

**Article:** Opening the door to university health research: Recommendations for increasing accessibility for individuals with intellectual disability

**Key Points:**

- People with Intellectual Disability (ID) have health disparities that put them at risk of negative health outcomes.
- People with ID have been excluded from research in the past. They need to be included in research to understand health disparities.
- This article reviews what makes it hard to be included in research and why people with ID are left out.
- This article makes 7 Suggestions to help researchers include more people with ID in their research studies.

**Glossary:**

**Barrier:** Things that make it hard to do something.

**Health Research:** Research studies that focus on health of certain groups or health of the whole population

**Health Disparity:** difference in health between two groups that are caused by things that could be prevented such as access to health care or discrimination.

**Research Consent:** you understand what the study is about, and you want to participate in a research study.

**Research Assent:** Assent means the person understands the study and wants to participate and they also have someone who legally makes some decisions for them. People who have a legally authorized representative (guardian) give **Assent** and their guardian gives **Consent**.

**Self-Advocate:** A person who speaks for themselves and advocates for their needs. They are an expert in the conditions or diagnoses they have.

**Why this article matters:**

We need to include more people with ID in health research to understand how to improve their health and get rid of the health disparities.

**Description of the Study:**

Self-advocates with ID, community members, and researchers worked together to find out what makes it hard to join research and how researchers can make it easier for people with ID to join research.

To find what makes it hard for people with ID to join research, they:

1. Searched in published research articles.
2. Met with a representative of the institutional review board. The Institutional review board is a group of people who review research for the university to make sure it is ethical and safe for participants.
3. Reviewed the laws that control research to see if there were ways the law might be making it harder for people with ID to participate in research.

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Then a working group was created to come up with ideas on how to make it easier for people with ID to join research. A working group is a group of people who can help answer a research question. The working group included self-advocates with ID, family members of people with ID, staff from community organizations, and researchers.

The working group met 4 times. Together the group came up with 7 ways researchers could include more people with ID in their studies. They also developed 4 products to support researchers and wrote this paper together.

### **Research Questions:**

- What makes it hard for people with ID to participate in research studies?
- How can researchers make it easier for people with ID to join research?

### **Important Results:**

There are lots of things that make it hard for people with ID to join research studies (Barriers). Researchers can make it easier for people to participate in research.

Suggestions for researchers to make it easier for people with ID to participate in research:

1. Tell people and other researchers about how you are including people with ID and talk about the strengths and benefits of including people with ID in your research.
2. Work with people and communities to create relationships and trust.
3. Use plain language and a glossary for terms that are complicated.
4. Simplify consent and assent process. Consent and assent are new ideas to lots of participants. Explain the process in plain language and make it easy to understand.
5. Don't test people's IQ or cognition. Make sure people know about the study and can provide informed consent and assent.
6. Offer supports and adaptations to everyone in the study to make participation easier.
7. Share your results in plain language with the community.

Tools to support researchers:

1. Plain Language Glossary
2. Understanding Consent and Assent in Plain Language
3. Supports I Need document
4. Easy-Read Article Summary Template

### **How the results will be used:**

- Researchers should work to apply the recommendations and include more people with ID in their research
- Researchers can also use this article to understand the things that make it hard for people with ID to participate in research (barriers) and work to remove the barriers.