

Beginning a new chapter: Two decades of AAC service delivery in South Africa

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African saying...

As jy vinning wil loop, loop dan alleen.
As jy ver wil loop, loop saam met mense.

If you want to walk quickly, walk alone.
If you want to walk a long way, then walk
with other people.



Disability in developing countries

- Approx 10% of world population have some form of disability (WHO, 2005)
 - 650 million people
 - 200 million children
- 80% of people with disability live in developing countries (UN, 2006 ; Iwakuma & Nussbaum, 2000)
 - 520 million people!
- Statistics limited, but lends support to the association between disability and poverty



Disability & Poverty

Disability is both a **cause** and a **consequence** of poverty.

Disability increases the risk of poverty (i.e. less than 1% of people with disabilities in South Africa are employed ; expenses related to disability)

Poverty creates the conditions for increased risk of disability-related impairments (e.g. poor nutrition, lack of access to proper healthcare and vaccination, and education).



Disability and poverty

“Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 ... goal(s) agreed to by more than 180 world leaders at the United Nations Millennium Summit in September 2000.”

James D. Wolfensohn, President, World Bank
December 3, 2002

UN Convention of the Rights of Persons with Disability

Article 32 defines disability as a mainstreaming issue to be considered in development programming rather than as a stand-alone issue



Prevalence studies

- **Why important?**

- Provide accurate, reliable, consistent data for valid comparison of results
- Evaluate the effectiveness of service delivery
- Impact of policy development
- Plan future services (Christianson et al, 2002)
- Steps to ameliorate under-reporting
- Develop reliable screening and assessment tool that can be adapted for cultural differences
- Use of WHO terminology: ICF and ICF-CY

Prevalence studies

- **Why difficult in developing countries?**
 - Different terminology to describe nature, degree and severity of disability
 - Limited sharing of information and recording of health data between service organizations due to no common “disability” language
 - No “universal standard test” for disability (Loeb & Eide, 2004)
 - Poverty – disability is both a cause and a consequence of disability (Emmett, 2005)
 - “*stories of abuse, total exclusion, hiding, and witchcraft are numerous, and a part of the fabric of the disability experience in developing countries*” (Loeb & Eide, 2004)
 - Gender roles and hierarchy (Milaat et al., 2001)



First study



- 19 Schools for children with intellectual impairment
- Pretoria area
- 142 teachers
- 1344 children (ages between 6 – 15yrs)
- Non speaking: less than 15 intelligible words

- SA: **39%** (Bornman & Alant, 1997 ; Alant, 1999)
- North Dakota: **2,4%** (Burd et al., 1988)
- Washington state rural areas: **6%** (Matas et al, 1985)



First study



Why this high prevalence?

- Very little knowledge about AAC
- Lack of professionals (health and educational sector)
- Few qualified teachers and therapists who specialize in AAC
- Services are inaccessible and / or limited
- Almost no positive role models and advocates
- Extreme poverty
- High rate of illiteracy
 - 1 in every 5 SA (>20yr) didn't receive formal schooling (Nelson Mandela Foundation, 2004)
 - Illiteracy varies: urban **27%** rural areas **50%** (Lecoko et al., 2002)
 - Even if attended formal school, many cannot read above a 4th grade reading level (Davis et al., 1990)
 - This might account for as many as 15 million people (Nelson Mandela Foundation, 2004)



Second study



- Repeated original study – minor modifications to measuring instrument
- 9 Schools for children with intellectual impairment
- Cape Town area
- 18 teachers
- 190 children (ages between 6 – 15yrs)
- Non speaking: less than 30 intelligible words (Harris & Reichle, 2004)
- **31%** (Stehr, 2009)
- **1/3** of sample (53/156) unable to communicate verbally in Orange Farm (peri-urban area outside Johannesburg) (Saloojee et al., 2006)

Why this decrease?

- In 1990 the Centre for AAC was established – at the University of Pretoria
- National support organization for families : Interface
- Focus of the Centre for AAC : 3-tiered approach to promotion of AAC in SA
 - Formal degree training
 - Informal training : community-based engagement
 - Research
- Integrated service-delivery approach (different disciplines involved)
- Family focused community intervention approach



Challenges

- Cultural frameworks
 - not customary to speak to a child until he/she reaches certain age (Marfo, 1993).
 - Accepting information non-interactively, without objections or questioning (Marfo, 1993)
- Multi-lingualism in SA is increasing – therapists speak mostly only 2 languages (Drennan & Swartz, 2004)
- Interpretation: more than translation. Involves knowledge of condition, culture, verbal & non-verbal skills.
- 80% + health related interaction in SA include a 3rd party (Penn, 2007)



Challenges

- Fragmentation in the disability sector
- Population is changing: severity of disability is increasing
- University functioning typically does not fit into the service delivery model → negatively impacts on sustainability



Next steps...



- Mainstreaming disability: Creation of alliances between disabled and non-disabled persons
- Linking different vulnerabilities to poverty – unified “*disability sector plan*”
- Closer local networking, e.g. database of existing therapists
- Utilization of international resources
- Empowerment
- Expanding knowledge of disability



Next steps: Partnerships

Partnership: a relationship involving close cooperation between parties having specified and joint rights and responsibilities

Partnership is a **relationship**.

A relationship is a matter of **heart** and **mind**,
a way of working and not a set of activities, strategies, principles or outcomes.

The focus of the relationship is the child's wellbeing.



In conclusion...Next steps...

We all have

dreams

hopes

great expectations

But only if all of us have great expectations for each other, especially for people with disabilities and their families, can we lead truly meaningful lives.



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