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.

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
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/m²) 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
Data Collection: Congruence with Intervention

Curriculum developed by Marks, Heller, and Sisirak (2006). The health promotion curriculum was modeled after education (45 minutes) and physical activity (45 minutes). The intervention consisted of two components: curriculum-guided health session) for a total of 36 hours. Each intervention session activity intervention took place twice/week (1.5-hours/session) for a total of 36 hours. Each intervention session consisted of two components: curriculum-guided health education (45 minutes) and physical activity (45 minutes). The health promotion curriculum was modeled after curriculum developed by Marks, Heller, and Sisirak (2006).

Data Collection: Congruence with Intervention

Goals and Self-Report Issues

To assess the progress of the young participants during their involvement in the healthy lifestyle program, we assembled a panel of measures congruent with intervention goals. Many of the measures were recommended and previously employed in research conducted by the curriculum designers. Measures were taken at baseline, immediately post intervention (approximately 12 weeks after baseline), and 3-month follow-up (approximately 12 weeks after the post-intervention measure). We used self-reported measures, biophysical indicators, and fitness performance tests to answer research questions about the health promotion program outcomes. Youth participating in the study were asked to rate their health on a single self-reported health item (Likert-type scale with 1 = poor health to 4 = excellent health). They also completed a 10-item child depression inventory adapted for young adults with ID. Details about the measures and participants’ scores at baseline, post-intervention, and follow-up have been previously reported (Pett et al., 2013). The youth fitness and biophysical indicators, discussed in this report, are listed in Table 1 and were measured at the same time points.

Activity intervention took place twice/week (1.5-hours/session) for a total of 36 hours. Each intervention session consisted of two components: curriculum-guided health education (45 minutes) and physical activity (45 minutes). The health promotion curriculum was modeled after curriculum developed by Marks, Heller, and Sisirak (2006).

### Table 1: Criteria used to determine who would be eligible to participate in a healthy lifestyle study involving youth and young adults with intellectual disability.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
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<tr>
<td>Transition aged youth and young adult (18+ years old)</td>
<td>Significant health concerns (e.g., functional or structural gastrointestinal problems or conditions that precluded moderate exercise)</td>
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<tr>
<td>Residing at home</td>
<td>Pregnancy or lactation</td>
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<tr>
<td>Overweight or obese (BMI &gt; 25 kg/m²)</td>
<td>Cardiovascular event or cancer diagnosis in the last 12 months</td>
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<tr>
<td>Able to feed by mouth</td>
<td>Disordered eating</td>
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<td>Mild-moderate intellectual disability as reported by parents based on clinical diagnosis or educational assessment resulting in special education placement</td>
<td>Severe psychiatric conditions that would prevent participation in group activities</td>
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<td>A healthcare provider release was required</td>
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Some of the measures used were standardized measures intended for use with the general population, e.g. the Tinetti balance test (Hilgenkamp, van Wijck, & Evenhuis, 2010) and Sit to Stand 60 second (Bohannon, 1995). The paper–pencil self-report measures focusing on choice making and nutrition knowledge were specifically intended for use with populations with ID, e.g., the Choice Making Inventory ([ICMI-2] Center for Outcome Analysis, 2004) and the Adapted Nutrition Activity Knowledge Scale (Illingworth, Moore, & McGillivray, 2003). These self-reported health measures required adaptations to meet the literacy and comprehension levels of this population.

The value of self-determination was critical to our selection of instruments and data collection methods. Our research team was committed to youth reporting their own health behaviors as part of study participation. We also acknowledged our need to involve parents in the study. Because parents shape the home environment where family eating habits and activity patterns are formed and expressed, we involved them in the intervention delivery but were careful to exclude them as proxy respondents for their children’s experiences. Given these values, we included youth with ID directly in both the planning and measurement of self-reported outcomes of our healthy lifestyle intervention research.

