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Community-Based Participatory Research to Adapt Health Measures for Use by People With Developmental Disabilities

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Abstract

Background: People with developmental disabilities (DD) are often not included as participants in research owing to a variety of ethical and practical challenges. One major challenge is that traditional measurement instruments may not be accessible to people with DD. Participatory research approaches promise to increase the participation of marginalized communities in research, but few partnerships have successfully used such approaches to conduct quantitative studies people with DD.

Objective: To use a community-based participatory research (CBPR) approach to create an accessible, computer-assisted survey about violence and health in people with DD, and to psychometrically test adapted health instruments.

Methods: Our academic–community partnership, composed of academic researchers, people with DD, and supporters, collaboratively selected and modified data collection instruments, conducted cognitive interviews and pilot tests, and then administered the full survey to 350 people with DD.

Results: Although team members sometimes had opposing accommodation needs and adaptation recommendations, academic and community partners were able to work together successfully to adapt instruments to be accessible to participants with a wide range of DD. Results suggest the adapted health instruments had strong content validity and all but one had good to excellent internal consistency reliability (alpha, 0.81–0.94). The majority of participants (75%) responded that all or most of the questions were easy to understand.

Conclusions: Researchers should consider using participatory approaches to adapting instruments so people with DD can be validly included in research.

Keywords

Community-based participatory research, process issues, health care surveys, health services research, disabled persons, measurement adaptation, developmental disabilities

People with DD are often not included as research participants owing to a variety of ethical and practical challenges.^{1,2} A major challenge is that traditional measurement instruments may not be accessible to people with DD, especially to people with intellectual disabilities or

individuals on the autism spectrum. Instruments may have different characteristics if items are not comprehensible or require complex judgments or quantifications,³ and the underlying constructs the instruments are designed to measure may be different for people with DD.⁴ Furthermore, researchers

may overestimate barriers to participation for people with DD or lack strategies for addressing them. These challenges become particularly important when trying to collect information about sensitive topics such as violence and health.⁵

CBPR may be a particularly promising way to decrease barriers to participation in research by people with DD.^{5,6} CBPR allows researchers and community members to serve as equal partners throughout all phases of the research process.⁷ Although CBPR has most often been used in partnership with communities defined by race or ethnicity,⁸ CBPR and other participatory approaches have been successfully used to conduct research with communities defined by disability status,⁹ including the autistic self-advocacy community^{10,11} and the community of people with intellectual disabilities.¹² A CBPR approach may theoretically be used to increase validity of data collection by directly including community members throughout the measurement adaptation process.¹³ However, there are relatively few examples of the use of CBPR for adapting measurement instruments to be more accessible to people with DD or other minority groups.¹⁴

Our parent Partnering with People with Developmental Disabilities to Address Health and Violence study used a CBPR approach to assess the association between interpersonal violence, disability, and health outcomes in people with DD. In this article, we discuss how we used the CBPR process to adapt the instruments in the parent study to make them accessible to people with DD. We focus on the methods we used to collaboratively select and adapt instruments, as well as the psychometric properties of the adapted health measures.

Our experience may serve as an example to other researchers and communities interested in adapting instruments to be more accessible to people with DD or other minority groups.

METHODS

CBPR Partnership

The goal of our project's parent study was to use a CBPR approach to conduct a computer-assisted, cross-sectional survey assessing the relationship between violence, disability, and health in people with DD. To include both rural and urban populations, the project spanned two sites—rural Montana and the Portland, Oregon, metropolitan area. It involved three universities (one in Montana and two in Oregon) and four community-based organizations led by, and serving, people with DD (two in Montana and two in Oregon). The study was conducted by a consortium composed of a Steering Committee, two community advisory boards (CABs, one at each site), and additional consultants and research assistants. The Steering Committee included the three principle investigators, the project manager for each site, and a leader from each of the four community based organizations. All four of the community leaders are people with DD. Each CAB included six individuals: four people with DD, one family member, and one disability services professional with experience supporting people with DD. CAB members were identified and recruited by the Steering Committee members at each site. Because members sometimes had more than one disability, the Steering Committee and CABs included six people with intel-

