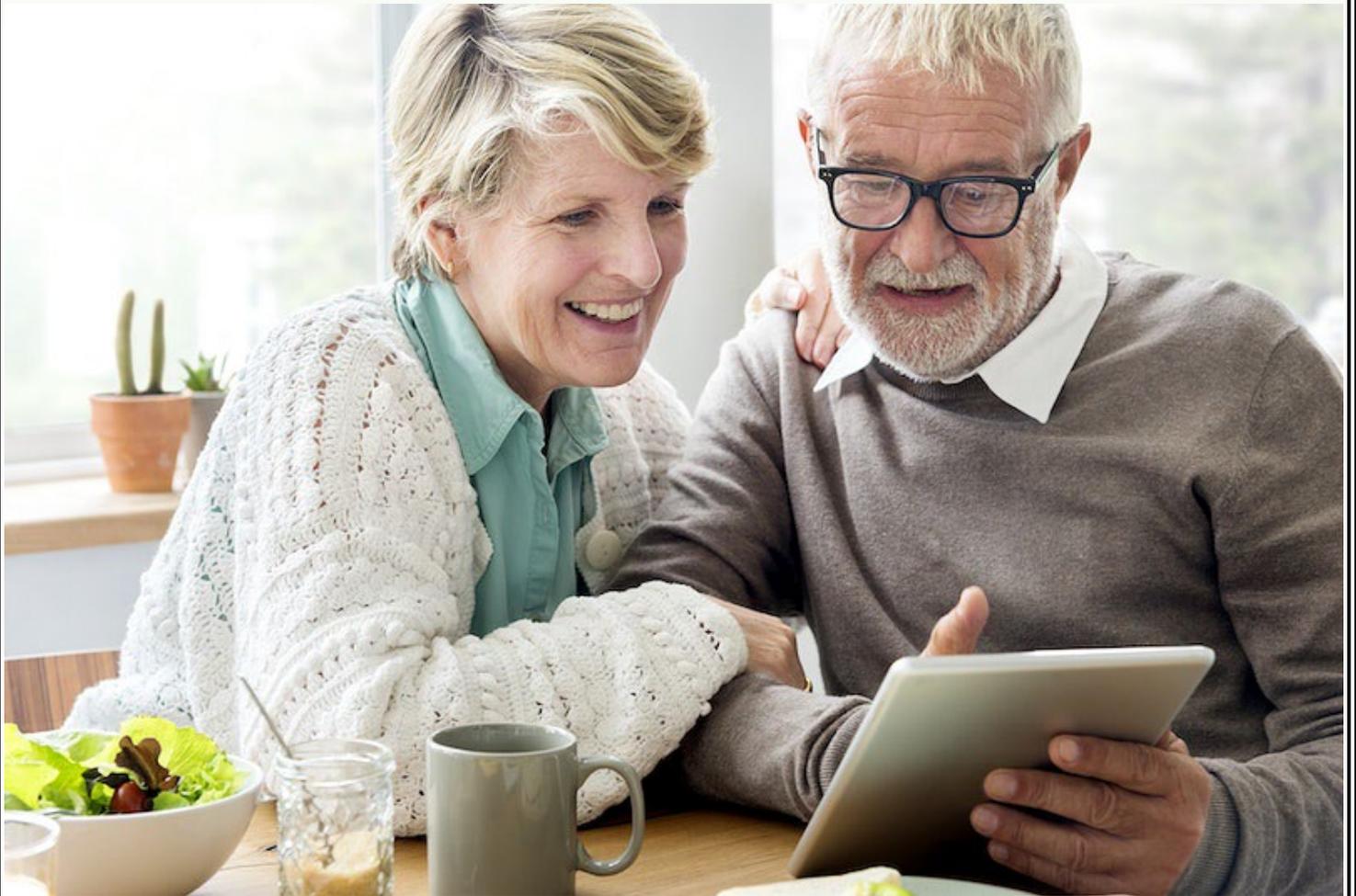


Getting Health Information Directly From Adults with Intellectual Disability (ID)



