DISABILITIES AND HUMAN RIGHTS

Intensive Course on Health and Human Rights
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I’d give half of my life to someone who makes a crying child smile.

Tawifiq Zayad
Background Information

According to recent estimates about 600 million people in the world experience disabilities of various types and degrees (or approximately 10% of the world population). If families of people who experience disabilities are taken into account, at least 25% of people are directly affected.
Disability in Palestine

- Currently, 50.2% of the Palestinian population are children under the age of 18 of whom “2.3% with the narrow definition of disability and 7% with the wider definition, are children with various disabilities, “PCBS report 2007”

- A large proportion of childhood physical disabilities are caused by preventable accidents such as falls and burns
• Developmental disabilities. Interventions most effective if parents and health workers receive the necessary training and support to prevent, identify and treat problems early on.

• To date, there are very few centers that deal with the needs of these children
Palestinian Context Unique Factors

• No state infrastructure yet, since the country is still under occupation!
• During the first Intifada, thousands of Palestinians became disabled as a result of their injuries, and the attitude towards them changed from ridicule to being viewed as heroes.
• Resilience
Palestinian Context Unique Factors

- Concept of Human Rights seems to be widely known, as well as Education for All.
- Solidarity and support within the community.
Key problems attributable to disability service provision in Palestine

- Absence of comprehensive National program for rehabilitation
- Barriers to access services including the separation Wall and checkpoints
- Internal political division
- Lack of sufficient number of qualified professionals and paraprofessionals in the field of disability and rehabilitation
Key problems attributable to disability service provision in Palestine

• Limited reliable statistics in Palestine,
• Few specialized persons in clinical psychology, counseling, physical therapy, speech therapy, occupational therapy, music therapy and special education.
• Professional training opportunities in this field are limited in Palestine
• Some successful initiatives but these are generally small and replication is inconsistent
Palestinian Happy Child Centre

“PHCC”

- The Palestine Happy Child Center (PHCC): established in 1994 as a grassroots community-based non-governmental organization (NGO)

- **Mission: to promote welfare and wellbeing of Palestinian children**
Philosophy and Approach

- Health and Education Nexus: PHCC believes strongly that every child has the right to protection, good education, healthcare and well-being.

- The unsettled political, social, emotional, economic and environmental conditions in Palestine have deprived many children, especially those with special needs, of these rights.
Philosophy and Approach

Dignity

• PHCC aims to help children with special needs to fulfil their potential as fully participating members of society.

• PHCC’s activities encourage individual and collective initiatives aimed at developing a positive outlook and discouraging dependence.
Philosophy and Approach

- The centre aims to reinforce children’s natural resilience and confidence and to prepare them to function mentally and physically as capable members of Palestinian society.
- Priority is given to encouraging parental involvement and sibling participation in programmes, which is viewed as essential for children’s positive growth and development.
Scope of Work

Phcc

Child

School & Community

Family & Parents
PHCC Chart

90 Diagnostic, treatment & rehabilitation sessions weekly
# Activities & Services

<table>
<thead>
<tr>
<th>Child Development Clinic</th>
<th>Epilepsy Clinic &amp; EEG</th>
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</thead>
<tbody>
<tr>
<td>&quot;Diagnostic, treatment &amp; rehabilitation&quot;</td>
<td></td>
</tr>
<tr>
<td>Psycho- Therapy, Counseling &amp; Behavioral Therapy</td>
<td>Occupational Therapy</td>
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<tr>
<td>Behavioral Change &amp; Communication &quot;BCC&quot;</td>
<td>Sand &amp; Music Therapy</td>
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<tr>
<td>Recreational &amp; Ventilation Activities</td>
<td>Physical Therapy</td>
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<tr>
<td>Parents Support Groups</td>
<td>Special Education</td>
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<tr>
<td>Fun Days, Home Visits &amp; School Visits</td>
<td>On – the job- Training</td>
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<tr>
<td></td>
<td>Meetings, Workshops &amp; Conferences</td>
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Who do we Serve?

Since its establishment, PHCC has provided services to 38,000 children throughout the West Bank & Jerusalem.

- Villages: 55%
- Cities: 29%
- Refugee Camps: 16%
- 22% from Jerusalem

Since its establishment, PHCC has provided services to 38,000 children throughout the West Bank & Jerusalem.
Ahmad

• Ahmad’s parents first learned about the PHCC from a mother of a child with special needs who was served at the center. Ahmad came to us when he was only three years and six months old. A special tailored-made plan was prepared immediately to meet Ahmad’s needs. After a detailed evaluation and diagnosis, Ahmad was diagnosed as a child with Autism Spectrum Disorder.
Ahmad

- Ahmad received 1,482 hours of therapy and wasted 1,872 hours on the road and checkpoints in 6.5 years!! Ahmad is currently integrated into a regular school in his village; he’s now in the 5th grade, doing well, a happy child and has friends.
Integration of Children in Kindergartens and Schools 2000 - 2013
Factors Contributing to Success of PHCC Model

PHCC model has received international recognition as an effective and sustainable approach for serving children with special needs in Palestine and beyond is guided by:

- Grassroots led initiative
- Community involvement
- Cultural sensitivity
International Cooperation

**PHCC Volunteer Consultants**

- Royal College of Pediatrics and Child Health - UK
- University of North Carolina “UNC”
- John Hopkins School of Public Health
- American University of Beirut – Lebanon
- Al Ein University – Arab Emirates
- Shaffalah Centre for Children with Special Needs - Qatar
- Ghent University, Genetic Department - Belgium.
- McGill University - Canada
International Cooperation

Convention on the Rights of Persons with Disabilities (CRPD)

• Article 32 International Cooperation

• 1(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices
International Cooperation

PHCC and FXB Center Response

• Interdisciplinary initiative PHCC and FXB Center for Health and Human Rights, Harvard School of Public Health.
• Cross cultural study on societal attitudes to individuals with developmental and intellectual disabilities with a focus on autism.
Blame and Guilt Paradigm

• Interviews with mothers in Palestine on cause of autism
• Review of literature in USA on influence of cultural beliefs on parental response to autism
• Preliminary findings suggest convergence points across cultures
• Autism caused by ‘evil eye, magic’ in Palestine
• Autism caused by ‘refrigerator mothers’ (Bettelheim)
• Parental guilt – cause and response
Why Does this Matter?

- Limited research available to date suggests that cultural beliefs influence parents response to autism and developmental disabilities
- Impacts: access to appropriate interventions, stigmatization, and ultimately – outcome
- Children with developmental disabilities become adults with disabilities
- USA – high service disengagement post special education entitlement
Conclusions and Recommendations

• Intellectual disability and autism is generally a lifelong disability hence the urgent need to adopt a lifespan approach to disability within the community.

• Research focusing on adolescents and young adults with disabilities an imperative both locally and internationally
Conclusions and Recommendations

• Strengthen cooperation regionally and internationally. We can learn much from each other.

• Increase international networking highlighting PHCC model and other related models to share best practices.
Finale!

- Dr Jumana Odeh received the “2008 Nobel Prize for Children”, and last year - The Humanitarian Hero of the Year Award for her work at the PHCC
Hope

Beautiful Palestine