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# **Challenges in identifying and measuring disability among children**

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# What is the purpose of collecting disability data on children?

- Health monitoring of the total population
- Service provision and resource allocation
  - Unmet need
  - Services for children less well-developed than for adults
  - 16-17 year olds least well served
- Equalisation of opportunity
  - Schooling
  - Employment

# Extra significance of collecting disability data on children?

- Health advantages
  - Early intervention
- Economic advantages
  - Getting children to school and work
- Improve social cohesion
  - Removing negative attitudes primarily social exclusion and discrimination
- Quality of life improvements
  - Children know problems are recognised

# UN Convention on the rights of people with disabilities (2008)

- **Article 7: Children with Disabilities**
  - Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
- **Article 31 - Statistics and data collection**
  - Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.

# Difficulties in estimating the number of disabled children in the world

- UN General Assembly Special Session on Children (2001) highlighted the difficulty in gathering accurate data on the incidence of disability among children and referred to the fact that..
  - countries have used different definitions of both impairment and disability;
  - the quality of statistical data varies widely;
  - too little research has been done on the lives of disabled children.

# The European Action Plan on disability (2006/7)

- Definitions and criteria for disability vary according to policy objectives, legislation and administrative standards.
- Population surveys provide subjective data, affected by differing cultural perceptions in individual Member States.
- Data focus on the working age population, and exclude children and people living in institutions. (Commission of the European Communities; 2005).

# Can disabled children be counted? UK review (Read, 2007)

- Prevalence rates vary from 5%-18% depending on definition or measure.
- Different sub-classifications limit comparisons between surveys.
- No survey designed to cover the whole population of disabled children.
- Data sources limited by age, geography, size of subgroups and place of residence.
- Very few data sources collect data on social and demographic circumstances.
- Few take account of how age and development of children may shape functioning and ability

# Challenges in collecting disability statistics on children

- Geopolitical and administrative issues
- Conceptual issues
  - What does disability mean for a child?
- Operational issues
  - How does one operationalise the concept?
- Logistical issues
  - How does one obtain data about children?
- Ethical issues



# Who is responsible for national policies on disabled children?

- Government ministries which have responsibility for disability tend to be primarily concerned with employment, pensions, or social affairs.
- Their main focus is on equalisation of opportunity in the labour market, having a comprehensive and coherent system of disability benefits or promoting equitable access to health, social, educational and vocational services.
- Child disability statistics do not fit easily within one government ministry and cut across health, education, social affairs.

# Defining disability for children

- **Applicability**
  - Questions addressed to adults are inappropriate or different in kind for children (e.g. falling over, reaching and stretching, behavioural problems).
  - Questions addressed to children are sometimes inappropriate for adults (e.g. crawling, running, communicating).
  - Variations by culture.
  - When should developmental delay be regarded as disability.

# Developmental delay

- What is “normal” for a child’s age or sex?
  - Children are by their very nature in the process of development. Different activities are regarded as the norm for particular age groups.
  - When should children be expected to walk or to read or to communicate complex ideas? Should any delay from the norm be regarded as a disability? General delay versus specific delay.
  - Variations by culture when children are expected to wash, dress, feed or toilet themselves.
  - Do parents know what these norms are; delays may reflect poor parenting skills?

# Defining disability for children

- Measuring capacity and/or performance
  - In some activity domains, seeing and hearing, walking or climbing, parental responses should be valid and reliable. However, questions relating to the child's behaviour (particularly for older children) may be less reliable.
  - Parents may not know about their children's activities and behaviour at school.
  - With or without disability equipment or assistance.
  - Does one look at what child can do, does do, wants to do or is allowed to do?

# Defining disability for children

- **Influence of the family**
  - What the child can do, is allowed to do or actually does is dependent on the child's family, particularly for their emotional and psychological development.
  - Attitudes of parents towards diet, exercise, learning and life-style behaviours are all relevant.
  - Functioning of the child can not be seen in isolation but in the context of the family system. The consequence of this interaction and inter-dependence is that a survey about disabled children requires as much if not more information about the family – structure, behaviour and attitudes.

# Defining disability for children

- Influence of the educational environment
  - Schools as well as families have a role in the social participation and the social integration of children.
  - The school has a big influence on the child's development.
  - Does information need to be collected from teachers? If so, which teacher?

# Defining disability for children

- Influence of the health, social and welfare environment
  - Apart from family and school, the need for, provision, and use of health, social and welfare services are key – who can help the child, in what capacity and at what time?
  - One can argue that disability can be measured by contact with services.
  - Dangerous because: misses out unmet need, may reflect of severity and availability of local services.

# What life situations should be covered? (McConachie et al., 2006)

- Participation essential for survival
  - Eating, sleeping, basic hygiene, sleeping
- Participation in relation to child development
  - Social interaction, play and exploration, mobility
- Discretionary participation
  - What child wants to do given available resources
- Educational participation





# ICF for Children and Youth (ICF-CY)

- Takes account of all the influences.
- Clinical utility of the ICF-CY has been tested.
- Participants with access to clinical populations are completing questionnaires for children in four age groups:
  - 0-2; 3-6; 7-12; 13-18
- These can be used as a framework for developing instruments for epidemiological research.

# How are children dealt with in censuses and surveys?

- Censuses

- which include all children (from birth)
- which include children from a certain age.

