

Why is it Important that We Include ALL Adults with Intellectual Disability (ID) and Developmental Disabilities (DD) in Research?



Government offices and disability agencies can better understand what services & supports are needed when research includes more adults with ID/DD.

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INTRODUCTION

What health and disability professionals know

about adults with intellectual disability (ID) and developmental disabilities (DD) **is based on who they can contact.**

They have learned about SOME adults with ID/DD using:

- Studies (e.g., *research projects that ask questions and look for answers*)
- Surveys, personal interviews, and group discussions



Adults with ID/DD (who they contact) tend to use the service delivery system. For example:

- Adults who receive case management services from a County Board of Developmental Disabilities or a Provider Agency
- Adults in the Service Support Administration (SSA) system



THE PROBLEM

Based on what we know, **almost 60% of all adults with ID/DD are NOT receiving services or supports from county or state programs.**

Most adults with ID/DD are NOT KNOWN, so they are hard to contact.

We DO NOT know:

- Who they are
- Where they live or work
- What services and supports they need



We know very little about adults with ID/DD who are hard to contact.

We DO NOT know about their:

- Education level (e.g., *did they get a high school diploma or a college degree?*)
- Employment status (e.g., *do they have a job or work full- or part-time?*)
- Income level (e.g., *how much money do they make?*)
- Support needs (e.g., *do they need a service provider or support staff?*)
- Health and well-being (e.g., *do they need a doctor or counselor?*)

CONCLUSION

We DO NOT know about MOST adults with disabilities.

What we know about SOME adults may not apply to others.

We need to include MORE adults with disabilities in research.

Tips

Health and disability researchers can contact MORE adults with disabilities in:

- Advocacy groups (e.g., [Ohio Self-Determination Association](#))
- Community programs (e.g., [Next Chapter Book Club](#))
- Disability organizations (e.g., [See a list of disability organizations](#))
- Faith communities



Adults with disabilities can learn how to get involved in research at [this link](#):



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