

**Pre-Congress Workshop 24-25 Nov
2012, Agra (India)**

CBR & Intellectual Disabilities: Medical Aspects

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Barriers to Access Health Services

- Learning & understanding difficulties (failure to realise significance of symptoms and/or importance of healthy lifestyle.)
- Difficulty in communicating discomfort or pain
- Poor carers and professional awareness (misinterpret changes & assume manifestation of disabilities)
- Discrimination (health needs not important)

Barriers to Access Health Services

- Physical and information barriers (unsuitable buildings, signs, information about appointments & admissions, treatments..etc
- Social factors (services insensitive to the social, ethnic, cultural and economic backgrounds
- economic, attitudinal, informational and environmental barriers

Special Health Care Needs

- In addition to the ordinary ones
- Greater health care needs than general population
- Higher rates of mental health problems, epilepsy, sensory impairments ..etc
- Certain conditions carry particular health risks



Special health risks

- People with Down's Syndrome are at greater risk of congenital heart disease, visual and hearing impairments, thyroid disorders, leukaemia and pre-senile dementia (increased in general – WHO initiative)



Prevention

- Access to preventative health information and services.
- Reduce the risk of developing health conditions through living healthy lifestyles.
- Encourage immunisation.
- Ensure proper nutrition. This can include education on low cost locally available foods that are rich in iron and vitamins, training on how to assist children who have feeding difficulties, and promoting breast feeding.



Prevention

- Facilitate access to maternal and child health care.
- Help to prevent injuries in the home, community, workplace and schools.
- Help to prevent secondary conditions.



Early Detection

- Detection of intellectual disabilities should be as early as possible.
- Mostly detected by parents if awareness exist
- If not during the immunization process
- If not during ECD or education programs
- Proper diagnosis very important
- Comprehensive or simple assessment according to local capacities should follow.





Breaking the News (good practices)

- Medical staff inform both parents about the disability of their child together in a session for at least an hour
- Session need to be well prepared and structured to inform the parents in a sensitive way, provide them with full information about the case
- Refer parents to parents support groups or local CBR programs
- Provide parents with leaflets and brochures or simple illustration on available services and full explanation about the case of their child.



Breaking the News (bad practices)

- Medical staff are reluctant to advise parents that a child has some degree of impairment and parents are left to discover this by them selves. This action delays the parent's acceptance of the situation which is vital for the family to effectively support the child for the future.
- Medical staff promote the belief that impairments are curable and therefore encourage the families to proceed with lengthy costly treatments that in the end are shown ineffective

Early Intervention

- Crucial.. results in significant improvements
- NOT confined to medical staffs and NOT through a medical approach
- Individualised intervention plans following developmental milestones of various developmental domains (cognitive, growth motor, fine motor, communication & language, self- help, eye hand coordination...etc



Early Intervention

- Developmental checklists and simple guided activities to promote child development proved to be among the best tools in CBR for children with intellectual disabilities
- Intervention mainly provided through family members with external support and specialised guidance
- Preferably home-based at early ages



Early Intervention

- Require mother support groups + mother to mother + siblings involvement (hopefully fathers)
- Referrals to professionals and specialists when needed.
- Drugs & medicines ???
- Different specialists versus one generic (CBR workers) ???
- Pillars of success: Love, play & stimulation (later on behaviour management)



Mental Health

- Evidences reveal higher rate of mental health needs among persons with intellectual disabilities compared to the general population
- Aspect considerably neglected as most likely mental health problems underreported (due to lack of understanding and communications)
- Challenging behaviour often results of carer stress and reactions that reinforce that abnormal behaviour pattern over time.
- Evidences reveal higher prevalence of dementia and at earlier ages (specially for people with Down's Syndrome)

Requirements for meeting the health care needs of persons with Intellectual Disabilities

- Equal access to all health services
- Disability awareness integrated in staff training
- Access to specialised health services through referral systems
- Community-health workers (CBR workers) linked to PHC centres
- Individualised intervention plans
- Partnerships, coordination and collaboration between various service providers



Requirements for meeting the health care needs of persons with Intellectual Disabilities

- Improving the understanding and communication of symptoms of persons with intellectual disabilities to clinicians (simple communication boards describing pain)
- Training families and carers on key symptoms to look for that could be overlooked (sudden loss of appetite, weight gain or loss, dramatic changes in behaviour..etc)
- Building positive attitudes among health practitioners, particularly on the right of persons with intellectual disabilities and to be free from pain in cases of debilitating conditions.
- CBR programs need to address the increasing older population



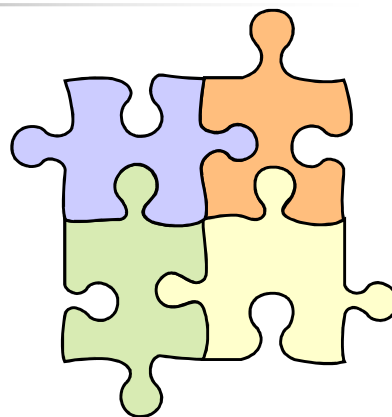
Group Discussions Questions

- Recommendations to CBR implementers
(What could you do to improve the health component at your CBR program in relation to intellectual disabilities?)
- Recommendations to duty bearers
(what would you advocate for at national and local levels to improve health provision to persons with intellectual disabilities)
- Recommendations to specialists and professionals
(what would be their roles in the context of CBR)



Conclusion

- To be developed after the groups discussions.....



Thank you

Photos from Caritas-Egypt SETI Center