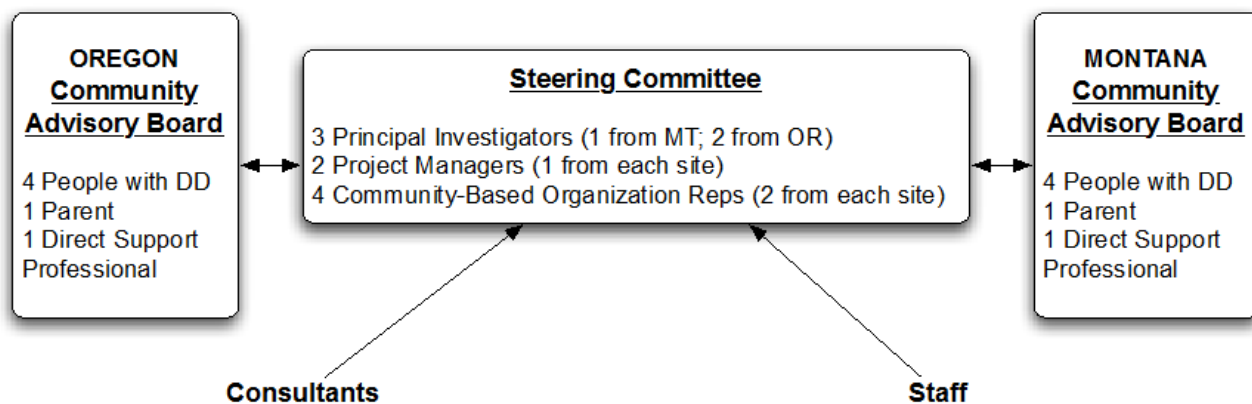


Figure 1. Organizational Chart

DD, developmental disabilities.

lectual disabilities, four people on the autism spectrum, four people who were blind or had visual impairments, one deaf person, and six people with physical disabilities. A majority of academic partners also had disabilities, were close family members of people with DD, or both. Our partnership is depicted in Figure 1.

The Montana principal investigator was responsible for oversight of the entire project, in close collaboration with the Oregon principal investigators and the project managers. The Steering Committees at each site made the major decisions and prepared agendas and materials for the CAB meetings (Table 1). Original efforts to hold joint Steering Committee meetings with both sites failed owing to lack of a remote collaboration system accessible to all parties. Thus, Steering Committee meetings were conducted in person and separately at each site. The principal investigators, project managers, research staff, and, when indicated, consultants from both sites met together regularly via telephone.

In the initial CAB meeting, Steering Committee and CAB members at each site created ground rules for group discus-

sion to maximize accessibility and participation. Procedures to promote accessibility and participation included: 1) emailing materials in advance (including files compatible with screen readers), 2) having a community member of the Steering Committee review current project status at the beginning of Oregon CAB meetings, 3) holding optional in-person pre-meetings with investigators to allow CAB members additional time to review agendas and meeting materials, 4) providing American Sign Language interpreters, 5) reading materials out loud for CAB members who were blind or had limited reading skill, 6) using large print for CAB members with visual impairments, 7) offering individualized support, such as explaining the meaning of words and encouraging them to bring their personal assistants to meetings if desired, 8) using accessible meeting spaces, 9) using web or teleconferencing in Montana when needed (e.g., when CAB members were unable to attend in person owing to unavailability of a personal assistant), and 10) providing sensory objects to help CAB members focus during meetings. CAB members received \$50 stipends for attending each meeting and were

Table 1. Overview of Team Members and Research Studies: CBPR Team

| Group | Members | Primary Roles and Responsibilities |
|-------------------------------------|---|--|
| Principal Investigators/Consultants | Academic researchers, a majority of whom have disabilities or are close family members of people with DD | Select initial constructs to be measured Select measures to choose from for adaptation Coordinate between study sites Reconcile differences Ensure scientific rigor and funder priorities are being addressed |
| Steering Committee | Three principal investigators Two project managers Four community leaders (all 4 of whom themselves are people with DD) | Prepare agendas for CAB meetings Prepare materials for CAB meetings, including making initial, more obvious changes to measures Monitor and address any concerns with the CBPR process or power Co-lead CAB meetings |
| CAB | Eight people with DD Two family members of people with DD Two disability services providers | Finalize choice of constructs to be measured Select measures to be adapted from those presented to them Discuss issues with measures and make recommendations for edits to address the issues Discuss and finalize storyboard for survey Test, recommend edits to, and finalize the ACASI Ensure community priorities are being addressed |
| Project Managers/Staff | Two project managers, one of whom has a disability Four research assistants, one of whom is a person with DD | Implement recommendations and decisions made by CAB and investigators Implement recommendations and findings from cognitive interviews and usability study Coordinate meetings and logistics Collect data from participants |

Abbreviations: ACASI, audio computer-assisted self-interview; CAB, community advisory board; DD, developmental disabilities.

either reimbursed for transportation and parking costs or had transportation provided by the research staff.

The measurement adaptation process, including instrument review and adaptation, cognitive interviewing, incorporation of the measures within an accessible computer survey system, and pilot testing, was conducted over a period of 18 months, as pictured in Figure 2. During the measurement adaptation phase of the project, the two CABs met in person one to two times per month for 3 to 5 hours. Project managers kept minutes and field notes from all meetings. All team members contributed conceptually to this article. The CABs discussed a file in which the full text of the manuscript appeared on one side of the page and a lay version on the other. An external evaluation team conducted an ongoing evaluation of our CBPR process, results of which will be presented elsewhere.

