Overcoming Challenges to Conducting Research with Individuals with Intellectual Disabilities

AUCD/CORE Webinar
- September 23, 2013
- 2:00-3:30pm ET
Webinar Overview

- Introductions and Overview of CORE
  - Kelly Roberts, Chair, Council on Research and Evaluation (CORE) and Associate Professor, University of Hawaii

- Presentations
  - Karen Ward, Professor, University of Alaska
  - Roxann Lamar, Research and Evaluation, University of Alaska
  - Virginia Miller, Assistant Professor, University of Alaska
  - Glenn Fujiura, Professor, University of Illinois
  - Elena Andresen, Professor, Oregon Health and Science University
  - Edlynne Sanchez, Student, Honolulu College

- Q&A (submit questions via chat box on right side of screen)
- Evaluation Survey
Representative Samples
Karen Ward, Virginia Miller, & Roxann Lamar
Alaska Center for Human Development
Research Designs

- **True Experiments** – the “gold standard” for representativeness
  - More control allows for large samples to detect small effects that are meaningful

- **Quasi Experiments**
  - Less control and sample sizes large enough to detect moderate to large effects

- **Observational Studies**
  - No experimental manipulation, focused on depth of information within defined limits
Examples of when smaller samples are common

- Studies of populations that are vulnerable or access is restricted
  - Disability, mental illness, disease
  - Disadvantaged (e.g., poverty)
  - Life experiences (e.g., victims of violence)

- Studies that need more of a relationship between researchers and participants
  - Case studies
  - Interview studies
Romantic Relationships Study Example

Increasing representativeness of a sample in an interview study.
Challenges

- Vulnerable population, access restricted
- Highly sensitive questions
- Interview methodology, over an hour for each participant
- Limits of time and funding
Sampling Frame

- Service providers made numbered lists of individuals (1…n) who met inclusion criteria = 172 total population
- Researchers provided computer generated lists of numbers in random order
- Service providers used random numbers to identify who to approach first, second, etc.
- The target was a 25% sample, actual was 37%
Cancer Screening Study Example

Reaching a vulnerable population - a study of women with disabilities and access to cancer screening.
Challenges

- Physical challenges – climate, weather, geography, transportation
- Identification and recruitment for participation
- Data collection – capturing the perspectives/experiences of the women, not their care providers
- Follow-up interviews
Recruitment Strategies

- Collaboration with community agency partners
- Non-traditional recruitment techniques
  - Innovative approaches
  - Personal approach of recruiters
- Coordination with care providers
Family Outcomes Example

Increasing representativeness in family outcome evaluation for Part C Early Intervention services.
Program Prescribed

- Survey mailed out for every child who received services in a year
  - Investment is in reaching all eligible participants with large, multiple mailings

- Disadvantages:
  - Low response rates
  - Entirely self-selected responders
  - Minority and rural families tend to be under-represented
Alternative Design

- 20% "target group" randomly selected from all eligible families
  - Stratified by race and area of residence
- Simple instrument with multiple ways to respond (mail, online, toll-free phone)
- Investment is in the response (at least 50%)
  - Phone calls to non-responders
  - Postcard reminders
  - Incentives (drawing for $25 gift cards)
Karen Ward
karenw@alaskachd.org
907-264-6229

Virginia Miller
jenny.miller@uaa.alaska.edu
907-264-6252

Roxann Lamar
roxy@alaskachd.org
907-264-6238
The Conundrum of Self Report and Persons with Intellectual Disability

Glenn T Fujiura
Department of Disability and Human Development
College of Applied Health Science
Key Points

• The Fundamental Importance of Self Report

• Lack consensus about its use and its reliability and validity

• Many recommendations but no simple solutions
Importance of Self Report

• Reporting Outcomes

• Values: empowerment, self determination and choice

• Good science – epistemology of experience
What we Know About Its Use and Reliability and Validity

• An old story: Sigelman (1980) and colleagues
• Lessons from Quality of Life
• The assessment of health
Many Recommendations But No Simple Answers

- Reframing the Task
- A cognitive perspective
- Methodological accommodations
Summary and Final Messages

• The challenge: ID is not a “thing”
• Handle like weapons of mass destruction: “Trust but verify”
• The social elements of data collection
Suggested Articles


Reliability of Reports with Families, Providers, & Care Providers

Presented by: Elena M. Andresen, PhD
Professor, Department of Public Health & Preventive Medicine
Chief, Disability & Health Research Group
Institute on Development & Disability
Oregon Health & Science University UCEDD
Director: Oregon Office on Disability & Health
Office: 503-494-2275
email: andresee@ohsu.edu

September 23rd, 2013
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- SLU Prevention Research Center; CDC National Center on Child Development & Developmental Disabilities U48/CCU710807-SIP3-96
- OHSU Center for Excellence in Developmental Disabilities (UCEDD); Administration on Developmental Disabilities 90DD0684 01
- Oregon Office on Disability & Health; CDC National Center on Birth Defects & Developmental Disabilities 1U59DD00942-01
- Research participants who have answered my questions for over 20 years
- Alan Meyers, PhD
Focus Today

• Why we use/accept proxy reports
  – Proxy/surrogate reports are substitutes
  – Evidence for proxy validity is sparse

• Best methods for evidence about proxy reports

• Sparse direct research for IDD
  – indirect evidence sets parameters for interpretation & suggests future research
Background: Why Proxies?

