Vincent Campbell:
Measurement of Disability in Special Populations – People with Limited Cognitive Functioning
Measurement of Disability in Special Populations – People with Limited Cognitive Functioning

Vincent A. Campbell, Ph.D.
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
vbc6@cdc.gov
ICD-10 Mental Disorder Categories

- F00-F09 Organic, including symptomatic, mental disorders
- F10-F19 Mental and behavioural disorders due to psychoactive substance abuse
- F20-F29 Schizophrenia, schizotypal and delusional disorders
- F30-F39 Mood (affective) disorders
- F40-F48 Neurotic, stress-related and somatoform disorders
- F50-F59 Behavioural syndromes associated with physiological disturbances and physical factors
- F60-F69 Disorders of adult personality and behaviour
- F70-F79 Mental retardation
- F80-F89 Disorders of psychological development
- F90-F98 Behavioural emotional disorders with onset usually occurring in childhood or adolescence
ICF/DH Conceptual Model

Disorder/Disease
ICD-9/10

Impairment of Structure or Function

Activity Limitation

Participation Restriction

Environmental Factors

Personal Factors
ICFDH Impairments - Cognition

Functions
- Global Mental Functions
  - Orientation
  - Intellectual
- Specific Mental Functions
  - Attention
  - Memory
  - Thought
  - Higher level cognitive
  - Specific mental functions of language
  - Calculation functions
  - others

Structures
- Structure of the nervous system
  - Structure of the brain
ICF DH Activity Limitations - Cognition

<table>
<thead>
<tr>
<th>Cognitive activities affected</th>
<th>Noncognitive activities affected incidentally</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Learning &amp; applying knowledge</td>
<td>• General tasks &amp; demands</td>
</tr>
<tr>
<td>– Basic learning</td>
<td>• Communication</td>
</tr>
<tr>
<td>– Rehearsing</td>
<td>• Self care</td>
</tr>
<tr>
<td>– Learning to read, write, calculate</td>
<td>• Domestic life</td>
</tr>
<tr>
<td>– Acquiring skills</td>
<td></td>
</tr>
<tr>
<td>– Basic learning, NOS</td>
<td></td>
</tr>
</tbody>
</table>
Prevalence - Conditions

Condition:

- Mental Retardation 0.8%\(^1, {}^2\)
- Learning disability 1.3%\(^1\)
- Traumatic Brain Injury \(~2.0\%\)
- Age-related dementia 0.8%\(^1\) (2.8 – 28%)
- Stroke \(~1.4\%\)
- Stroke, dementia, TBI (SC), period prevalence, 1991-2000 6.3%

Activity:

- BRFSS, 12 sites, 1998 (L/R/C) 6.6%

\(^1\) SIPP, 1999 \quad \(^2\) Larson, et al., 2000 \quad \(^3\) NHIS-D1, prevalence of MR
Mental Retardation

• Socially determined and psychometrically documented
  – Presence of medical condition
  – Comparison with children of similar age
  – School performance

• Multitude of causes
  – Genetic causes
  – Prenatal factors and events
  – Perinatal factors and events
  – Postnatal factors and events
  – Normal distribution
Distribution of Intelligence (IQ)

Adapted from The Psychological Corporation, Test service bulletin, 48 (1955).
Life Course Prevalence of Mental Retardation - Reported in Kiely, 1988
Administrative Prevalence of Mental Retardation
Southern State, USA, 1992 & 1993

- Mild
- Mod/Sev/Pro
- Total
Percentage of estimated resident population of children, ages 6-17 years, enrolled in MR or SLD special education by state, United States, 1994-95
10 questions for identification of ‘serious’ mental retardation – Analysis of results for questions on learning

<table>
<thead>
<tr>
<th>Cognition</th>
<th>True Condition</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Screen</td>
<td>Y</td>
<td>45</td>
</tr>
<tr>
<td>N</td>
<td>1</td>
<td>870</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>1580</td>
</tr>
</tbody>
</table>

- Sensitivity: 97.8%
- Specificity: 55.1%
- PV+: 6.0%
- PV-: 99.9%

Type 1 error (false + rate): 44.9%
Type 2 error (false - rate): 2.2%
Prevalence: 2.9%
2000 US Census

- No disability questions on short form (everyone completes)
- Long form (Approximately 1 in 6 households):

Does this person have any of the following long-lasting conditions:

a. Blindness, deafness, or a severe vision or hearing impairment?

b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?

Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities:

a. Learning, remembering, or concentrating?

b. Dressing, bathing, or getting around inside the home?

c. (Answer if this person is 16 YEARS OLD OR OVER.) Going outside the home alone to shop or visit a doctor’s office?

d. (Answer if this person is 16 YEARS OLD OR OVER.) Working at a job or business?
NHIS-D1 Question on Developmental Disabilities

• I am going to read a list of medical conditions. Tell me if anyone in the family has any of these conditions, even if you have mentioned them before.)

• Does anyone in the family, that is (read names) have – learning disability, cerebral palsy, cystic fibrosis, Down syndrome, mental retardation muscular dystrophy, spina bifida, autism, hydrocephalus
Operational Definition of Mental Retardation – NHIS, 1994/1995

Larson et al., 1999

• If “Yes” to presence of MR
• If MR cause of activity limitation
• If MR cause of limitation in communication, getting along w/ others, ADLs, IADLs, or reason for service
• Acromegaly
• Amino acid transport disease
• Autism
• Bronched chain amino acid disturbance
• Cerebral palsy
• Congenital anomaly
• Congenital birth defect
• Congenital CMV
• Congenital hypothyroidism
• Congenital syphilis
• Copper metaboloc disorder
• Deformity of skull
Operational Definition of Mental Retardation - continued

- Encephalopathy
- Epilepsy
- Hydrocephalus
- Klinefelter’s syndrome
- Leukodystrophy
- Lipodosis
- Noxious substance affecting newborn
- Other brain or CNS conditions or deformities
- Other developmental delays
- Reduction deformity of the brain
- Sec chromosome anomaly
- Spina bifida
- Thalassemias
- Tuberous sclerosis
- Unknown congenital or birth injury
Cognitive Components of the Response
(Tourangeau, et al. 2000, p. 8)

**Comprehension**
- *Attend to questions and instructions*
- Represent logical form of question
- Identify question focus
- Link key terms to relevant concepts

**Retrieval**
- Generate retrieval strategy and cues
- Retrieve specific, generic memories
- Fill in missing details

**Judgment**
- Assess completeness and relevance of memories
- Draw inferences based on accessibility
- Integrate material retrieved
- Make estimate based on partial retrieval

**Response**
- Map judgment onto response category
- Edit response
Problems Related to Surveys

Errors of nonobservation – related to coverage, nonresponse and sampling errors (Groves, 1991)

– Coverage
  • Inaccessibility of research and surveillance tools for people with disability (Meyers & Andresen, 2000) especially problematic with regard to cognitive limitations
  • Many surveys exclude institutional populations

– Nonresponse
  • Reluctance to self-identify
Problems Related to Surveys, Cont’d

Observational errors - measurement errors (Groves, 1991)
- Interviewer
- Respondent
- Questionnaire – wording or phrasing may be too demanding
- Mode of data collection

Proxy vs. Self Report
- Todorov & Kirchner (2000) reported differences in response strategies between self and proxy reports for NHIS-D1
Respondent Status for Conditions (Response = "Yes")
NHIS-D1, 1994

<table>
<thead>
<tr>
<th>Condition</th>
<th>Self</th>
<th>Self-Partial</th>
<th>Proxy</th>
<th>DK</th>
</tr>
</thead>
<tbody>
<tr>
<td>SLD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Down</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MR</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Musc Dyst</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spina Bifida</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polio</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sample</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Response Biases Associated with Limited Cognitive Impairment (i.e., MR)

- Responsiveness
- Reliability
- Consistency
  - Acquiescence
  - Nay-saying
  - Recency

(Heal & Sigelman, 1995)
Personality Factors Bearing on Survey Responses – Mental Retardation

- Stigma (Dudley, 1997; Edgerton, 1967, 1993; Edgerton & Bercovici, 1976)
- Social/environmental deprivation (e.g., Greenbaum & Auerbach, 1998)
- Experience of failure; outerdirectedness; positive reaction tendencies; negative-reaction tendencies; diminished self-concept (Zigler, et al.)
Summary

• Cognitive limitation is vaguely defined
• Prevalence estimates vary widely
• People with cognitive limitations are underrepresented in national surveys and census
• Surveys are cognitively demanding
• Behavior of people with cognitive limitations affected by diminished intelligence AND personality patterns
• Alternative survey formats have advantages and disadvantages
Recommendations

• Incorporate the knowledge and emotions of people with cognitive limitations, and their family and friends, into the survey development process
• Targeted surveys for cognitive limitation – household-based
• Include environmental variables
• Data collection on people in institutional settings
• Additional research into bias of proxy reporting
• Use of alternative question and response formats for people with cognitive limitations
References


References


References


