration almost all the radical changes, and the tools being developed since the UN Declaration on Human Rights.

An increased number of stakeholders are being added to the ID challenging difficulties.

ID will not viewed as a health issue, it is rather more global and multi-focal. ID does not mean anymore an individual impairment – body or mind- it includes rather a legitimate right to socio-economic, cultural, legal capacity, citizenship, and gender space. The challenges and difficulties of persons with ID, should never be

blamed for being so, they are viewed as such by other. Persons with ID usually strive to be like others, and to adapt to the changing circumstances. They should be given the chance, the tools, the support, and the proper respect to be partners in their communities. People with intellectual Disability are in need for ramps just like PWD, but the ramps which they need should build within the architectures of hearts and minds of others.

Being a father of two gentlemen with intellectual disability, and part of Inclusion International, I will try to make some comments on the contents of the Atlas:

Findings by themes:

### Terminology & Classification

- 1- I would prefer to stress the importance of terms which are compatible with human rights, and peoples first.
- 2- It is frustrating to have classifications based on Medical and psychiatric concept. (ICD & DSM)

### Policies & Programs

- 1- I believe that policies and programs should be in the context of comprehensive public health strategies. The fact of indiscriminate Well Being for every citizen should be in the principles of policies.
- 2- There may be some stress on special policies for Intellectual Disability where there is not Inclusive Comprehensive Health planning.
- 3- It striking that among programs addressing Intellectual Disability those which are related to **Income**. It showed that in Low Income Countries is only 10% (Average. 27,8%). Where it is known the poorest among the poor are those people with intellectual disability and their

families. The same for the Departments responsible for Funding 2,4%. (Average 12,2%) Funding for adults does exceed 4.8% (Average 15%).

### Legislation & Awareness

- 1- It is shown that the Low Income countries do have legislation protecting children 53%, adult 46,3%, where no any protection for PWID 43.9%. Besides not all the legislation are applicable, and has any real translation on the ground.
- 2- Awareness Campaigns are conducted in almost all countries, some of them even did celebrate specific days for ID; however there should be efforts to address “Disability Culture”.

### Financing

- 1- Funding of services for PWID are not systematically organized in Low Income Countries. Funding is mainly covered by NGOs and our of pocket. This fact increases the burden and worsens the poverty of PWID and their families. That indicates the necessity of addressing this issue. 17% only depends on Tax Payers, social and health insurance 0.5%.

### Government Benefits

It is evident by the Atlas the 50% of Low Income Countries are living without any benefit from Government programs. 49.6% of PWID benefits only less than 10% of the Gov Benefits.

### Services for PWID

- 1- **Organization** : Atlas does not show the magnitude of the role of Governments in service organization. In Low Income Countries services are mainly provided by NGOs.
- 2- **Specific services:** Low Income Countries (LIC) mainly depend on Asylum-type 33-54%
- 3- **Health Services:** most of the indicators show average of 60-70% for the LIC; however it is not well known how are these estimations are realistic. More that 75% of PWID in LIC are out of any kind of services. PHC may have more services where ID is partially addressed.
- 4- **Services Specific to ID:** That is shown in the Atlas for LIC with significant low level of Early intervention Services 62%, average is 75%. Again the data is not reliable since services are not available for more than 68% in LIC.
- 5- **Education:** Atlas shows that LIC provide segregated type in 82-94% , while preschool programs 47-74%. The HIC 97%.
- 6- **Work:** Sheltered Workshop ranges between 16%-72% in LIC & Med IC, while its 96% in HIC. General Work Skills in LIC 35.5% where in HIC 100%.
- 7- **Other Services:** That services are leisure (LIC 55% HIC 100%) , transportation (LIC 21% HIC 94%), advocacy (LIC 61%, HIC 94%), assistive technologies (LIC 25%, HIC 93%), food & basic necessities (LIC 47%, HIC 74%).
- 8- **Services to Families:** I have to draw the attention to the fact that the UN Convention had stressed the importance of support and help to families of PWD.