Self-report is a complex cognitive process. Self-reported health behaviors require any respondent (with or without a cognitive impairment) to engage in at least four processes:
interpreting what the question is asking, retrieving the information, resolving ambiguity in the request for information, and then deciding how to respond (Tourangeau, 1984). Because we used self-reported health behavior questionnaires as part of our study, these processing concerns were important to resolve. As discussed in detail by Fujiura and the RRTC Expert Panel on Health Measurement (2012), it is futile to ask if self-report is appropriate and can be reliably completed by any group of research participants with ID. “...People with [intellectual disability] may be too heterogeneous in terms of personal history and linguistic and cognitive abilities for any single questionnaire to be valid for the whole population” noted Finlay and Lyons (2001, p. 329). The question is not “if” people with ID can complete self-report, suggests Fujiura, but “how” we can maximize the possibility that the interpretation, retrieval, judgment, and decisions involved in self-report can be facilitated to maximize reliability. Strategies to improve accuracy of self-reported health measures in this population include simplification of both the query and the response format, avoidance of time-based inquiries (“Are you better, worse, or the same compared with ...”) and elimination of hypothetical scenarios (“how do you feel about...”). Furthermore, response formats can be improved through replacement of abstractions in formats (eliminating the 1–5 numeric Likert-type response choices) with pictorial response choices or concrete and descriptive word choices (Fujiura & the RRTC Expert Panel on Health Measurement, 2012).

Process Evaluation of the Intervention Components

A process evaluation is often used in community-based research to determine which components of an intervention affect implementation and program effectiveness in real-world settings (Bartholomew et al., 2011; Glasgow, Vogt, & Boles, 1999). This process is iterative, involving the examination of several program characteristics including the context, data collection tools, and measurement procedures (Saunders, Evans, & Joshi, 2005). As part of our process evaluation, we recorded the strengths and limitations of the measures used during data collection in order to identify what worked and what changes needed to be considered to increase success during community driven implementation. The research team was keenly aware of how measurement challenges could impact the data collection process and ultimately the outcomes of our study. We carefully critiqued our methodology in weekly research team meetings in order to improve the measurement process by cataloging and sharing our experiences and recommendations for future research. The carefulness with which we collected the data assisted to ensure its reliability and produced robust study outcomes.

The following discussion offers details of our data collection process along with the successes and challenges the team encountered and discussed in the process evaluation research team meetings. The procedures, modifications, and contextual factors are described to advance the discussion of how to incorporate children and youth with disabilities in health promotion research and adequately measure their outcomes.

Biophysical Measures

The biophysical measures included: venipuncture to determine each participant’s cholesterol panel and blood glucose levels; blood pressure as an indicator of cardiovascular health; weight and height to calculate BMI (body mass in kg/height in m²); and waist and hip circumference. Each was measured at 3 points in time: pre-intervention, immediately post-intervention, and at 3-months’ follow-up.

The most daunting biophysical measure in our repertoire was the blood draw. We were wary of causing pain and emotional distress for the research participants and concerned about possible high refusal rates for venipuncture. We chose to minimize the physical and emotional trauma of a repeated blood draw by using the less-traumatic finger stick method for expressing whole blood. Participants were asked to complete three finger sticks (one at each data collection session). By using a spring-loaded lancet, the puncture to the finger was swift. The test was completed on-site at the community recreation center within 3 minutes, including processing time. By connecting the Cholestech LDX (Cholestach, Hayward, CA) machine to a compatible miniprinter, we could immediately verify that the sample was sufficient and readable, and test results could be provided to the participant on-site.

We also used planned distraction during the blood draw, following the advice of Burkitt, Breau, and Zabalia (2011), to increase the use of active and effective pain coping strategies. For example, during the blood draw the research staff assigned to the finger stick station asked the participant if he or she had a pet. If so, we asked questions about the pet. If not, we asked about past pets or the kinds of pets that would be best if one could have any pet in the world. This led, in most cases, to an animated, distracting, and pleasant conversation.