Selection of Instruments and Measurement Adaptation Process

The request for proposals from the Centers for Disease Control and Prevention/Association of University Centers on Disabilities included specific research questions related to the relationships among violence, disability, and health. The principal investigators further specified those research

questions and identified which constructs would likely need to be measured. The principal investigators then discussed these questions and constructs with the Steering Committee and CABs until the full team reached consensus. The team chose to assess the following information in the parent study: demographic and disability-related characteristics, physical symptoms, substance use, secondary conditions, depression, posttraumatic stress disorder, perceived stress, social support, child abuse, adult abuse, perpetrator characteristics, barriers to help seeking, help-seeking behaviors, and the participants' experience taking the survey. The investigators then identified multiple existing instruments that might be used to measure each construct. The Steering Committee reviewed these potential instruments and selected which ones to further discuss with the CABs.

The investigators led initial meetings with both CABs to discuss what was possible and desirable when adapting instruments. The researchers explained that items should only be changed if they caused significant problems (e.g., if CAB members could not understand them, if they thought that many others with DD would not be able to understand them). Adaptations of standardized measures based simply on a mild preference were discouraged. Adaptation strategies included

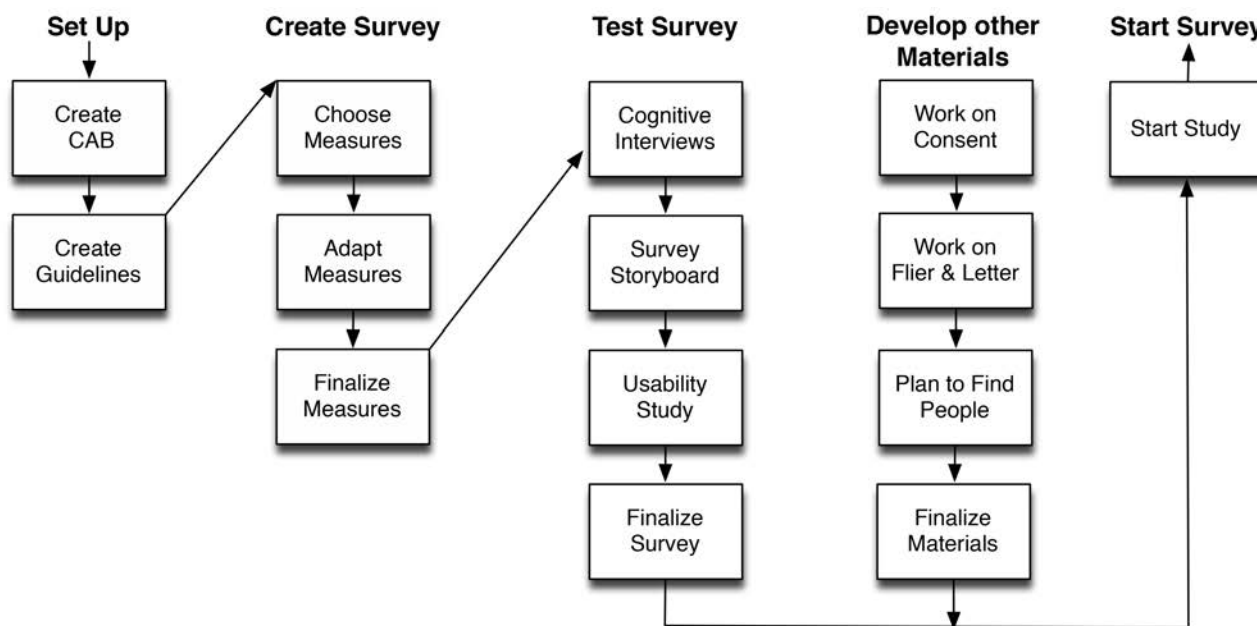


Figure 2. Measurement Adaptation Process

CAB, community advisory board.

1) the addition of hotlinks to define difficult or vague terms or to offer examples, 2) the addition of graphics for response options using Likert-type scales, 3) changes to prefaces to make instructions clearer, and 4) changes in wording to increase clarity, as long as the underlying idea remained the same. Items that were part of a scored scale could not be split into separate items or removed entirely. Finally, changes were not made that would affect the intended meaning.

We decided to work on the depression severity construct first. Both CABs separately reviewed three potential instruments—the Center for Epidemiological Studies Depression Scale (CESD–10),¹⁵ the Patient Health Questionnaire Depression Scale (PHQ–9),¹⁶ and the Geriatric Depression Scale¹⁷—to determine which they thought would work best for people with DD and gave suggestions for adaptations. Because groups chose the CESD–10, raised similar concerns, and offered similar suggestions for adaptations, we split the primary responsibility for selecting and adapting measures for the remainder of constructs between the two CABs, with the other CAB in a secondary review role.

