

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)

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The
Conundrum of
Self Report
and Persons
with ID

Glenn T Fujiura

The Conundrum of Self Report and Persons with Intellectual Disability

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College of Applied Health Science



Overcoming Challenges to Conducting Research: A webinar Sept 23, 2013

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

- Finlay, W. M., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13*(3), 319-335.
- Fujiura, G. T. (2012). Self-reported health of people with intellectual disability. *Intellectual and developmental disabilities, 50*(4), 352-369.
- Emerson, E., Felce, D., & Stancliffe, R.J. (in press). Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellectual and Developmental Disabilities.*



Webinar: Overcoming
Challenges to Conducting
Research with Individuals
with Intellectual Disability

Reliability of Reports with Families, Providers, & Care Providers

Presented by: Elena M. Andresen, PhD

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- 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 themselves
- **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)

Example Disability & Proxy Study

- **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

Measure <i>(Behavioral Risk Factor Surveillance System)</i>	PWD answer	Proxy answer & difference					
		Relatives		Friends		Healthcare	
General health excellent	6%	8%	+	3%	-	12%	+
Personal care needs	48%	49%	+	31%	-	77%	+
PWD is limited	72%	86%	+	69%	-	88%	+
Not good physical health days in last 30	10 days	8	-	9	-	6	-
Not good mental health days in last 30	8 days	6	-	6	-	6	-
Pain days in last 30	9 days	7	-	8	-	6	-

Results: Example content items. Differences between PWD & proxy

Measure <i>Activities of Daily Living (ADL) Need some help</i>	PWD answer	Proxy answer & difference					
		Relatives		Friends		Healthcare	
Getting across small room	36%	46%	+	31%	-	68%	+
Dressing	26%	26%	...	12%	-	21%	-
Personal grooming	15%	15%	...	3%	-	29%	+
Eating	14%	18%	+	0%	-	15%	+
Overall ADL scale mean	4 points	4.3	+	2.9	-	7.8	+

Results: Example content items. Differences between PWD & proxy

Measure <i>Instrumental ADL Need some help</i>	PWD answer	Proxy answer & difference					
		Relatives		Friends		Healthcare	
Use telephone	6%	12%	+	9%	+	21%	+
Take medications	22%	26%	+	16%	-	44%	+
Managing money	17%	23%	+	16%	-	38%	+
Doing laundry	17%	14%	-	23%	+	15%	-
Overall IADL scale mean	4 points	5.0	+	3.5	-	7.8	+

Results: Example content items. Differences between PWD & proxy

Measure <i>Short-Form 36 scales</i>	PWD score 0-100 *	Proxy answer & difference					
		Relatives		Friends		Healthcare	
Physical functioning	42	36	-	36	-	18	-
Role-physical	56	54	-	48	-	47	-
Bodily pain	61	61	...	62	+	66	+
Vitality	52	48	-	47	-	55	+
Social functioning	84	84	...	86	+	85	+
Role-emotional	83	79	-	77	-	72	-
Mental health	74	71	-	74	...	71	-
Physical summary	35	34	-	33	-	31	-
Mental summary	55	54	-	54	-	56	+

* All scale scores: higher is better function, health-related-quality of life

Results: Example content items. Differences between PWD & proxy

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

* Measured as intraclass correlation coefficient or weighted kappa

Summary of the Literature on Proxies

- 1. Proxies are better at 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

References & Further Reading

Andresen EM, Vahle VJ, Lollar D. Proxy reliability: Health-related quality of life measures for people with disability. *Qual Life Res* 2001;10: 609-619.

Examples of measurement standards

Andresen EM. Criteria for assessing the tools of disability outcomes research. *Arch Phys Med Rehabil* 2000;81:S15-S20.

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Terwee CB et al. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Qual Life Res* 2012;21:651-657.

Applications of COSMIN to systematic reviews

Paalman CH et al. Instruments measuring externalizing mental health problems in immigrant ethnic minority youths: a systematic review of measurement properties. *PLoS One* 2013;8:e63109

Oftedal S et al. A systematic review of the clinimetric properties of habitual physical activity measures in young children with a motor disability. *Int J Pediatr* 2012; :976425.

Edlynne Harrell-Sanchez



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



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R E S E A R C H , E D U C A T I O N , S E R V I C E

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 purpose 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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