Blood pressure was measured at the three data collection points. In addition, we also encouraged weekly self-monitoring of blood pressure to increase participants’ knowledge of their own blood pressure values and to build their self-efficacy in self-monitoring for the future. We purchased 3 high-quality self-inflating blood pressure monitors (Microlife BP3ac1-1pc) for the study, choosing models typical of those sold for home-use at medical supply and drug stores.

Standard protocols were adopted to assess body weight, height, and waist circumference of participants wearing light clothing. One research team member collected all of these measures using the following procedures. For weight, each participant was instructed to stand on a calibrated digital scale (Model Taylor Glass Electronic Scale, Taylor Precision Products, Oak Brook, IL) and body weight was recorded to
the nearest 0.1 lb. We chose a scale that was easily portable to conform to the community setting.

Height was assessed to the nearest 0.1 inch using a stadiometer (Portable Adult/Infant Measuring Unit, Perspective Enterprises, Portage, MI). Using a flexible non-stretchable measuring tape, waist circumference was measured at the smallest circumference of the natural waist or approximately 1 inch above the umbilicus if the natural waist was hard to identify. The hip circumference was measured at the widest part of the buttocks, typically at the level of the greater trochanter of the femur. We attended to privacy during measurements by conducting the measures away from other research participants in an adjoining room at the community recreation center. To provide feedback to the group, we charted individuals’ weekly weight loss in pounds as linear trajectories on a large graph paper with different colors for each participant.

**Fitness Measures**

A variety of measures were used to assess physical fitness and performance at baseline, post intervention, and 3-month follow up with a focus on the areas of strength, balance, flexibility, and endurance (Table 1). Because there are few, if any, fitness measures that have been designed specifically for this priority population, the research team elected to use measures that were identified in the literature as reliable and valid for typical community-dwelling youth and adults. The decision to use tools that were developed for populations different from the study group is supported by the literature (Hilgenkamp et al., 2010) and was guided by recommendations indicated in the curriculum used during the “Yes We Can!” intervention (Marks et al., 2006). There is limited rationale for adapting performance standards on youth fitness measures for youth with ID. Even so, a 10% reduction in fitness attainment has been suggested as an acceptable fitness performance standard for youth with ID (Winnick & Short, 1999).

**Exemplars of Solutions to Measurement Challenges**

Our ability to successfully collect biophysical and fitness data from our participants was attributed to a few adjustments in the standard procedures along with additional strategies that made the process more appealing and understandable to the participants (Table 2).

**Organizing the Data Collection Process**

During the data collection phases of this study the team set up assessment days, structured similar to a health fair. We arrived at this round-robin measurement strategy after an

<table>
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<th>Table 2</th>
<th>Successes in measuring biophysical and fitness variables.</th>
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<tr>
<td><strong>Biophysical measures</strong></td>
<td><strong>Successes</strong></td>
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| Venipuncture | • Participants expressed relief that a finger stick, rather than traditional antecubital venipuncture, was employed  
• The immediacy of the procedure following consent prevented perseveration about the procedure and limited the time for emotional escalation  
• Conducting the procedures in the main data room provided an atmosphere of positive peer support  
• Participants enjoyed being able to choose from among adhesive bandages with pop culture and comic strip designs |
| Blood pressure | • Affordable and self-monitoring equipment did not require a trained healthcare professional to auscultate the sounds of Korotkoff  
• Participants became familiar with the equipment, demonstrated no apprehension about weekly measures, and quickly incorporated this into the routine |
| Weight, height, waist circumference | • This routine process was recognized by participants as a structured part of the bi-weekly group sessions  
• The graph of individual weight loss provided immediate, visual reinforcement about weight loss trajectories  
• Weight loss was graphed with an inverted, positive slope This was understood by most participants as “going in the right (upward) direction” when they lost weight  
• One trained individual with demonstrated intra-administrator reliability performed all waist, height and circumference measures |
| **Fitness measures** | **Successes** |
| Administration procedures | • One evaluator administered the assessments to all participants for consistency |
| Environment | • Supplemental instructions that included more descriptive words and practice movements  
• Health fair structure with personalized card showing progress through stations  
• Collated data collection folder carried from station to station by participants resulted in data being aggregate and prepared for data entry |
| Equipment | • Community-based partner provided the needed equipment  
• Simple modifications (like labeling the machines with geometric symbols) improved progress from station to station for participants with low literacy |
earlier and unsuccessful trial of group progress through all stations. With the group rotation, most stations were empty and a single station was overly full, causing long wait times and a mismatch of resources to needs.