The CAB with primary responsibility for the construct chose among available instruments and made initial adaptations. The alternate CAB reviewed the adapted measures and made additional edits, as needed. As the project progressed, we learned various ways to improve our efficiency. For example, the Oregon team found it was particularly helpful for the Steering Committee to prepare draft adaptations of measures before CAB meetings. The principal investigators reconciled differences and finalized the measures in preparation for the cognitive interview portion of the study.

Space limitations preclude discussion of all measures, and thus this article focuses on the adaptation of the following well-established health measures: the 10-item version of the CESD–10,^{15,18,19} the PTSD Checklist,^{20,21} an 8-item version of the Medical Outcomes Study (MOS)–Social Support Scale,^{22,23} and the PHQ Physical Symptom Scale (PHQ–15)²⁴ and the 4-item version of the Perceived Stress Scale PSS–4²⁵.

Participant Eligibility and Recruitment

We conducted three studies with participants not included in our community–academic team: cognitive interviewing, pilot testing, and the full survey study (Table 1). To be eligible for any of the studies, participants had to 1) be at least 18 years

of age, 2) demonstrate the ability to give informed consent, 3) communicate at a level needed to answer in-person questions with accommodations provided, 4) understand English or American Sign Language, and 5) have a developmental disability, which was defined as a condition that began before the age of 22 years, is likely to continue indefinitely, and affects at least three major life functions. We recruited participants for the cognitive interviewing and pilot studies via word of mouth. For the full survey study, researchers at each site established agreements with state developmental disability agencies to mail study fliers to adults receiving their services. CAB members and project staff also distributed information by word of mouth, and by posting fliers to electronic listserves, community-sponsored events, and other locations such as independent living centers and DD support brokerages. Participants were paid \$30 to participate in a cognitive interview, pilot test the survey, or participate in the survey study. The study was approved by the institutional review boards at each site, and participants completed a written informed consent process. Consent materials were themselves developed collaboratively using a similar CBPR process to ensure accessibility.

Cognitive Interviewing and Pilot Testing

We used cognitive interviewing to assess content validity, that is, to make sure instruments were understandable and participants' understanding of items was similar to what was intended. The project managers and two trained research assistants conducted the cognitive interviews, using a structured interview guide. We chose three items per measure to include in the cognitive interview, focusing on the most challenging items, as determined by our CAB. Interviewers showed, read, or signed each item to participants and asked if the item was clear. They then asked participants to paraphrase what the item was asking. For participants with expressive language barriers, the researchers offered optional descriptions of the items and asked participants to choose the option that most closely matched the item. The project staff showed response items first without graphics and then with graphics and asked whether the graphics helped, hurt, or made no difference. In Oregon, staff first showed the original element (i.e., instructions, items, responses), then showed the adapted elements, and asked participants which one they preferred, if any.

Interviewers kept careful field notes, including 1) how participants paraphrased each item, 2) how much they seemed to struggle with understanding items, and 3) when applicable, the nature of the problem and the participants' suggestions. The investigators reviewed the results, focusing on items that multiple participants found unclear or where a single participant identified a major problem likely to affect others with similar characteristics. Based on these results, the investigators made straightforward or minor edits. In cases where a solution was less straightforward, we brought the information back to the CABs to decide on the best approach to further adapting the item. In some cases, edits were made to all the items in an instrument, not just the items included in the cognitive interview guide, if the issue being addressed affected the entire scale. The principal investigators again finalized all measures.

The Steering Committees and CAB worked together to finalize the order of the instruments, write transition statements, and design an accessible audio computer-assisted self-interview (ACASI) program. ACASI programs have previously been used to improve survey accessibility for individuals with disabilities,^{26–28} as well as to improve disclosure of sensitive information^{28–32}; however, we further tailored our ACASI to the specific needs of individuals with DD. Our ACASI features include read-out-loud and American Sign Language options, compatibility with screen-reading software, hot links to definitions for difficult words, and user-defined preferences for text size. We reduced the level of computer literacy needed by designing a simple user interface, providing instructions, and developing a protocol whereby research personnel worked with the participant during the earlier, less sensitive parts of the survey to provide training and support, if requested.³³ CAB members pilot tested the ACASI and noted potential technical and user interface problems. After those problems were resolved, we pilot tested the ACASI with additional participants who met the inclusion/exclusion criteria noted. We made minor additional changes to optimize survey clarity or user experience. Details of the development of the ACASI program, the usability testing, and the survey administration protocol are presented elsewhere.^{33,34}

Data Collection and Analysis for the Full Survey Study

The ACASI was administered on laptop computers at safe

and private locations chosen by the participants. Project staff followed an administration protocol that allowed for varying levels of support, based on participants' needs and preferences. Details of the ACASI administration and participants' evaluation of their experience using the ACASI system are presented elsewhere.³³ We assessed internal consistency reliability by calculating Cronbach's alpha for each scale. We present alpha values for the whole study sample, as well as for two potentially overlapping subgroups: one for participants who identified as having an "intellectual, cognitive or other thinking disability, such as childhood traumatic brain injury or stroke" and another for those who identified as being on the autism spectrum. We evaluated participants' perception of understandability of the instruments with the item "How many of these questions were easy to understand?" Response options were "some," "about half," "most," and "all or almost all" (with a graphic representation of responses using cylinders filled to different degrees).

