

Adapting PREP Participant Surveys to Increase Accessibility for Youth with Intellectual & Developmental Disabilities (I/DD)

Reunite, Reignite, Re-energize: Innovating for the Future

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Introduction

- Oregon’s PREP grant funds the implementation of a comprehensive sexuality curriculum for transition and community programs serving young people with intellectual and developmental disabilities (I/DD).
- The standard PREP participant entry and exit surveys present challenges to youth with I/DD.
- Researchers have consistently found certain question formats and language to be less valid and accurate when administered to people with I/DD.
- Youth with I/DD may also need assistance from educators for survey participation, raising issues with data privacy, sensitive topics, and triggering language.
- As important as relevant and accessible curricula are to effective sexuality education, it is equally important that data collection and evaluation methods be assessed and adapted to be made accessible to learners.

A Collaborative & Community-Involved Approach

- State PREP grantee Oregon Health Authority (OHA) collaborated with subgrantee the University Center for Excellence in Developmental Disabilities at Oregon Health & Science University (OHSU UCEDD) to research best practices in survey design and implementation for youth with I/DD.
- The OHSU UCEDD also supports the National Core Indicators—Intellectual & Developmental Disabilities Survey, which is administered nationally to people with I/DD.
- Other collaborators consulted to review the survey included the Sexuality Health Equities for Individuals with Intellectual & Developmental Disabilities (SHEIDD), an established community advisory group that includes people with I/DD, and the Oregon Department of Education.

Methods & Data

- Holistic coding was used on the standard PREP participant entry and exit surveys. The authors and collaborators reviewed each survey item to identify elements that could be problematic for respondents with I/DD.
- Four topics emerged from the coding that identified problematic elements for respondents with I/DD:
 - a. Complex question structures (e.g., matrix items, Likert scales with several response points);
 - b. Abstract or multiple concepts (e.g., reflecting across a lengthy period of time, indirect language)
 - c. Sensitive or triggering topics (e.g., questions about sexual experiences and behaviors, questions about financial control and planning)
 - d. Advanced reading comprehension levels

12. For each of the items below, please mark how true each statement is of you.

MARK ONLY ONE ANSWER PER ROW

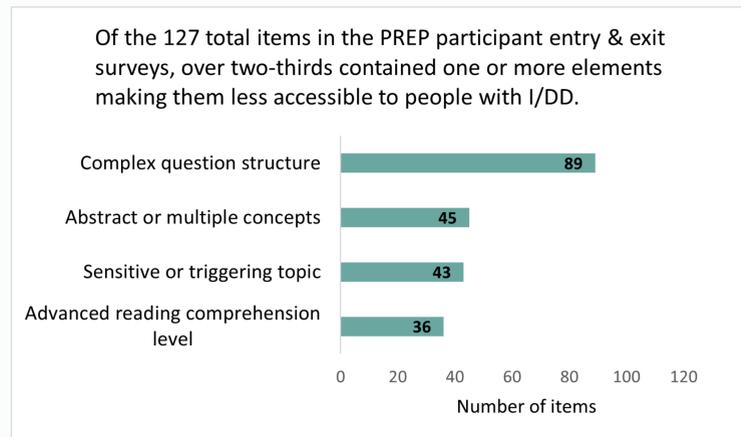
Entry Survey	Not true at all	Somewhat true of me	Very true of me
a. I understand what makes a relationship healthy.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would be able to resist or say no to someone if they pressured me to participate in sexual acts, such as kissing, touching private parts, or sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I would talk to a trusted person/adult (for example, a family member, teacher, counselor, coach, etc.) if someone makes me uncomfortable, hurts me, or pressures me to do things I don't want to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Even if your program didn't cover this topic would you say that being in the program made you more likely, about the same, or less likely to... (Note: If the program has not affected your likelihood to do the following, choose "About the same".)

MARK ONLY ONE ANSWER PER ROW

Exit Survey	Much more likely	Somewhat more likely	About the same	Somewhat less likely	Much less likely
a. talk with your parent, guardian, or caregiver about things going on in your life?.....	<input type="checkbox"/>				
b. talk with your parent, guardian, or caregiver about sex?	<input type="checkbox"/>				

Annotations: People with I/DD experience higher rates of sexual assault than the overall population, meaning this item can be triggering. Additionally, complications with confidentiality arise when a participant receives assistance in responding. This item scores at a college reading level. The separation between the opening & the following statements makes the items overly complex. A five-scale response option is overly complex. Items involving sexual experience or behavior (such as assault) were removed, but items relating to healthy relationships are maintained for fidelity. Language has been modified to be more accessible and to limit the number of concepts. Response options are limited and concrete. The standard opening and following statements have been combined into single items.



Results

- The figure above displays example items from the standard PREP participant entry and exit surveys along with further notes on how the codes were identified and determined.
- The graph to the left displays the aggregated coded data: The majority of the PREP survey items were assigned at least one of the four codes.
- OHA used these data to prepare and submit a waiver request to FYSB that included proposed changes to the PREP participant surveys and justifications for each change. This waiver request was approved.

Survey Adaptation

- The figure below displays the example PREP participant entry and exit survey items after being adapted with further notes on how these edits better serve youth with I/DD.
- The PREP Entry and Exit Survey Measures Guide was consulted throughout to ensure fidelity with the standard survey items.
- The PREP Survey Administration Guidelines were also revised to include additional information on accessibility aids to help with participant understanding.
- By adhering to best practices and community feedback and adapting the PREP survey instruments appropriately, the authors expect to see strong survey participation, more accurate responses, improved participant experiences, and more rigorous evaluations of the program.

Entry Survey

I understand what makes a relationship healthy.

I would speak up or ask for help if I was being bullied in person or online.

Exit Survey

Has being in the program made you more likely to talk with your parent, guardian, caregiver, or another trusted person about things going on in your life?

Has being in the program made you more likely to talk with your parent, guardian, caregiver, or another trusted person about sex?

Annotations: Items involving sexual experience or behavior (such as assault) were removed, but items relating to healthy relationships are maintained for fidelity. Language has been modified to be more accessible and to limit the number of concepts. Response options are limited and concrete. The standard opening and following statements have been combined into single items.

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References

1. Bakker-van Gijssel EJ, Lucassen PLBJ, Olde Hartman TC, Assendelft WJJ, va Schrojenstein Lantman-de Valk HMJ. Constructing a health assessment questionnaire for people with intellectual disabilities: A cognitive interview study. *J Appl Res Intellect Disabil*. 2020;33(3):345-353. doi:10.1111/jar.12676
2. Fang J, Fleck MP, Green A, et al. The response scale for the intellectual disability module of the WHOQOL: 5-point or 3-point?. *J Intellect Disabil Res*. 2011;55(6):537-549. doi:10.1111/j.1365-2788.2011.01401.x
3. Stancliffe RJ, Wilson NJ, Bigby C, Balandin S, Craig D. Responsiveness to self-report questions about loneliness: A comparison of mainstream and intellectual disability-specific instruments. *J Intellect Disabil Res*. 2014;58(5):399-405. doi:10.1111/jir.12024