- Surveys

- which ask questions about all household members including children
- which ask questions about all household members including children from a certain age.

- Separate surveys of children

- Choice of procedure depends on policy priorities, statistical infrastructure; resources available.

# Main methodological issues in surveys of child disability

- Sample design and sampling procedures
- Research design: one or two phase studies
- Interviewing procedures
- Questionnaire design
- Analytical strategies



# Sampling children for national surveys

- Sampling school records
- Screening the population (enumeration or by mail)
- Using centralised records - health or benefits
- Piggy-backing on other surveys

# Survey design: to screen or not to screen

- Advantages of one phase designs
  - Distribution of dimensional measures
  - Facilitates risk and protective factor analysis
  - Facilitates future longitudinal studies
  - Increases response rate
  - Reduces respondent burden
  - Less biased and greater precision of statistics
- Disadvantages of one phase design
  - Cost



# Single versus multiple respondents

- Advantages of multiple respondents
  - Different information from different sources
  - Better predictor of disability
  - Enhances specificity of prevalence estimates
- Combining data from multiple respondents
  - Three sources (parent, child, teacher)
  - Qualitative and quantitative data



# Ethical issues in surveying children

- Participation of children
  - capability
  - confidentiality
  - privacy
- Severely disabled children
  - appropriateness of questions
  - distress to parents
- Child abuse
- Suicidal thoughts

# CASP: Child and Adolescent Survey of Participation (Bedell, 2004)

- Paying attention, concentrating
- Remembering people, places
- Problem solving or judgement
- Learning new things
- Controlling behaviour or mood
- Motivation (lacking interest)
- Depression or anxiety
- Speech
- Vision
- Hearing
- Movement (balance and coordination)
- Strength or activity level
- Reacting to sensation or stimulus
- Physical symptoms (headaches, dizziness, pain)





# CASP: Child and Adolescent Survey of Participation (Bedell, 2004)

## Assessment of Activity and Participation

- Using books and computers
- Doing family chores
- Moving around the neighbourhood
- Doing self care activities
- Household chores (washing dishes)
- Social, play or leisure activity with friends
- Educational activities in the classroom
- Structured community events



# CASP: Child and Adolescent Survey of Participation (Bedell, 2004)

- **Age expected:** your child participates in the activities the same as or more than other children his or her age (*With or without assistive devices or equipment*)
- **Somewhat limited:** your child participates in the activities somewhat less than other children his or her age (*May also need occasional supervision or assistance*)
- **Very limited:** your child participates in the activities much less than other children his or her age (*May also need a lot of supervision or assistance*)
- **Unable:** your child does not participate in the activities, although other children his or her age do
- **Not applicable:** other children your child's age would not be expected to participate in the activities.



# LIFE-H: Assessment of Life Habits

## (Fourgeyrollas et al., 1998)

### Area

- Nutrition
- Fitness
- Personal care
- Communication
- Housing
- Mobility
- Responsibilities
- Interpersonal relations
- Community life
- Education
- Work
- Recreation

### Example

- Setting the table
- Physical activities
- Using the toilet elsewhere
- Writing, telephone, computer
- Making the bed, light cleaning
- Riding a bicycle
- Managing pocket money
- Maintaining social ties
- Scouts, religious groups
- Taking part in school activities
- Babysitting, paper delivery
- Sports events



# LIFE-H: Assessment of Life Habits (Fourgeyrollas et al., 1998)

## Level of accomplishment

- No difficulty
- With difficulty
- Accomplished by a proxy
- Not accomplished
- Not applicable

## Description

- No discomfort or effort (even if adaptation, assistive device or human assistance required)
- With discomfort or effort (even if adaptation, assistive device or human assistance required)
- Essential activities (washing, dressing, moving around accomplished by other person)
- Non-essential activity (going to cinema) can not be done by some one else
- Never done and no need to do



# The Activities Scale for Kids (Young et al., 2000)

- I put toothpaste on my toothbrush and brushed my teeth.
- I fastened my clothes by myself.
- I had a snack myself.
- I did my handwriting by myself.
- I walked in crowded areas.
- I carried a drink or food to the table without spilling it.
- I stood still for ten minutes without resting (in a queue at bus stop or shop).
- I got through heavy doors by myself.



# The Activities Scale for Kids (Young et al., 2000)

- I played team sports with others in my class
- I did climbing activities (trees, rocks, over a fence)
- I played some sports by myself or with a few friends (kicking a ball around).
- I played sport with local competitive club (football, hockey, netball, basketball).
- I keep my balance while playing rough games.
- I did activities I usually enjoy for a long time without getting tired out (swimming, jogging, tennis).
- I worked carefully with my hands (lego, models, sewing).



# The Activities Scale for Kids (Young et al., 2000)

- All of the time
- Most of the time
- Sometimes
- Once in a while
- None of the time
- I did it every time I needed to.
- I did it almost all of the time I needed to, once a while I didn't do it.
- I did it about half of the time I needed to, about half of the time I didn't do it.
- I did it once last week when I needed to but most of the time I didn't do it.
- I did not need to do it at all when I needed to.



# Conclusion

- National surveys on child disability can be carried out successfully.
- All the problems are recognised; the solutions are known but widespread.
- Need a synthesis of all the work done so far to arrive at a feasible strategy.
- The ICF-CY is the overarching topology to bring it all together in a meaningful way.