• The *Gold Standard* source for reporting is the person, in their self report
  — Some information doesn’t need the person’s report if good records are available (lab tests, procedures, school grades)

• When the information related to subjective reports of experience, interpretation of impact, symptoms & feelings, the information is best from the person
  — Feelings related to diagnosis of depression
  — Pain experience
  — Quality of health care interaction
  — Social support
Background: Why Proxies?

• Sometimes it isn’t “legal” to ask people for research consent or participation without added considerations
  ─ NIH classifies “adult” at age 21
  ─ Special procedures: using “assent” with a legal guardian’s consent, demonstrating appropriate consent circumstances exist, etc.
  ─ People who are incarcerated

• Some people cannot consent or provide research information
  ─ People in persistent vegetative states
  ─ “Diminished capacity” for research consent & accurate information
Background: Use Proxies for People with Diminished Capacity?

- **No:** when the person themselves can give their own, valuable private information
  - Typically added effort needed for informed consent & valid data: it is worth it
- **Yes:** when the legal or pragmatic research & scientific details interfere with collecting study-specific useful information
  - A study of dental procedures & stress cannot use proxies just because some adults with ID seem to be “difficult” patients
  - When assistive technology, interest, choice, attention, & accommodation fails, you will need to use proxies
Background: Using Proxies

• Study specific screening determines if someone should not/cannot participate
  —E.g., cognitive screen relevant to research procedures
• Caution: professional judgments about ability of people to consent/participate
  —Example: ward RNs in a nursing home versus a screening interview (the MMSE)
• As with all research, some participant problems are better solved by experienced research staff, not proxies
  —Interviewers with good communication & social skills
Understanding Proxy Data

• Proxy validity should be measured
  — You may have external data for some elements (e.g., records of hospital procedures, prescriptions filled, checked for a subgroup)
  — You cannot measure the validity of proxies when you have no information collected from the person themself

• By definition, you need some information, on some “relevant” participants, where both a proxy & the person provide answers to the same questions
  — While imperfect, this estimates the differences in proxy reports, & their potential biases
  — Direction of the differences may be systematic)
• Proxy response: adults with disability (PWD)
• Measures of interest where health-related quality of life (HRQoL)
  – Mental health, physical health, function, disability, activities, pain
• N=131 person/proxy sets
  – proxies nominated by the PWD: 1 or more
• We ranked “best” proxy as (1) relative, (2) friends, & (3) healthcare providers
• Calculated % agreement, direction of difference, kappa (chance-correct agreement), scales (ICC)
• Patterns varied across domains, measures & not all in agreed with other research
### Results: Example content items. Differences between PWD & proxy

<table>
<thead>
<tr>
<th>Measure (Behavioral Risk Factor Surveillance System)</th>
<th>PWD answer</th>
<th>Proxy answer &amp; difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Relatives</td>
</tr>
<tr>
<td>General health excellent</td>
<td>6%</td>
<td>8%</td>
</tr>
<tr>
<td>Personal care needs</td>
<td>48%</td>
<td>49%</td>
</tr>
<tr>
<td>PWD is limited</td>
<td>72%</td>
<td>86%</td>
</tr>
<tr>
<td>Not good physical health days in last 30</td>
<td>10 days</td>
<td>8</td>
</tr>
<tr>
<td>Not good mental health days in last 30</td>
<td>8 days</td>
<td>6</td>
</tr>
<tr>
<td>Pain days in last 30</td>
<td>9 days</td>
<td>7</td>
</tr>
</tbody>
</table>
### Results: Example content items. Differences between PWD & proxy

<table>
<thead>
<tr>
<th>Measure Activities of Daily Living (ADL) Need some help</th>
<th>PWD answer</th>
<th>Proxy answer &amp; difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Relatives</td>
</tr>
<tr>
<td>Getting across small room</td>
<td>36%</td>
<td>46%</td>
</tr>
<tr>
<td>Dressing</td>
<td>26%</td>
<td>26%</td>
</tr>
<tr>
<td>Personal grooming</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Eating</td>
<td>14%</td>
<td>18%</td>
</tr>
<tr>
<td>Overall ADL scale mean</td>
<td>4 points</td>
<td>4.3</td>
</tr>
</tbody>
</table>
### Results: Example content items. Differences between PWD & proxy