Using a health fair format streamlined the data collection process. The consent process began the health fair, and once consented, youth rotated between different data collection stations. Since the time lapse between consent and data collection was only a few minutes, drop-outs and no-shows were not a problem. Each participant received a personalized card showing which stations they needed to attend and in what order. Following the order on the card, the participant moved through a series of assessment stations and presented their data folder to the health professional administering each successive measurement. Each data collection station was staffed by a member of our interdisciplinary team assigned to collect data in his or her specific area of expertise. Using the same person to collect the same data across participants and over time also maintained consistency in procedural administration of the measures and assured methodical data recording. The health fair format also provided opportunities for the participants to receive peer and caregiver support during the testing process. Comfort with the data collection process for participants was enhanced by familiarity, as weekly biophysical measures of blood pressure and weight were conducted in the same way at post-test and follow-up measurement periods using the same data collection format.

**Reducing Unpleasant and Painful Aspects of Measurement**

Administration of the measures improved when simple changes were made to the procedures to accommodate the needs of the participants and the environment. Several of the adaptations we made are supported by the literature. For example, many youth are concerned about providing a blood sample. Youth with ID are often sensitive to pain stimuli as a result of their medical histories and exposure to repeated painful procedures (Charlton, 2005). The pain and unpleasantness of venipuncture is exacerbated by fear and anxiety, and repeated exposure to venipuncture combined with negative affect produces a conditioned negative response (Janssen, 2002). In response to pain, people with cognitive limitations typically have a shorter list of pain coping skills, and those they use are the least effective (Burkitt et al., 2011). Techniques like distraction and positive self-talk are least-often used by people with ID, despite their being potentially more effective than passive coping strategies, including crying or screaming to elicit social support (Burkitt et al., 2011). Use of poor coping strategies could be attributed to the lack of formal instruction in how to effectively cope with pain. Knowing this in advance, researchers and clinicians can promote more effective coping strategies for momentary pain (like a finger stick blood draw). Discussing pets with youth with ID, as we did, is one way to distract attention from the painful stimulus.

**Simplifying, Demonstrating, and Prompting Measurement Activities**

Villamonte et al. (2010) in their report of balance measures used with a comparable population of youth with ID describe how multistep instructions and dual task performance complicates test instructions and introduces complexity into the performance of the test that results in inconsistent performance on individual components of a test, and the overall battery of tasks that comprise each test. We addressed this challenge by making simple changes to the instructions and providing concrete examples with opportunities to practice prior to scoring performance. Examples that can improve this process include: demonstrating 1:1 instruction with each participant prior to administration, offering opportunities to ask questions and offering clarifying information as needed. During administration of the Tinetti balance test (Hilgenkamp et al., 2010), which involves the participant maintaining a static standing posture while the administrator applies a brief push to the participant’s chest, increased consistency was achieved by utilizing additional instructions e.g. “show me how strong you are, don’t let me move you”. In our study, every participant completed practice trials of the tasks prior to a scored performance (Lavay, Reid, & Cressler-Chaviz, 1990). Coaching, prompting, or “cheerleading” was used to increase the likelihood that the participants’ performance was reflective of ability.