RESULTS

Measurement Selection and Adaptation

Table 2 lists the instruments selected to measure each underlying health construct and describes the adaptations made to each instrument. Several issues were common to multiple instruments. First, some team members thought that response options, especially those using Likert scales, were confusing or difficult to use. Graphics were added to increase clarity and, at times, wording of response options was changed to be more precise. Second, many instruments used incomplete sentence fragments for individual items, which were seen as confusing, especially given team members' preference for displaying one item per screen. All items were stated in complete sentences that could stand alone without the introductory prompt. Third, when possible, we substituted a difficult vocabulary word, confusing term, or figure of speech with an equivalent, more straightforward term. However, at times, it was not possible to make a substitution without either changing the meaning of the item, making it more vague, or necessitating a more complex sentence structure. In those cases, we added hotlinks that either defined the term or gave examples. Last, other edits were made in an attempt to simplify sentence structure or remove confusing grammar.

Table 2. Instrument Adaptations

| Original | New |
|---|---|
| Physical Symptoms • Measure: PHQ-15²⁴ | |
| Instructions | |
| During the past 4 weeks, how much have you been bothered by any of the following problems? | The next questions as about your physical health during the past 4 weeks. |
| Systemic | |
| Items are sentence fragments, e.g., “Back pain.” | Items are complete sentences, e.g., “During the past 4 weeks, how much have you been bothered by back pain?” |
| Response options: “Not bothered at all”; “Bothered a little”; “Bothered a lot.” | Added graphics to response option text: smiley face, neutral face, sad face (3 icons). |
| Phrase changes to individual items | |
| stomach pain | stomach problems |
| (knees, hips, etc.) | (for example, knees or hips) |
| fainting spells | fainting or passing out |
| feeling your heart pound or race | feeling your heart beat very hard or feeling your heart speed up |
| sexual intercourse | sexual activity |
| constipation, loose bowels, or diarrhea | bowels, such as constipation or diarrhea |
| feeling as if your future will somehow be cut short | feeling as if your life would end quickly |
| Hotlink additions | |
| other problems with your period; sexual activity; nausea, gas, or indigestion | |
| Depression • Measure: CESD10^{15,18,19} | |
| Instructions | |
| Please indicate how often you have felt this way during the last week. | The next questions are about ways you have felt or behaved in the past week. |
| Systemic | |
| Original does not include time framing with each item, e.g., “I was bothered by things that usually don’t bother me.” | Each item includes a time frame, e.g., “During the past week I was bothered by things that don’t usually bother me.” |
| Response options: “0 = Rarely or none of the time”; “1 = Some or a little of the time (1–2 days/week)”; “2 = Occasionally or a moderate amount of time (3–4 days/week)”; “3 = Most or all of the time (5–7 days/week)”. | Removed number of days per week from response options. Reworded response options as: “Rarely or none of the time”; “A little bit of the time”; “A moderate amount of the time”; “Most or all of the time”. Added graphics to response options: cylinders filled to 4 levels. |
| Phrase changes to individual items | |
| depressed | sad and depressed |
| everything I did was an effort | everything I did was hard |
| sleep was restless | trouble sleeping |
| I was happy | I felt happy |
| could not “get going” | had trouble getting started on activities |
| Hotlink additions | |
| fearful | |