<table>
<thead>
<tr>
<th>Measure</th>
<th>PWD answer</th>
<th>Proxy answer &amp; difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Instrumental ADL</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need some help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use telephone</td>
<td>6%</td>
<td>12% + 9% + 21% +</td>
</tr>
<tr>
<td>Take medications</td>
<td>22%</td>
<td>26% + 16% - 44% +</td>
</tr>
<tr>
<td>Managing money</td>
<td>17%</td>
<td>23% + 16% - 38% +</td>
</tr>
<tr>
<td>Doing laundry</td>
<td>17%</td>
<td>14% - 23% + 15% -</td>
</tr>
<tr>
<td>Overall IADL scale mean</td>
<td>4 points</td>
<td>5.0 + 3.5 - 7.8 +</td>
</tr>
</tbody>
</table>
## Results: Example content items. Differences between PWD & proxy

<table>
<thead>
<tr>
<th>Measure</th>
<th>PWD score 0-100 *</th>
<th>Proxy answer &amp; difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Relatives</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>42</td>
<td>36</td>
</tr>
<tr>
<td>Role-physical</td>
<td>56</td>
<td>54</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>61</td>
<td>61</td>
</tr>
<tr>
<td>Vitality</td>
<td>52</td>
<td>48</td>
</tr>
<tr>
<td>Social functioning</td>
<td>84</td>
<td>84</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>83</td>
<td>79</td>
</tr>
<tr>
<td>Mental health</td>
<td>74</td>
<td>71</td>
</tr>
<tr>
<td>Physical summary</td>
<td>35</td>
<td>34</td>
</tr>
<tr>
<td>Mental summary</td>
<td>55</td>
<td>54</td>
</tr>
</tbody>
</table>

* All scale scores: higher is better function, health-related-quality of life
Results: Example content items. Differences between PWD & proxy

<table>
<thead>
<tr>
<th>Measure</th>
<th>PWD score answer</th>
<th>Best proxy answer &amp; difference</th>
<th>Agree *</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General health (excellent, very good, good, fair, poor)</strong></td>
<td>Statistically significant trend toward ratings of worse health by proxy</td>
<td>0.51</td>
<td></td>
</tr>
<tr>
<td>Overall ADL</td>
<td>4.1</td>
<td>4.6</td>
<td>+</td>
</tr>
<tr>
<td>Overall IADL</td>
<td>4.3</td>
<td>5.1</td>
<td>+</td>
</tr>
<tr>
<td>SF-36 Physical summary</td>
<td>35</td>
<td>33</td>
<td>-</td>
</tr>
<tr>
<td><em>SF-12 Physical summary</em></td>
<td>36</td>
<td>34</td>
<td>-</td>
</tr>
<tr>
<td>SF-36 Mental summary</td>
<td>55</td>
<td>54</td>
<td>-</td>
</tr>
<tr>
<td><em>SF-12 Mental summary</em></td>
<td>49</td>
<td>47</td>
<td>-</td>
</tr>
</tbody>
</table>

* Measured as intraclass correlation coefficient or weighted kappa
Summary of the Literature on Proxies

1. Proxies are better are giving information that is more objective
   Does (your daughter) walk across the room without assistance?

2. Proxies are worse at providing valid information that about subjective feelings, emotions, pain

3. Proxies tend to over-report physical functional problems, & underreport pain & emotional problems

4. The closer the relationship (personal & living situation), the more accurate the proxy is
A Small Sample of Potentially Useful Research Techniques

1. Add an interviewer/rater assessment of the quality of information from each participant, whether they are a proxy or the person with ID
   a. Formal rating (excellent, good, fair, poor or similar)
   b. Subjective comments setting the context

2. Add “mini studies” of the quality of data, e.g., formal validity or reliability studies
   a. Self report of physical activity vs. activity meter for a random sample
   b. Depression screening symptoms questions administered twice in a week for a sample
Selecting Measures & Considering Proxy Value

1. Examine how your possible selected measures rate when used in your proposed participant sample
2. Consider a formal standards rating to decide on their value in your study
3. Hopefully there is a study or even better, a review of measurement issues, & suggestions for participant versus proxy response
4. If not, consider methods research before deciding on the value of proxy respondents

**Examples of measurement standards**


**Applications of COSMIN to systematic reviews**


Edlynne Harrell Sanchez

About Me:
• Student at Honolulu Community College
• Third Semester
• Currently in Math 9
• Volunteer at library
Experience in research

Pacific Alliance:
Participated in math camp
Stipend
Access to assistive technology

Duel Enrollment with Individualized Supports (DEIS):
Person Centered Planning
Coaching twice a week
Mobile device supports
Employment readiness supports
Recommendations for working with individuals with disabilities:

A. meeting with coach twice a week – establishing one on one relationship
B. being able to talk to someone when have trouble understanding some stuff - so openness to the individual
C. not being scolded when do something wrong or ask questions
D. listening
E. get to know the individual
If a researcher is doing a survey on experiences of individuals with disabilities, how should the person be approached?

a. introduce yourself  
b. inform the person about the purposed of the research  
c. answer all questions and assure understanding
What about an online survey?

- Same thing but communication is different
- if there is a way to communicate online - through e-mail or chat room, etc. this would be best. Or even call.
Questions?

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