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.

RESULTS

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

• Small sample size
• Potential bias in answers

ACKNOWLEDGEMENTS

I would like to thank my mentors Dr. Leonard Abbeduto and Dr. Angela Thurman for their guidance and support throughout this project as well as my colleague Adriana Perez. Finally I thank Dr. Janice Enriquez, and the MCHC RISE-UP program for this opportunity.
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• Discrimination, stereotyping, and bias has often excluded many with IDD from participation in research. Resulting in research studies not reflecting their interests and concerns.
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.
Participants

15 Participants were recruited.

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<table>
<thead>
<tr>
<th>Groups</th>
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<tbody>
<tr>
<td>Researchers</td>
<td>1. Barriers to conducting research with people with IDD and their families</td>
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<td>2. Barriers to recruiting and forming partnerships</td>
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<tr>
<td>Self-Advocates &amp; Caregivers/Providers</td>
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Data Analysis

4 major themes emerged after a review of transcripts:

1. Inclusion/Exclusion Criteria
2. Accommodations
3. Research Recruitment
4. Recommendations
Barriers to Research with People with IDD

**Inclusion/Exclusion Criteria**
- Language
- Eligibility Requirements
- Cultural Diversity
- Cognitive Ability

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

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

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

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"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

"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

"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

"A credit on the final publication... I feel like my input is just as valuable as the person who has the idea."
- Self-Advocate
This research aimed to address barriers to research participation among individuals with IDD. Based on a qualitative analysis of focus group transcripts. It can be concluded, that when developing a research study incorporating individuals with IDD as well as their families to discuss experiences and share ideas is an essential step to improving research participation.

**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
Scan the QR code to see references