table continues

Table 2. Instrument Adaptations

| Original | New |
|---|---|
| Perceived Stress • Measure: Perceived Stress Scale, 4-item version ^{25,44} | |
| Instructions | |
| The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way. | The next questions ask about your feelings and thoughts during the last month. |
| Systemic | |
| Response options: “Never”; “Almost never”; “Sometimes”; “Fairly often”; “Very often”. | Added graphics to response options: cylinders filled to 5 different levels. |
| Phrase changes to individual items | |
| felt confident about your ability to handle your personal problems | felt you could handle your personal problems |
| felt things were going your way | felt things in your life were going well |
| difficulties were piling up so high that you could not overcome them | you had so many problems that you could not handle them |
| PTSD • Measure: PTSD Checklist ²⁰ | |
| Instructions | |
| Below is a list of problems and complaints that veterans sometimes have in response to stressful life experiences. Please read each one carefully, put an “x” in the box to indicate how much you have been bothered by that problem <i>in the last month</i> . | Next is a list of problems that people may have in response to <u>stressful life experiences</u> . Please pick the answer that best matches how much you have been bothered or upset by each problem <i>in the last month</i> . |
| Systemic | |
| Items are sentence fragments, e.g., “Loss of interest in things that you used to enjoy?” | Items are complete sentences. For items 1–3, 5, and 9–17, sentences begin with “In the past month, how often have you been bothered or upset by . . .” For item 4, sentence begins with “In the past month, how often have you been bothered by . . .” For items 6–8, sentences begin with “In the last month, how much have you . . .” |
| Uses “stressful experiences” and “stressful experiences from the past” in different places. | Uses “stressful experiences from the past” consistently. |
| Response options: “Not at all”; “A little bit”; “Moderately”; “Quite a bit”; “Extremely.” | Added graphics to response options: smiley face to distressed face (5 icons). |
| Phrase changes to individual items | |
| Repeated, disturbing memories, thoughts, or images | repeated bad memories, thoughts, or pictures in your mind |
| Repeated, disturbing dreams of | repeated bad dreams about |
| Suddenly acting or feeling as if | suddenly acting or feeling like |
| physical reactions (e.g., heart pounding, trouble breathing, or sweating) | physical reactions |
| Avoid thinking about or talking about a stressful experience from the past or avoid having feelings related to it | tried not to think about, talk about, or have feelings about a stressful experience from the past |
| being unable to have loving feelings for those close to you | not being able to have loving feelings for those close to you |
| feeling as if your future will somehow be cut short | feeling as if your life would end quickly |
| Hotlink additions | |
| stressful life experiences; physical reactions; avoided; things that you used to enjoy; emotionally numb; irritable; angry outbursts; difficulty concentrating; on guard | |

table continues

Table 2. Instrument Adaptations

| Original | New |
|--|---|
| Social Support • Measure: MOS Social Support Survey, MOS-SS, 8-item version^{22,23} | |
| Instructions | |
| People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? | People sometimes look to others for friendship, assistance, or other types of support. The next questions ask about support that would be there for you if you needed it. |
| Systemic | |
| Items are sentence fragments, e.g., “Someone to help with daily chores if you were sick.” | All items are complete sentences, e.g., “How often would you have someone to help with daily chores if you were sick?” |
| All but last items with response options: “A little of the time”; “Some of the time”; “Most of the time”; “All of the time”. | Added graphics to response options: cylinders filled to 5 different levels. |
| Last Question Only, response options: “Very Much Satisfied”; “Somewhat Satisfied”; “Not at All Satisfied”. | Added graphics to response options: smiley face, neutral face, sad face (3 icons) |
| Phrase changes to individual items | |
| someone to help you if you were confined to bed | if you had to stay in bed for many days, how often would you have someone to help you |
| someone to help with daily chores if you were sick | if you were sick and could not do your daily chores, how often would you have someone to help you |
| someone to love and make you feel wanted | someone whom you love and makes you feel wanted |
| someone to confide in or talk to about yourself or your problems | someone with whom you can share personal information about yourself or your problems |
| relationships with others | relationships |

Abbreviation: CESD10, Center for Epidemiologic Studies Depression Scale; MOS, Medical Outcomes Study; PHQ, Patient Health Questionnaire Physical Symptom Scale; PTSD, Posttraumatic stress disorder.

Process Observations

Much of the time, all CAB members, regardless of disability type, shared similar concerns regarding instruments and agreed on potential adaptations. However, we noticed a distinct pattern of potentially conflicting needs and accommodations. CAB members with intellectual disability raised concerns about difficult vocabulary words or long, complex sentences, but changes to simplify vocabulary words or shorten sentences sometimes made items incomprehensible to CAB members on the autism spectrum. Conversely, attempts to adapt items experienced as too vague or imprecise by CAB members on the autism spectrum sometimes resulted in longer or more complex sentence structure, which caused difficulties for people with intellectual disabilities. Similarly, changing response options from Likert scales to yes/no was sometimes preferable by people with intellectual disabilities, but our partners on the autism spectrum felt strongly that

this would make it harder to understand the items because they would not know how to respond if something did not happen all or none of the time. At first, the CABs were more likely to reach an impasse, spending substantial time on each item and expressing frustration and fatigue. As time went on, group members, including community and academic partners, learned about one another’s adaptation needs; thus, the group became much more adept at finding compromises that were acceptable to everyone. By the end of the process, team members often predicted others’ concerns and offered suggestions that were more quickly accepted.

Establishing a mutually beneficial pace for discussion was critical. In Oregon, pacing strategies included holding to planned break times, using the 5-finger process³⁵ as a means for each CAB member to voice confusion or concern, and appointing a community member of the CAB to be process monitor who would pause the discussion if multiple conversa-

tions were underway or if a member was having difficulty being heard by others. At both sites, at the end of each meeting, the members shared their perspectives on what aspects of the meeting went well and which changes or adjustments were needed for the next meeting.

