



# Measurement Considerations for Achieving Equity in Research Inclusion for Transition-Aged Youth with Disabilities

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Measuring health for youth with intellectual disabilities (ID) is important for tracking progress toward national health goals. Measures of biophysical and fitness indicators are important but difficult to obtain in youth with ID, particularly in community settings. This paper describes obstacles encountered and strategies used to measure outcomes in a community-based study. Proposed best practices include adaptations in procedures to maximize comprehension; preparation of the environment to provide privacy and predictability; and appropriately sized equipment to obtain accurate readings. Reliable and valid measures, specific to youth with ID, would improve promote research inclusion and reduce health disparities for this population.

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THE SURGEON GENERAL'S *Call to Action* (U. S. Department of Health and Human Services and Office of Disease Prevention and Health Promotion, 2005) and *Healthy People 2010 and 2020* (USDHHS, 2000; 2009) have emphasized the need to extend health promotion and wellness services to children and adults with disabilities, including those with intellectual disabilities. Underlying these calls to action is an acknowledgement that people with intellectual disabilities have unmet health promotion needs as a result of systematic health service deficiencies. As child health researchers attend to health disparities and equity considerations, they are likely asking the next question: *Once I include children with disabilities in my health promotion research, how do I make practical adjustments to the research protocol to accommodate their needs while maintaining the measurement rigor of my study variables?* To address these practical considerations, we draw on the measurement lessons learned by our research team in a health promotion study of youth and young adults with intellectual disability.

Intellectual disability, formerly known as mental retardation, is defined as “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18” (American Association on Intellectual and Developmental Disabilities, 2009). The majority of people with ID have mild-to-moderate impairment. Mild-moderate ID is characterized by IQ scores of 50–70 and can include diagnoses such as Down syndrome and other chromosomal rearrangements. *Closing the Gap* (U. S. Department of Health and Human Services & Public Health Service, 2002) and the *National Goals & Research for People with Intellectual & Developmental Disabilities* (Coulter, 2005) emphasize the need for providers, researchers, and policymakers to remediate deficiencies in health promotion programming and encourage individual health empowerment in people with ID (Coulter, 2005; Powers, Dinerstein, & Holmes, 2005).

Ironically, children with disabilities have been excluded from mainstream research on child development and health promotion; yet their participation is essential to provide the evidence needed to minimize the health disparities they

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experience. A recent review of 15 years of published research found up to 89.9% of studies excluded children with disabilities, and 74% provided no justification for their exclusion (Feldman, Battin, Shaw, & Luckasson, 2013).

The purpose of this paper is to summarize the lessons learned over our year-long involvement in a health promotion research intervention study. The 12-week community-based health promotion intervention involved transition-age youth and young adults with ID. Drawing on our experiences, we present recommendations for best measurement practices specific to biophysical and fitness variables in youth with ID.

It is not our intent to reiterate in great detail the published findings of our intervention study, *Yes We Can!* (Pett et al., 2013). An in-depth description of the design and outcomes of the intervention can be found in that report. Rather we have elected to focus on unmasking the data collection issues (and solutions) that we experienced while collecting on-site biophysical and fitness measures of persons with ID in a community-based setting. Our hope is to facilitate an open dialogue concerning the challenges—and rewards—of including youth with disabilities in research. An ultimate outcome would be the implementation of more rigorous measurement practices and increased inclusion of this population in future health related research.

## Background

Why do researchers exclude children with intellectual disability in research? Low literacy, impaired physical abilities, and limits in reading comprehension of questionnaires or rating forms are among the most cited concerns of researchers seeking to include people with ID in research (Andresen & Meyers, 2000; Finlay & Lyons, 2001; Fujiura & the RRTC Expert Panel on Health Measurement, 2012). Furthermore, measures of health and health promotion variables specifically designed for people with disabilities are hard to find. A few highly researched variables can be measured with a proliferation of competing instruments. For example, at least forty different tools exist to measure the construct of participation among people with disabilities (Butler, Kane, Larson, Jeffery, & Grove, 2012). The vexing counter-problem is an inadequate bank of measures for other less popular but arguably equally critical research variables. For example, researchers seeking an appropriate self-reported measure of health-related quality of life for people with ID would find virtually no appropriate instruments (Fujiura & Behrens, 2011). As a result of these measurement gaps, researchers focus on a narrow range of variables simply because those measures exist, leaving equally important variables unexplored.

Rather than ramp up their measurement expertise to compensate for these challenges, researchers may find themselves defaulting to other sources of data instead of focusing on direct measurement of children and youth with

ID. These alternate data sources include physician examinations, record reviews, observations, and proxies (Temple, Frey, & Stanish, 2006). Parents and caregivers often serve as a proxy voice on behalf of the child with ID. They are asked to complete psychosocial questionnaires, write journal details of activities and health events, or respond to interview questions as if their answers are equivalent to those of the child. Proxies can provide useful data, with accuracy improving with increasingly close proxy–subject relationships (Fujiura & the RRTC Expert Panel on Health Measurement, 2012). Scientists and clinicians may be understandably lured by the relative ease of collecting proxy data compared to direct data collection from children, particularly those with ID. However, bypassing data directly elicited from children threaten their autonomy and privacy as human subjects and compromises ethical research design (McDonald & Raymaker, 2013). Parents serving as proxy respondents often have an incomplete and, at times, erroneous understanding of basic child health behavior, as evident in Sobo and Rock's (2001) report on parents' error-ridden reports of children's dietary intake. The target areas of our report, biophysical and fitness indicators, are nearly impossible to estimate. Proxies reporting on behalf of children are inadequate substitutes for direct measurement of the child's strength, endurance, or body composition.

## *Yes We Can!* Healthy Lifestyle Research Study

As indicated, an in-depth description of this institutional review board-approved intervention and report of the results of the *Yes We Can!* healthy lifestyles pilot project has been reported elsewhere (Pett et al., 2013). Briefly, the purpose of the intervention was to evaluate the effectiveness of a 12-week curriculum-guided and recreation center-based healthy lifestyle intervention for 30 overweight or obese (BMI 25–54 kg/m<sup>2</sup>) transition-age youth (18–35 years old, mean = 24.2) with mild to moderate intellectual disability who were residing at home with their parents. Inclusion and exclusion criteria are presented in Textbox 1.

The study included three cohorts: (1) youth and young adults who received only the young adult intervention; (2) a youth-parent cohort that received both the young adult intervention and an intervention involving the parents; (3) a parent-only cohort that received the parent intervention. After one cohort completed the intervention, the next cohort started. By staggering participation in the interventions, the second cohort served as a pre-/post intervention wait list control group for the first cohort.

The young adults and their parents completed the informed consent/assent process prior to starting the 12-week youth/parent intervention conducted at a centrally located community recreation center that provided recreational services to people with disabilities throughout the region. The *Yes We Can!* health education and physical

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