Participation for Adults with Intellectual Disabilities: How Parents and Support Staff Scaffold Respectful Facilitation

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Self-determination for people with intellectual and developmental disabilities (IDD)

- **Fewer opportunities** to make choices, **denied ability** to enact choices, and are **less self-determined** overall than peers without disabilities (Wehmeyer & Abery, 2013; Khemka, 2021; Mahoney et al., 2016).

- $\uparrow$ **self-determination** = $\uparrow$ **quality of life and life satisfaction** (Mumbardó-Adam et al., 2020; McDougall, Evans & Baldwin, 2010; Schalock & Verdugo, 2002).

- **Care partners** can support self-determination (Dean et al., 2021; McCausland et al., 2022; Shogren et al., 2021).
Exclusion in Research Participation

- People with IDD historically have faced exclusion in research participation

  - Systematic exclusion due to eligibility criteria or federal regulations (DeCormier Plosky et al., 2022; McDonald, Schwartz & Sabatello, 2022; St John et al., 2022)

  - Inaccessibility of research environment (St John et al., 2022)

  - Perceived lack of ability or interest in participation (Horner-Johnson et al., 2013; Sabatello et al., 2019; St John et al., 2022)
## Theory

<table>
<thead>
<tr>
<th>Neoliberalism</th>
<th>Transactionalism</th>
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<tr>
<td>● Emphasizes choice and individualism</td>
<td>● Person, environment, and occupation are not individual constructs but function <em>in relation</em> to each other</td>
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<td>● Health and well-being are a result of people’s own choices</td>
<td>● Constructions are inextricably intertwined</td>
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(Gappmayer et al., 2019; Lee Bunting, 2016)
Methods

Larger Study - Wisconsin Partnership Program

• Interviews, Surveys, and Photovoice data examining impact of COVID-19 pandemic for adults with IDD in Wisconsin

Photovoice data: daily occupations impacted by pandemic
What is Photovoice?

Participatory, qualitative research method

• “...a process by which people can identify, represent, and enhance their community through specific photographic technique.” (Wang & Burris, 1997)

• Developed to give voice to communities who have been marginalized

Adapted to support research participation for people with IDD to include their opinions, experiences, and change policy

(St. John et al., 2018, St. John et al., 2018, Heffron et al., 2018; Watchman et al., 2022)
Our Photovoice Study

Our Research Question:
How has the COVID-19 pandemic changed things you do every day for your health and well-being?

For example:

…your life at home or living situation?
…your work?
…your community?
…your healthcare?

Captions: P I C

Purpose: Why did you choose to take this picture?

Information: Describe what is happening in this picture.

Caption: What does this picture tell us about you, your experience, or your health?
Photovoice Data: Photos & Captions

“I learn how to cook and bake, which increased during COVID. Take baked goods / treats to grandma and her friends. It was hard realization that I couldn't give your grandma a hug.”

“Killing germs and keeping people safe. I'm washing hands. Soap on hands. Keeping other people safe and not spreading germs around.”

“I'm distancing myself from everything. Protect self and follow all safety procedures to prevent COVID. I'm still doing socially distancing to prevent self from getting COVID.”

“Playing bingo via Zoom. Used to play bingo at bowling alley but moved to Zoom.”
Methods

Secondary Analysis

- Care partners were integrated into our recruitment and data collection
- We observed *something special* about their participation

Research Question

How do care partners scaffold respectful facilitation, within the research study and at large in the community?
Methods

Data Sources

• Researcher’s field notes and voice memos
• Transcripts of focus groups sessions
Identified Key Support People

- 2 Family Caregivers
- Residential Housing and Disability Support Services Director
- 2 Representatives from Community-based organizations
Methods

Data Analysis

• Rapid Coding of focus group transcripts & researcher memos (Taylor et al., 2018)
  • Inductive: Category/Theme development
  • Deductive: Examples of themes
Results

Logistics and Pragmatics

Individual Level Advocacy

System Level Advocacy

Scaffolding Respectful Facilitation Primary Themes
Results

- **Logistics and Pragmatics**
  - Transportation to community and research events
  - Serving as communication liaison
  - Bridging social familiarity with new people or groups
Results

Logistics and Pragmatics

Care partner actions
- Coordinated introductions & follow-ups on research events

Individuals with IDD actions
- Created non-profit with physical space
- Space for community events & research
- Increased trust in research partners and activities

Access to Community Participation

Access to Research Participation

Care partner actions
- Coordinated introductions & follow-ups on research events

Individuals with IDD actions
- Created non-profit with physical space
- Space for community events & research
- Increased trust in research partners and activities
Results

Individual Level Advocacy

• Identifying meaningful activities in the community based on the individual's interests and needs
• Providing appropriate reminders of rules, goals, and processes during research
• Scaffolding communication
Results

Individual Level Advocacy

Care partner actions
Served as communication broker

Individual with IDD actions
Communicated with comfort & ease, highly engaged with new people

Full Participation in Study
(outcome: communication not a barrier)

Care partner actions
Offers choice of social distancing leisure

Individual with IDD actions
Engaged in safe pandemic leisure activity of model airplanes

Participation in Meaningful Occupations

Results

- Creating opportunities for meaningful occupational engagement when lacking
- Connecting appropriate candidates for research activities
- Navigating COVID-19 policies that impact occupational engagement
Results

PARTICIPATION FOR ADULTS WITH IDD

System Level Advocacy

Care partner actions
Connecting researchers and participants

Individual with IDD actions
Participation in Participatory Research

Research Diversity & Depth

Individual with IDD actions
Increased physical activity & social participation

Care partner actions
Became a Special Olympics Coach

Community Participation Ripple Effect
Discussion

- Dynamic interactions ↔ Participation & well-being

- Scaffolding → train clinicians and researchers → maximize autonomy and participation for people with IDD

- Supported decision-making → independence
  - Leads to greater satisfaction, sense of control, and quality of life
The Future of Occupational Science

- Prioritize participatory research methods that elevate lived-experiences
  - Care partners may play a role → What strategies can we use to facilitate areas where this balance is not naturally occurring?

- Consider theoretical and paradigmatic shifts that will have rippling effects within research and clinical practice


References


1. How do you involve care partners in your research or clinical practice? Have you observed something special?

2. What strategies have you used to intentionally include care partners while maximizing autonomy and self-determination?

3. How do you see this type of work applying to other populations?
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