Cognitive Interview and Pilot Testing

Nineteen individuals participated in cognitive interviews and twelve participated in pilot-testing (six individuals participated in both). Participant characteristics are presented in Table 3. Participants in the cognitive interviews were able

| Characteristic | Cognitive Interviews & Pilot Study (n = 25) | Full Survey Study (n = 350) |
|---|---|-----------------------------|
| Age (y) | | |
| Mean ± standard deviation | 42.4 ± 13.5 | 38.6 ± 13.5 |
| Range | 18–62 | 18–78 |
| Sex | | |
| Female | 13 (52%) | 177 (51%) |
| Male | 12 (48%) | 172 (49%) |
| Race/ethnicity | | |
| Non-Hispanic White | 23 (92%) | 249 (71%) |
| Disability type(s) ^a | | |
| Intellectual, cognitive, or other thinking disability such as traumatic brain injury or stroke | 11 (44%) | 226 (65%) |
| Autism spectrum disorder | 6 (24%) | 46 (13%) |
| Mobility or other physical disability such as cerebral palsy or amputation | 4 (16%) | 77 (22%) |
| Blindness of other vision problems | 4 (16%) | 31 (9%) |
| Speech | 1 (4%) | 71 (20%) |
| Mental health condition such as on-going depression, anxiety, schizophrenia or bipolar disorder | 4 (16%) | 144 (41%) |
| On-going health condition such as diabetes, obesity, arthritis, or lupus | 3 (12%) | 128 (37%) |
| Deaf or other hearing loss | 4 (16%) | 40 (11%) |

^a Participants could check all the disability categories that applied to them, so totals add to more than 100%.

to paraphrase correctly most of the items selected for review. In the few instances in which they could not paraphrase, the researchers were able to work with them to get a clear understanding of what was causing the trouble. Most participants did not feel they needed the graphics for the response options, but five participants (26%) specifically stated that the graphics helped them to answer items. For example, one participant stated that the graphics helped her to understand the difference between “rarely” and “a little bit” on the CESD–10. None felt that the graphics impeded their ability to answer. In Oregon, where participants were asked if they preferred the original or the adapted measure, a majority of participants preferred the adapted measure for nearly all items. During pilot testing, participants were able to learn how to use the ACASI and to complete the full survey. They noted minor technical problems that were resolved before finalization of the survey.

Full Survey Study

Of the 363 people with DD participated in the survey, 9 participants were excluded because they did not meet eligibility criteria and four did not complete the survey, leaving a total sample of 350. Participant characteristics are presented in Table 3. With the exception of the adapted PSS, all other adapted scales had good to excellent internal consistency reliability (Table 4). In general, alphas were similar to those found in the literature from studies using the original instruments with general populations. The scales seemed to perform equally well in the full sample and in subgroups who self-identified as having an intellectual or cognitive disability or who identified as being on the autism spectrum. The majority of participants (75%) responded that all or most of the questions were easy to understand.

DISCUSSION

Our highly diverse team of academic researchers, people with DD, family members, and disability professionals collaborated effectively—using a CBPR process—to adapt health instruments to be accessible to people with DD. There is a small but growing literature on ways to include people with intellectual disabilities^{6,12,36,37} and individuals on the autism spectrum^{10,11} as partners in research. Our project further advances this field by providing an example of a way to partner

with people with different types of DD. Our experience can also serve as an example how a CBPR approach can improve accessibility of data collection instruments for people with DD.

Results of the cognitive interviews suggested that our adapted instruments have strong content validity. With the exception of the PSS-4, the adapted scales demonstrated good to excellent internal reliability. The original four-item PSS,²⁵ and prior attempts to adapt or translate it,³⁸ have demonstrated slightly higher internal reliability (alphas 0.72 and 0.69) than what we found in our sample (alpha 0.52), but not as high as those of the full 14-item version. It is unclear if our process would have yielded a more acceptable alpha if we had chosen to adapt the longer scale.

Research has documented many potential challenges to instrument validity when measures intended for general populations are used with people with intellectual disabilities. Problems often arise when instruments 1) require quantitative or generalized judgments, direct comparisons, or socially reflexive thinking, 2) use abstract concepts, or 3) have unfamiliar or sensitive content, difficult vocabulary, or complex sentence structure.³ During the measurement selection and adaptation process, our community partners with intellectual disabilities raised concerns related to each of these issues. In almost all cases, we were able to find ways to address such concerns. For example, we selected instruments that included fewer problematic concepts, simplified sentence structure or vocabulary, provided hotlinks with definitions or examples, or added graphics to response options.

Less is known about adapting measures to be accessible to people on the autism spectrum who do not also have an intellectual disability. In our experience, our community partners on the autism spectrum shared many similar concerns with our partners with intellectual disabilities, but they sometimes noted different challenges or suggested adaptations that directly conflicted with the needs of partners with intellectual disabilities. It is important to note that traditional adaptations made to improve accessibility for people with intellectual disabilities—for example, removing difficult vocabulary or shortening sentences—may inadvertently cause increased difficulty for people on the autism spectrum who need a high degree of specificity. Similarly, researchers have suggested changing response options that use Likert scales to yes/no for people with intellectual disabilities.³ However, in many situations, our community partners on the spectrum interpreted the “yes” or “no” as very absolute and thought they could not choose either one. Fortunately, our group was able to come to consensus on how to adapt each instrument. Ultimately, the scales seemed to function equally well for people who identified as having intellectual or cognitive disabilities and for those who identified as being on the autism spectrum.

