

1 + 1 is 11!

**Early Childhood Development
and Disability Rights**

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Changing Paradigms of Disability

X Problem within an Individual

√ Barriers in social systems make individual differences problematic

√ √ Constraints a person encounters in the “substantive freedoms he or she enjoys to lead the kind of life he or she has reason to value” (Capability approach, Sen, 1999).

Defining Disability

- The Convention on the Rights of Persons with Disabilities does *not* explicitly define disability;
 - ‘Disability is an **evolving** concept, and that disability results from the **interaction** between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others’
- International Classification of Functioning
 - Disabilities are difficulties in functioning along a general **continuum of human experience** based on levels of activity and participation, determined by individual, societal and institutional factors .

Convention on the Rights of Persons with Disabilities (CRPD)

To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

- No new Rights
- Persons with disabilities as holders of human rights
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Policy instrument which is cross-disability and cross-sectoral

Participation and Inclusion

- Full and effective participation and inclusion in society is recognized in the Convention as:
 - A general principle (article 3)
 - A general obligation (article 4)
 - A right (articles 29 and 30)
 - Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

With unprecedented participation of disabled people themselves in the drafting process, the CRPD is instructive as much in the process of its development, as in the specific content of its provisions (Lawson, 2009)

Non-discrimination

- Fundamental principle of international human rights law
 - Equality of opportunity
 - Accessibility
 - Equality between men and women
 - Appropriate provision, adaptations and accommodations

It is a ‘perversion’ of the true mission of social policy that “the default setting for considering disability has not generally been human rights...(but)...a mixture of charity, paternalism...(that serves to)...maintain people rather than to forge pathways into the mainstream” (Quinn, 2009, p. 247).

Inherent dignity

- Universal recognition to the dignity of persons with disabilities
 - ‘Subjects with rights’ not ‘objects of charity or protection’
 - Individual autonomy
 - freedom to make one’s own choices
 - ‘capable’ of claiming rights, considering choices, making decisions

The critical value of the CRPD as a human rights instrument is that it makes the ‘human being behind the disability visible, extending the benefits of the rule of law to all’ (Quinn, 2009, p. 248).

Rights in the Convention

- Equality before the law without discrimination (article 5)
- Right to life, liberty and security of the person (articles 10 & 14)
- **Equal recognition before the law and legal capacity (article 12)**
- Freedom from torture (article 15)
- Freedom from exploitation, violence and abuse (article 16)
- Right to respect physical and mental integrity (article 17)
- Freedom of movement and nationality (article 18)
- Right to live in the community (article 19)
- Freedom of expression and opinion (article 21)
- Respect for privacy (article 22)
- Respect for home and the family (article 23)
- Right to education (article 24)
- Right to health (article 25)
- Right to work (article 27)
- Right to adequate standard of living (article 28)
- **Right to participate in political and public life (article 29)**
- Right to participation in cultural life (article 30)

Reality of Persons with Disabilities

- Neglect
 - Immunization and well-child care (Ayora et al 2007)
 - Nutrition (Socrates et al 2000; Tompsett et al 1999)
 - 4 times less likely to survive (UN 2006)
- Lack of developmental and educational support
 - 1/3 of children out of school (Unicef, 2006)
 - Excluded from school data (Lansdown, 2009)
 - Institutionalization, Isolation (Unicef, 2005)
- Poverty
 - 20% of world's poorest (UN, 2006)
 - 3% literate; 80% unemployed (UN, 2006)
- Violence and abuse
 - UN Sec. Gen. Study (Unicef, 2005)
- Data and Definitions (Simeonsson, 2003)
 - Birth Registration
 - 0.4 – 35%!!!

Key Issues from Early Years Perspective

- Lack of timely attention to risks perpetuates disabilities
- Disabilities lie in barriers; Early identification and intervention increases the capabilities to challenge them
- Appropriate, comprehensive, early intervention increases chances that children with disabilities can successfully Participate in mainstream settings
- Later remediation is difficult, expensive and with poorer results

Preventable Risk Factors: Nutrition & Health

- Iodine Deficiency
- Iron Deficiency
- Nutritional Stunting (chronic under-nutrition)
- Intrauterine Growth Restriction (low birth weight)
- Infectious diseases
 - Postnatal brain infection
 - Cerebral malaria
 - HIV & AIDS
 - Diarrhea

Preventable Risk Factors: Psychosocial

- Lack of responsive, stimulating care
 - 10-33% parents engage in cognitively stimulating activities
 - 10-41% provide cognitively stimulating materials
- Maternal depression
 - High incidence across cultures and socio-economic groups
 - Cumulative, multilevel impact
- Barriers to early attachment
 - Difficulties in breast feeding
 - Institutional practices; social stigma
- Institutionalization
 - More than 2 million children in non-familial residential care (Walker et al 2011)