**Adults with ID can provide information
about their own health and feelings
when surveys are clear and easy-to-use.**

ORIGINAL ARTICLE:

Walton, K., Krahn, G. L., Buck, A., Andridge, R., Lecavalier, L., Hollway, J. A., Davies, D. K., Arnold, L. E., Havercamp, S. M. & the Nisonger RRTC on Health and Function. (2022). Putting "ME" into measurement: Adapting self-report health measures for use with individuals with intellectual disability. *Research in Developmental Disabilities*, 128(2022), 1-14. <https://doi.org/10.1016/j.ridd.2022.104298>

THE PROBLEM

Doctors and researchers do not always get health information directly from adults with intellectual disability (ID).

They may only ask a support person how the adult with ID is doing or feeling.

- A support person (parent, staff) may be needed to help with communication
- It is important to listen to adults with ID before asking someone else for help



Many health surveys are not easy to use.

Many questions about health are not easy to understand.

This can make it hard to:

- ask adults with ID how they are doing or feeling
- get answers to health questions directly from adults with ID

OUR RESEARCH STUDY

Our research team wanted to know if they could make health surveys better for adults with intellectual disability (ID) to use and understand.

How our research team made the new health surveys:

1. They chose 3 health surveys that they wanted to make better for adults with ID
2. They worked with a group of research partners with disabilities to make the questions & answer choices clear
3. They worked with a technology team to put the new survey online and in an app, so people could use text-to-speech to hear the words read out loud
4. Then, they asked the research partners to test the new survey on devices, such as laptops & tablets
5. They used ideas from the research partners to make final changes to the words and pictures in the new health survey



How our research partners helped the research team:

1. They told our research team what words were hard-to-understand and how to ask questions clearly
2. They told our research team to begin each question with a time period (for example, "*In the last two weeks*, how often did you feel sad?")
3. They told our research team to only use 3 answer choices: (a) almost always; (b) sometimes; and (c) almost never
4. They told our research team to use pictures of a two-week calendar with different days checked off to make answer choices easier to understand
5. They told our research team to use real-life photographs instead of icons, symbols, or cartoon faces to show different feelings



The research team also made a training part to start the new health survey.

The training part was added to teach people how to:

- use the technology options in the app and on the website, like:
 - clicking the text to read the words out loud
 - clicking buttons to answer questions, move on, go back, or skip
- understand the answer choices (almost always, sometimes, almost never)



Then, the research team tested the new health surveys with a group of adults with intellectual disability (ID).

- First, they asked 6 adults with ID to answer the questions and tell them what was hard-to-understand
- Next, they took out the questions that were not clear
- Then, they asked 41 other adults with ID to answer the questions using a tablet or computer on their own or with support

KEY FINDINGS

Adults with intellectual disability (ID) can provide information about their own health and feelings when surveys are clear and easy-to-use.

What the study did and learned:

- 41 adults with ID took the new health survey
- 24 of the adults took the survey twice to test if their answers changed or stayed the same
- Some did the survey in-person, and some did the survey in a Zoom meeting
- Each person was able to answer the questions on their own
- The survey was easier to use on a touch-screen tablet



More work is needed to test these new health surveys and make other health surveys better.

Why Is This Important?

Learning how adults with intellectual disability (ID) think and feel about their own physical and mental health is key to:

- **Respecting** their ability and independence
- **Understanding** their health and healthcare needs
- **Improving** their healthcare services and supports



Two key things helped the research team make health surveys better for adults with ID:

- 1. Asking a team of research partners with disabilities to help make choices:**
 - a. Which questions to ask
 - b. What words and pictures to use
 - c. How many answer choices to use
- 2. Putting the survey on an app and website with supports:**
 - a. Read-aloud, or text-to-speech
 - b. Touch-screen controls
 - c. Real-life photos and pictures



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