



# 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.

- 5 Self-Advocates from 2 focus groups
- 3 Caregivers/Providers from 2 focus groups
- 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.

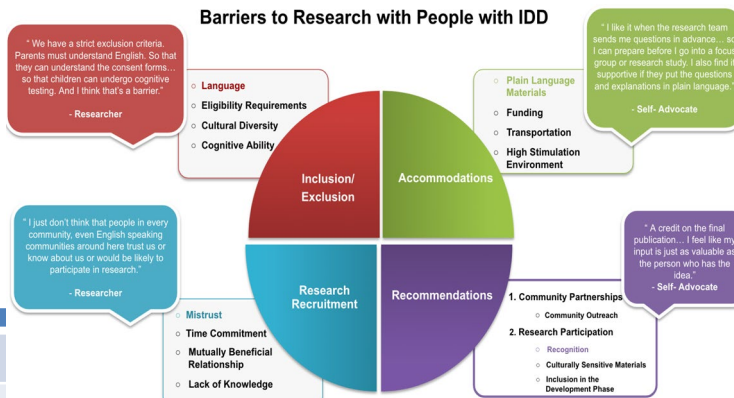
Groups	Questions
Researchers	<ol style="list-style-type: none"> <li>Barriers to conducting research with people with IDD and their families</li> <li>Barriers to recruiting and forming partnerships</li> </ol>
Self-Advocates & Caregivers/Providers	<ol style="list-style-type: none"> <li>Barriers to participating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

## ACKNOWLEDGEMENTS

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# OBJECTIVES

1. To identify barriers that exist in research from the perspectives of self-advocates, caregivers/providers and researchers.
1. To create a meaningful community partnership network between groups to improve participation and equity in research.

# METHODS

## Participants

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Groups	Questions
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# RESULTS

## Data Analysis

4 major themes emerged after a review of transcripts

1. Inclusion/Exclusion Criteria
2. Accommodations
3. Research Recruitment
4. Recommendations



# RESULTS

## Barriers to Research with People with IDD

“ We have a strict exclusion criteria. Parents must understand English. So that they can understand the consent forms... so that children can undergo cognitive testing. And I think that's a barrier.”

- Researcher

- **Language**
- **Eligibility Requirements**
- **Cultural Diversity**
- **Cognitive Ability**

**Inclusion/  
Exclusion  
Criteria**

**Accommodations**

- **Plain Language Materials**
- **Funding**
- **Transportation**
- **High Stimulation Environment**

“ I like it when the research team sends me questions in advance... so I can prepare before I go into a focus group or research study. I also find it supportive if they put the questions and explanations in plain language.”

- Self- Advocate

“ I just don't think that people in every community, even English speaking communities around here trust us or know about us or would be likely to participate in research.”

- Researcher

- **Mistrust**
- **Time Commitment**
- **Mutually Beneficial Relationship**
- **Lack of Knowledge**

**Research  
Recruitment**

**Recommendations**

- 1. Community Partnerships**
  - **Community Outreach**
- 2. Research Participation**
  - **Recognition**
  - **Culturally Sensitive Materials**
  - **Inclusion in the Development Phase**

“ A credit on the final publication... I feel like my input is just as valuable as the person who has the idea.”

- Self- Advocate

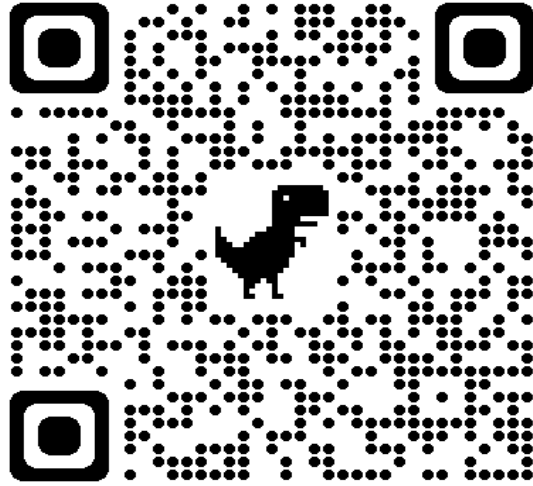
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# REFERENCES



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