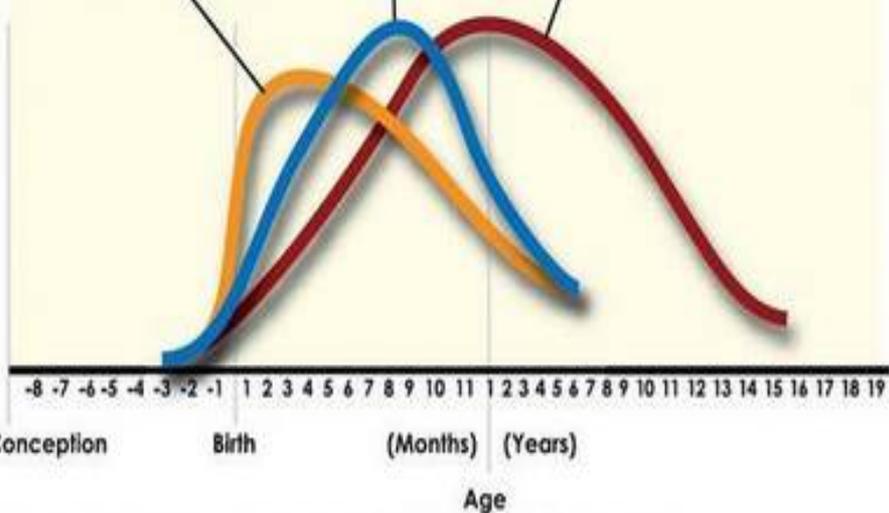
Increased Risk of disabilities

- Outcomes
 - Associated with low IQ scores, cognitive and language ability; delayed brain maturation, poor neurophysiologic functioning;
- Behavior
 - Lower levels of play, apathy, insecure attachment, social difficulties;
- Significant Scale
 - More than 200 million children fail to reach their developmental potential (Grantham McGregor, et al 2007)
 - Risk factors affect 20-25% children in developing countries (Walker et al 2007)
 - 23% of 2 to 9 year olds at risk of disabilities (Walker et al. 2011)
 - Risk increases with severity of stunting (Unicef, 2008)
- Cumulative, multilevel impact of risk factors
 - 80% of persons with disabilities are in developing countries
 - 1/3rd of children out of school are children with disabilities

Reducing Risks

Human Brain Development Synapse Formation Dependent on Early Experiences

Sensory Pathways (Vision, Hearing) Language Higher Cognitive Function



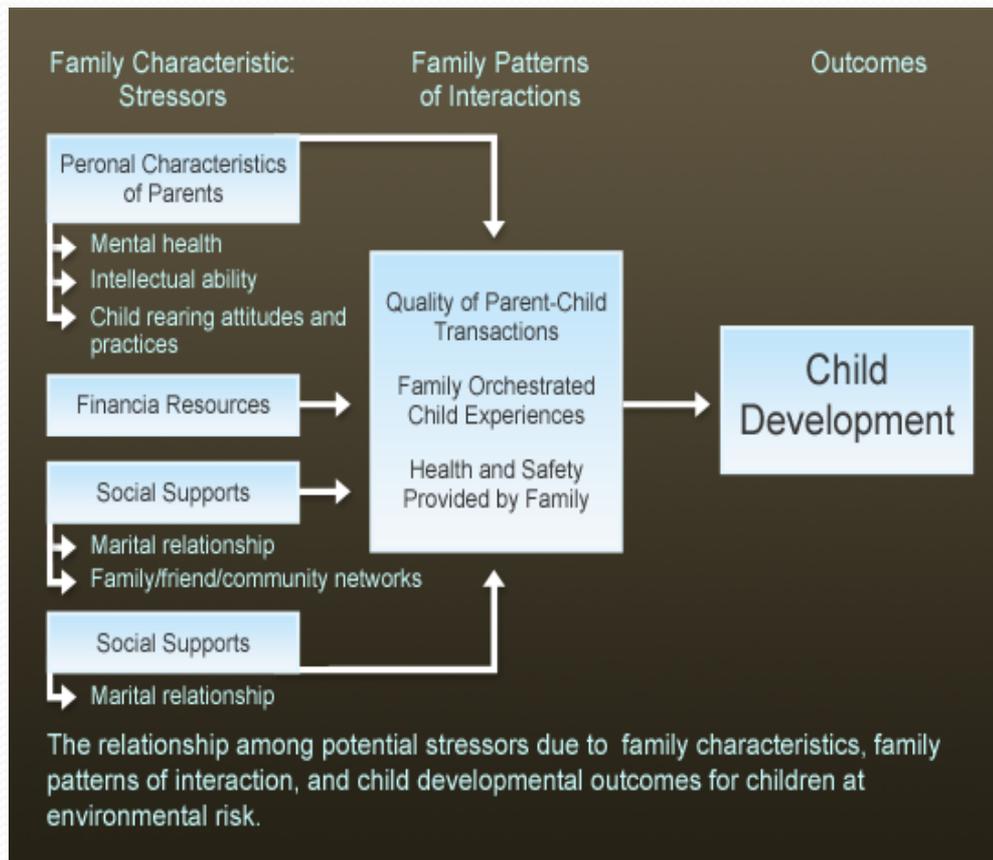
Source: Nelson, C. A., in *Neurons to Neighborhoods* (2000). Shonkoff, J. & Phillips, D. (Eds.)

