

# WHO: 2<sup>ND</sup> ANNUAL CONFERENCE ON INTELLECTUAL DISABILITY

ZUHY SAYEED, PRESIDENT  
CANADIAN ASSOCIATION  
FOR COMMUNITY LIVING  
November 2007.

# The Atlas: Strengths

- **Global in Scope**
- **Brings international attention to the issues**
- **Comprehensive in range of issues addressed**
- **Progressive Agenda (as in section on 'The way forward')**
- **Rights-Based Framework**

# The Atlas: Concerns

- **While this is an impressive and important document, and a progressive agenda, as families, we need to challenge some of the starting points:**
  - ◆ **How we define intellectual disability**
  - ◆ **Assumptions about the ‘burden’ of intellectual disability to families and society**
  - ◆ **Framing of ‘Prevention’ as the Public Health Issue**
  - ◆ **How family ‘support’ is conceptualized**

# How we define intellectual disability

- **All of the approaches/tools on pg. 100 – AAMR, ICF, DSM, ICD are all based on the notion that intellectual disability is a deficit, a problem**
- **In fact, it is a statistical effect of the normal curve – in this sense it represents unique developmental paths.**
- **As an early childhood educator, and as a mother, I know all children have unique developmental paths.**
- **We need to see disability as a natural part of human diversity. Our understandings of human genetic diversity have to include people with intellectual disabilities.**

# How we define intellectual disability

- **These systems of classification end up reinforcing the idea that there is only one way to develop, one way to communicate, one way to function.**
- **We need to challenge this idea, because it creates societal expectations that harms children, youth and adults.**

**In Fact; Research now shows us that  
The cost of NOT including people with  
Disabilities in EVERY aspect of society  
has a huge COST attached to it...**

**Takes the assumption of 'burden' away  
and challenges us to provide ways and  
opportunities to enable our sons and  
daughters to grow up included; learn and be  
full and productive citizens.**

**That can be and must be done... but it's all  
dependant on how we look at a child or adult  
with an intellectual disability....**

**We need an approach to assessment that recognizes unique needs and developmental paths and challenges, and establishes self-referenced approaches to goals and accomplishments, and to Individual needs.**

# Assumptions about the 'burden' of intellectual disability

- Pg. 72 'Recognize the role of families' states that "Care of children with disabilities by productive adults represents a substantial burden to society." The purpose of family support is seen as enabling adults to "remain as productive members of society."
- Caring for children with intellectual disabilities is not an unproductive role. We have recognized that early childhood development and family supports is essential to maximize a child's potential. This is as true for children without disabilities as it is true for those with disabilities.

# ... the 'burden?'

- **Children with disabilities do not cause a burden. What causes a burden and stress to families is:**
  - ◆ **Lack of needed disability supports (aids, speech and physio, etc.)**
  - ◆ **Lack of inclusive and supportive communities (schools, recreation, etc.)**
  - ◆ **Lack of back-up financial and other supports to families to help with the additional costs of child-rearing that disability brings.**

# Intellectual Disability as a Public Health Issue

- **'The way forward' suggests that a public health strategy for intellectual disability should focus on prevention. If we see intellectual disability as part of natural human diversity, our conclusion would be different.**
  - ◆ **We need public health strategies to build healthy families, healthy and inclusive schools and communities and workplaces that can account for and support the diversity that intellectual disability brings.**
- **This is not to say that we should not have good maternal health strategies – pre and post natal, including programs to educate women about the danger to their health from drinking while pregnant, etc.**

# ... as a Public Health Issue

- **But the rationale for these programs is not because intellectual disability might result. Rather, we want to prevent behaviours that we know are negative for women's health.**
- **A continued focus on prevention of intellectual disability through genetic technologies and changing behaviours only sends one message to society. People with intellectual disabilities are not valued. They are to be prevented. It would be better if they were not born. It is this belief that creates unhealthy, exclusionary communities.**

# ... as a Public Health Issue

- **We need public health strategies that challenge the creation of exclusionary, unhealthy communities, rather than strategies that reinforce them.**
- **We need public health strategies that focus on:**
  - ◆ **Helping children and families maximize developmental potential**
  - ◆ **Helping communities establish the inclusive environments where children, youth and adults can grow, develop, and be assured of belonging, participation and contribution.**

# What does this mean for 'family support'

- **If we start from these different starting points**
  - ◆ **Intellectual disability is not disease or impairment, but rather a natural part of human diversity**
  - ◆ **We need to consider how the full range of social determinants of health need to be shaped to maximize people's developmental potential**
  - ◆ **We need public health strategies that support children and families and communities...**
- **Then we might think about the need for family support in more expansive ways...**

# Towards a Family Support Agenda

- **In Canada, CACL has been working with Seniors Groups, children's groups, and other family and disability organizations. Together we have come up with a 6-point family support agenda that looks at the various dimensions of family support**

# ... A Family Support Agenda; in Collaboration with Inclusion International

- **Ensure Access to Needed Disability-related Supports in the Community**
- **Build Inclusive Communities**
- **Assure Economic Security of Families (current and future economic security – especially for women who stay out of the paid labour market)**
- **Secured Futures (help families plan and save for the future)**
- **Promote Family Networking, Leadership and Policy Engagement**

# Conclusion – As we go forward

- **Recognize intellectual disability as diversity**
- **Stop equating intellectual disability with ill-health**
- **Ensure inclusion of intellectual disability in other efforts to advance healthy child development, education and other social determinants of health**
- **Stop making intellectual disability a rationale for prevention efforts**
- **Don't equate families' efforts to nurture and raise children with intellectual disabilities as 'unproductive'**

# The Challenge to WHO, The UN and to us *all* is...

- **Create a proactive Family Agenda – with a broader understanding of supports needed in collaboration with families who have family members with intellectual disabilities, individuals with intellectual disabilities- or ‘self advocates’ as our people prefer to be known as, communities and governments .**

**We are at a critical threshold..  
An exciting time; but**

**There is NO time to lose....  
Our sons and daughters are  
Depending on us...**



SON LAS MARCAS  
CON LA QUE PUEDES  
PARTICIPAR





4/22/2008