Because the literature on adapting instruments for people with DD is still in a relatively early stage, one may learn important lessons from the larger literature on adapting instruments across language and culture. Traditionally, the “gold standard” approach has involved a series of steps focused on forward and back translation of instruments by professional inter-

Table 4. Internal Consistency Reliability

| Construct (No. of Items) | Original Instrument (Citations) | Cronbach's alpha in Original Studies (General Populations) | Cronbach's alpha for Adapted Scale | | |
|--------------------------|--|--|------------------------------------|--|--|
| | | | Full Survey Sample (n = 350) | Participants With Intellectual or Cognitive Disability (n = 124) | Participants on the Autism Spectrum (n = 46) |
| Physical symptoms (15) | PHQ – physical symptom scale, PHQ 15 (24) | 0.80 | 0.83 | 0.81 | 0.83 |
| Depression (10) | CESD10 (15, 18, 19) | 0.71–0.92 | 0.81 | 0.80 | 0.84 |
| Perceived stress (4) | PSS-4 (25, 38) | 0.69–0.72 | 0.52 | 0.47 | 0.61 |
| PTSD (17) | PTSD Checklist, PCL-17 (20, 21) | 0.94 | 0.94 | 0.93 | 0.96 |
| Social Support (8) | MOS Social Support Survey, MOS-SS (22, 23) | 0.92 | 0.89 | 0.87 | 0.88 |

Abbreviations: CESD10, Center for Epidemiologic Studies Depression Scale; MOS, Medical Outcomes Study; PHQ, Patient Health Questionnaire; PSS, Perceived Stress Scale; PTSD, posttraumatic stress disorder.

preters.³⁹ However, in recent years, many have challenged that approach, noting that despite its widespread use, it has little scientific basis.⁴⁰ Some have argued for team approaches, including varied teams of bilingual/bicultural interpreters,⁴¹ or the “two-panel” approach, where two varied panels of translators and lay people with a wide range of demographic characteristics work together to produce a quality translation and determine how it functions with the intended audience.⁴² Our process, although distinct from those recommended for cross-cultural adaptations, bears many important resemblances to these more recent approaches, especially in its use of varied teams of researchers and lay people to collaboratively create adaptations as opposed to the sole reliance on experts.

A few groups have included people with DD in the instrument adaptation process, although usually not as full partners of the research team. One group used focus groups to generate an item pool for an anxiety scale for people with intellectual disabilities, had experts create items based on focus group results, literature review, and clinician feedback, and then tested them with participants to assess internal consistency and congruent validity.⁴³ Additional examples exist where researchers have partnered with people with DD to conduct qualitative research.⁶ We hope that our experience will encourage researchers to also include people with DD as full members of the research team in quantitative research.

The success of our measurement adaptation process was likely closely related to the attention the group paid to individualized accommodations, the group’s willingness to improve continuously the processes for collaboration, and members’ honesty and consideration for others. The result was that the teams from both sites developed high levels of trust, respect, and commitment. The adaptation process required a significant investment of time and energy by all team members. The process took longer than expected, resulting in significant delays to the start of data collection for the cross-sectional survey study. That said, we strongly believe that the investment of time and resources was necessary and resulted in changes critical to the success of the overall project.

Our process had several limitations. First, although we paid great attention to making both the CBPR process and the survey instruments as accessible as possible, and our CAB members included individuals with significant disabilities, our process and survey would not be accessible to some people with more limited communication skills and/or profound intellectual impairments. It is still unclear how to include people with the most severe impairments in research. Second, we did not use the original instruments in the full survey, so we cannot be sure that the adapted instruments had improved psychometric properties. Third, it is possible that we could have made more effective adaptations by more narrowly defining our population or by creating separate instruments for people with different needs. We considered the latter possibility, but both academic and community partners decided that the compromises made were acceptable and that our work would be more meaningful if we could create one instrument that could be used for people with a wide range of DD.

Including people with DD as full members of the research team is not only feasible, but it enhances the team’s ability to adapt instruments to be accessible by people with DD. Although a cross-disability approach may add complexity to the process, it is possible to adapt instruments to be accessible to people with differing disability-related challenges, strengths, and preferences. Not only can accessible research materials and participatory approaches enhance instrument validity, they can also address a wide range of ethical and human rights concerns related to the inclusion of people with DD in research.¹ Researchers interested in obtaining survey data from or about people with DD should consider using a participatory approach to adapting instruments to increase accessibility so that people with DD can be integrally and validly included in research designed to improve their health and safety.

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