- ‘Catch-up’ only if nutritional status restored before 24 months
- Maternal Iodine level critical
- Iron therapy within six months to improve IQ scores
- Responsive, stimulating care
- Adoption of children in institutional care before 2 years
- Maternal Education is a strong protective factor

Interventions to address disabilities

- Sensitive periods of brain development
 - Early Identification and intervention for sensory impairment (6 months) (Yoshinaga-Itano et al 1998)
 - Cochlear implants before 24 months achieves language similar to hearing peers (Yoshinaga-Itano et al 2010);
- Appropriate, comprehensive early interventions provide equitable opportunities for optimal development
 - Universal, selected, indicated levels of intervention (Simeonsson, 2003)
 - Motor play differences between perceptually impaired infants and their peers minimized
- Development is a cumulative ‘bottom-up’ process
 - Large Scale evaluation of ECI highlights immediate benefits on cognitive measures with long-term social gains of school completion and economic independence (Karloly et al 1998)

Enabling Families, Enabling Children



- Family is primary access point for services;
- Relationships provide context for child development; attachment and bonding
- Stressors and supports determine outcomes by impacting quality of parent-child transactions

Facilitating Inclusion in Mainstream Settings

- One in three infants and toddlers who receive ECI services do not present later with a disability or require special education in preschool (Hebbeler et al 2007).
- High quality preschool settings that combine care and education enable children with a probability of developing special needs to move out of the 'at risk' status for cognitive measures (Taggart et al, 2006, p. 44).
- Early inclusion creates a momentum to continue maximum participation in inclusive settings over time (Guralnick et al, 2008).
- In Mumbai early intervention by trained teachers with specialist support enable children with disabilities to transition into mainstream primary school (Alur, 2006).

The Early Years Advantage

- **Reducing Disparities**

- Preventable risk factors compromise developmental potential and perpetuate inequalities
- Increased risk of disabilities

- **Enhancing Capabilities**

- Early Childhood Interventions (ECI) reduce the impact of impairments and established disabilities

- **Embracing Diversity**

- Interventions to enhance successful inclusion of children with disabilities in mainstream settings

Mainstreaming Disability

- Article 4.1.(c): ‘States Parties undertake to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programs’
- Mainstreaming of disability issues according to the Convention in:
 - Work of existing human rights treaty bodies
 - Human Rights Council
 - Millennium Development Goals (MDG) - national and international strategies
 - Common Country Assessment (CCA)/United Nations Development Assistance Framework (UNDAF)
 - Poverty Reduction Strategy Papers (PRSP)
 - The development activities of international donors and NGOs
 - Census data
 - Sectoral and cross-sectoral policies
 - Programmes and policies for women (article 6) and children (article 7)
 - and others...

Progressive Realisation

- Civil / Political vs Economic / social rights (Kauffman, 2004; Neier, 2006)
- CRPD is *Both* a development and a human rights instrument
- Positions economic, social and cultural rights as necessary components of anti-discrimination provision to claim civil and political space and make civil and political rights meaningful.
- Strengthens state accountability to use ‘progressive realization’ to demonstrate decisive action rather than inactivity on the plea of limited resources

‘Positive acts of social solidarity are often required to underpin freedom...’ and economic, social and cultural rights are required to ‘...set the terms of access, entry and participation in the mainstream’ (Quinn, 2009, page 250).

Universal design and Reasonable Accommodations

- CRPD not only guarantees that persons with disabilities are not excluded, but also ensures they have the required support to enhance their capabilities and overcome barriers that deny them access to such opportunities.
 - Universal design proactively takes potential diversity into account so that it is suitable for all people to the greatest extent possible.
 - Reasonable accommodations refer to the required individual modifications and adjustments to “...ensure that persons with disabilities can enjoy their rights on an equal basis with others” (CRPD, article 2).
- CRPD considers the denial of reasonable accommodations as a legitimate manifestation of discrimination.

Conclusion

- Persons with disabilities are capable, equal and active stakeholders in society; all young children are goal-directed, interactive learners whose emerging social and cognitive competencies must be nurtured through responsive, stimulating care and appropriate learning opportunities;
- Aspirations of the CRPD would remain notional unless profound ways to cherish human differences and foster capabilities of every human being were adopted;
- The early years offer the advantage of preemptive action to minimize risks and disabling conditions as well as timely developmental support to pursue an open ended, generative agenda of aspirations.
- Under a rights based agenda, the early years mark the first milestones on an exciting journey that encompasses the full range of human capabilities and endeavors, laying the foundations of an inclusive society.