### Factors that have impacts on access to services

The main 3 factors which affects access to service (PWID stay, location of Services, and socio-economic status). There were other factors which were not well stressed, in the Atlas collected Data did not give enough attention. Those are ethnic origin, believes, illiteracy, ignorance of the existence of services, sex, language, education of parents, the level of mobility of the PWID, and the

age of care givers. The last factors are extremely affecting and more sound in the LIC. The main factors affecting access to services are the most influential causes in delaying the sustainable development in LIC. Some additional factor may be added like the level of security, the quality of services, availability of active NGOs, or parents organizations.

### Prevention

First of all “prevention” should be well defined. It should address the causes of disabling factors. Besides it should stress the fact of indiscriminative “well being”. The Atlas lists almost all medical basis for preventive measures and its levels; however there was not enough stress on the environmental atmosphere. In other wards the availability of disabling factors, in the community. It is well known that what is called “prenatal preventive measures” to the extend of terminating pregnancy is prevailing in the LIC. That is due to the misleading instructions by professional to pregnant mothers.

### Professional service providers and standard of care

- 1- Atlas respondents stressed the role of special educators , and other paramedical professional. It is well known the limited numbers of some paramedical professions, like occupational therapy, speech-therapy and others. PWID in LIC are in bad need for such services.
- 2- Despite the importance for paramedical professions, there were be no any data about the level of qualification of other academic personnel who are supposed to be well informed and experienced in delivering inclusive education. Besides there were no any data about the level of administrative professional for all levels of inclusive education.
- 3- The standard of care are well illustrated; however all of the mentioned standards are in terms of medical measures. The Atlas did not give proper attention to other standards related

to non medical professionals. These are supposed to be well stressed specially in LIC.

- 4- Training of professionals – in all multidisciplinary - is usually much efficient and systematic in the HIC. Training programs in LIC are not appropriately done.

### The Roles of NGOs and International Organizations

I believe that LIC grass root organizations and NGOs are the main service providers for PWID. Most of resources for these organizations are from fundraising. Some of them are functioning through political or religious networks. Organizations of PWD and their families are not well developed in LIC.

Establishment of active NGOs in LIC has many limitations due to the prevailing political regimes in that countries. PWD along with other marginalized social groups usually face extreme difficulties in gaining almost all their rights specially their right in participation and denied from equal opportunities.

NGOs in M & HIC usually function as tools, mediators, or brokers, to facilitate the access to benefits for PWD. Almost all financial resources funds are allocated in the corresponding offices. They have a very efficient role in policy making, and advocacy. While in LIC NGOs are the main service provider, and the financial resource for that services are being collected mainly by fundraising activities. They do not enjoy the same role in policy making like those at the M & HIC.

Regarding the role of International NGOs they have very active role in supporting development programs in LIC.

Following the Globalization movement a lot of international non governmental agencies, and organizations are functioning within certain political frameworks. Some of them are political interest oriented. Many of them are used to promote certain ideology, and market for the interests of that ideology.

## Decommentation and Resources

It is evident according to the data of Atlas, the lowest level for such issue was among the LIC.

As I mentioned earlier that the IASSID Roundtable which organized in 2002 at WHO head quarter, almost all the researches and studies which were presented were about challenges faced by PWID in HIC.

## Open ended comments

This part of the Atlas introduced some examples on the respondents participated in the mapping. It drew the attention to the wide gap between the conditions in LIC and HIC, in various domains.

## <sup>as</sup>Silent Findings

I think I have already mentioned above my comments on the silent findings. I am still wondering about the Medically oriented themes of the Atlas. There are a very limited data about the Social-economic and cultural component of disability.

## The way forward

I think that this part of Atlas contain a kind of instructions and recommendation. What we need on this stage to have Road Map and a new WPA. The international community these days differs from that in 1981 IYD. Now we have dramatic changes in disability movement around the World. We have Regional Decades and Regional Programs of Action. We have powerful International Disability NGOs IDA, IDC, and organization of PWID and their families are gaining power.

Las but not least we can be enforced and we can invest the UN Conventions on protection of Rights for persons with Disability.

Finally I would like to express <sup>d</sup> deep appreciation for everybody who contributed to this outstanding work which will be an efficient tool to improve the life quality of PWID and their families.