

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	Barriers to conducting research with people wi IDD and their families Barriers to recruiting and forming partnerships
ı	Self-Advocates & Caregivers/Providers	Barriers to participating research with people with IDD and their families Barriers to recruiting and forming partnerships

RESULTS

Figure 1. Word Cloud from Focus Group Transcripts research project social media autism medical care adult transition different language experience services barriers diversity community member things gift cord regional center disability best way person anything participants time little bit provider study questions children email community group kind of research research year special need transportation family facilitator lot of time research team parents access way guy someone kind of things ISSUES next question somebody lot name information researchers brother flyer great way mir accommodation mom intellectual disability developmental disability

Figure 2. Pie Chart of Themes ans 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 equitible and inclusive research agenda.
- Trainings (Researchers & Community Members/Self-Advocates)
- Trust building activities in underrepresented community groups

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