**Managing the Environment**

Changes to the environment also need to be considered when including youth with ID in a health-related study. A goal of our intervention study (Pett et al., 2013) was to develop a community-based program that was sustainable for the local recreation center. Therefore, whenever possible, the researchers used resources available at the community center during data collection and the intervention. These resources included fitness equipment, weight machines, and the gymnasium. When we made adaptations to the equipment to improve accessibility for youth with ID, we had to bear in mind the general population that also used the equipment and recreation space. For example, adding geometric symbol identifiers to the weight lifting equipment (like a star or a circle) aided our participants who had lower literacy skills. Their personalized data collection card instructed them to locate a particular kind of equipment for strength evaluation. Reading the labels on the equipment was difficult and time consuming. It was far easier to match a symbol on their card to an identical symbol on a sticker placed on the equipment. The symbols on the equipment did not compromise the recreation center experience for other patrons of the center, making the accommodation well-suited to both the research participants and the environment.

**Ongoing Measurement Challenges**

As with many research studies, a few measurement challenges remained (Table 3). Interpersonal morphologic
variations among research participants (e.g. short limbs, and postural sway) may require more personalized measurement equipment. For example, the sit-to-stand test may be better accomplished if short-limbed individuals had access to lower chairs, and taller individuals had access to higher chairs as opposed to a single, standardized chair for all body types. Blood pressure, too, is more accurately measured with cuffs suited to the limb-length and adiposity of the participant. It can be difficult to find blood pressure cuffs for adults that are suited to shorter-limbed obese individuals.

Overall, ongoing measurement challenges for youth with ID are similar to challenges encountered in nearly any heterogeneous population. Adolescents, with or without disabilities, exhibit a variety of growth trajectories and body types, demonstrate a wide range of literacy and cognitive processing abilities, and may encounter anxiety with study measures. Continued development of our research methodologies is needed to establish standardized yet adapted physical performance tests for children, youth, and adults with ID.

**Discussion**

Health promotion intervention research has been criticized for channeling resources toward reductionist, unrealistically controlled clinical trials of non-representative samples (Glasgow et al., 1999). In measuring outcomes, it is well accepted that measurement tools and procedures are developed and tested on a subset of the population, usually college students. Expanding any measure to apply to other racial, ethnic, language, or ability level populations compromises measurement effectiveness and efficiency (Strickland, Dilorio, Coverson, & Nelson, 2007). Researchers studying children’s health promotion and disability require better instrumentation and guidance on how to anticipate challenges and develop new measures or adjust “standard” measures to function with psychometric robustness in new or “non-standard” populations (Butler et al., 2012).

Programs must be evaluated for effectiveness and transferability to real world settings (Durlak & DuPre, 2008). Translational research often involves community stakeholders (including children and youth with disabilities, families, and community service providers). Their engagement in collaborative decision-making increases the likelihood of achieving sustainable, empowering, and quality interventions (Durlak & DuPre, 2008). The best practices we outline for research measurement of biophysical and fitness variables with transition-age youth address translational research in community settings. We address considerations in the measurement processes to suit the community environment and the need for adapted measures appropriate for the population.

**Table 3** Challenges in measuring biophysical and fitness variables.

<table>
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<tr>
<th>Biophysical measures</th>
<th>Challenges</th>
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| Venipuncture for lipid panel and glucose measures | • Anxiety-related vasoconstriction resulting in an insufficient amount of blood expressed for analysis  
• Interpersonal morphologic variation presented as pronounced finger fat pads and required attention to proper lancet placement on the peripheral aspect of the finger to access well-vascularized tissue  
• The Cholestech machine had a 3-minute processing time which contributed to a few samples congealing if a backlog occurred  
• The random glucose measure would have been more meaningful if it had been taken as a fasting glucose |
| Blood pressure                             | • Ill-fitting equipment for short limbed and/or obese participants contributed to measurement error  
• Each of the monitors had occasional and inexplicable lapses, over-filling on inflation to the point of discomfort for participants |
| Weight, height, waist circumference        | • Physical differences, such as hemiplegia or postural irregularities resulted in weight and height measures that varied from typical populations  
• Consistent waist circumference difficult to achieve  
• Postural sway interfered with digital scale reading  
• Inconsistencies between our scale vs. theirs at home created confusion for some participants |

