



# Addressing Barriers to Research Participation Among Individuals with IDD

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## INTRODUCTION

- Individuals with intellectual and developmental disabilities (IDD) experience widespread disparities in health outcomes due to the long history of unequal services and exclusion.
- Discrimination, stereotyping, and bias has often excluded many with IDD from participation in research. Resulting in research studies not reflecting their interests and concerns.

## OBJECTIVE

The goal of this study is to identify the barriers that exist between researchers, self-advocates, and researchers. Then creating a meaningful community partnership network between groups to improve participation and equity in research.

## METHODS

### Participants

15 Participants were recruited.

- o 5 Self-Advocates from 2 focus groups
- o 3 Caregivers/Providers from 2 focus groups
- o 7 MIND Researchers from 1 focus group

### Data Collection

- Qualitative data were collected using focus group discussions.
- Participants were asked a variety of questions based on barriers they have experienced conducting or participating in research.

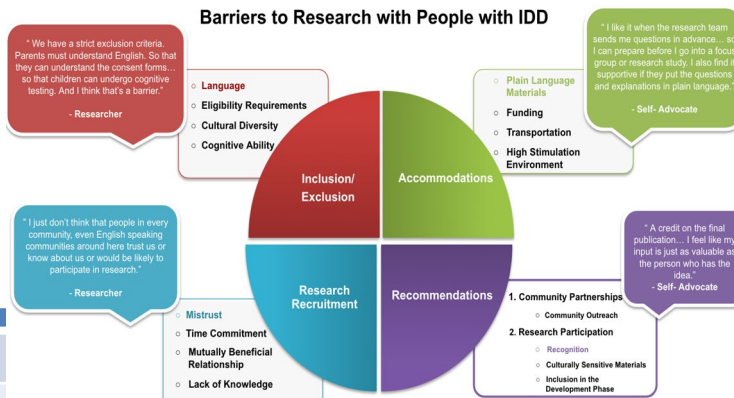
Groups	Questions
Researchers	<ol style="list-style-type: none"> <li>1. Barriers to conducting research with people with IDD and their families</li> <li>2. Barriers to recruiting and forming partnerships</li> </ol>
Self-Advocates & Caregivers/Providers	<ol style="list-style-type: none"> <li>1. Barriers to participating research with people with IDD and their families</li> <li>2. Barriers to recruiting and forming partnerships</li> </ol>

## RESULTS

Figure 1. Word Cloud from Focus Group Transcripts



Figure 2. Pie Chart of Themes and Subthemes Generated



## CONCLUSIONS

This research aimed to address barriers to research participation among individuals with IDD. Based on a qualitative analysis from focus group transcripts. It can be concluded, that when developing a research study incorporating individuals with IDD as well as their families discussing experiences and sharing ideas is an essential step to improve research participation.

## LIMITATIONS & FUTURE DIRECTIONS

### Limitations

- Small sample size
- Potential bias in answers

### Next Steps

- Community Academic Partnership Teams (CAP) will be formed to create an implement a more equitable and inclusive research agenda.
- Trainings (Researchers & Community Members/Self-Advocates)
- Trust building activities in underrepresented community groups

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