<table>
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<tr>
<th>Fitness measures</th>
<th>Challenges</th>
</tr>
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| Administration procedures                  | • Multistep instructions and dual task performance complicated tasks  
• Additional cues sometimes confused participants |
| Environment                                | • Over stimulating environment lead to distractions during testing and encouraged competition during some tasks |
| Equipment                                  | • Fitness equipment had limitations in adjustments, occasionally didn’t fit those with shorter limbs and or trunks  
• New fitness equipment was installed after several weeks of intervention, leading to a compromise in standardization across our measurement periods |
Addressing the health needs of children and youth with disabilities is becoming a major focus in the field of health promotion (U.S. Department of Health and Human Services & Office of Disease Prevention and Health Promotion, 2009) as well as an issue of social justice. Increasing healthy lifestyle behaviors among youth with intellectual disability presents healthcare providers and researchers with unique challenges but is an important undertaking that will assist in reducing health disparities experienced by this population. These needs are addressed by McDonald and Raymaker (2013) in their call for health research to be more ethical, respectful, and inclusive of people with developmental disabilities. Incorporating small but significant changes to research protocols would increase accessibility and inclusion of children and youth with disabilities in health-related research studies, bringing research practices more in line with human rights frameworks that emphasize inclusion. This course of action would expand health outcomes to be more representative of the general population, as well as improve studies that are meant to address this priority population’s specific needs.

We evaluated measurement successes and challenges encountered in a community-based participatory research study with transition-aged youth to inform the design of future health related studies with this population. Some of our suggestions are based on what worked for our team while others are based on what we see as continued needs in the process of measuring and addressing the health needs of this population. Many of the suggestions align with those made by McDonald and Raymaker (2013) which included modifying materials, research protocols, and the physical context to promote accessibility, simplifying instructions to be specific and concrete, and providing alternate modes of delivery for testing procedures.

We would also recommend more work be directed towards the evaluation, development, and modification of research measurements and equipment design in community settings. More scrutiny and creative adaptation in these areas would increase universal accessible and appropriateness for children and youth with disabilities. Outcome measures for health, fitness, and biophysical components need to be developed and tested to establish relevance for people with disabilities. This can be achieved by developing new tools specifically for this population and/or by testing the validity and reliability of existing measures among people with disabilities. Incorporating small but significant changes to research protocols would increase accessibility and inclusion of children and youth with disabilities in health-related research studies, bringing research practices more in line with human rights frameworks that emphasize inclusion. This course of action would expand health outcomes to be more representative of the general population, as well as improve studies that are meant to address this priority population’s specific needs.

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We would also recommend more work be directed towards the evaluation, development, and modification of research measurements and equipment design in community settings. More scrutiny and creative adaptation in these areas would increase universal accessible and appropriateness for children and youth with disabilities. Outcome measures for health, fitness, and biophysical components need to be developed and tested to establish relevance for people with disabilities. This can be achieved by developing new tools specifically for this population and/or by testing the validity and reliability of existing measures among people with disabilities. Incorporating small but significant changes to research protocols would increase accessibility and inclusion of children and youth with disabilities in health-related research studies, bringing research practices more in line with human rights frameworks that emphasize inclusion. This course of action would expand health outcomes to be more representative of the general population, as well as improve studies that are meant to address this priority population’s specific needs.

Conclusion

Discussing the impediments to measurement of biophysical and fitness variables in a sample of transition-aged youth with ID begins a dialogue about how we can improve measurement and ultimately harness research to benefit this population. Equalizing access to research participation for children and youth with disabilities is a social justice priority. Researchers can learn from their own—and others’—successive measurement attempts to best adapt and design measures to track a variety of health promotion variables. The ability of researchers to determine health promotion intervention effectiveness with marginalized populations is hampered by the lack of valid, reliable, sensitive, and appropriate measures to discern incremental change over time on health outcomes. The primary challenge is accurately measuring health promotion variables among children and youth with disabilities so that progress toward national health promotion goals can be adequately evaluated (HP 2020, DH-2).

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