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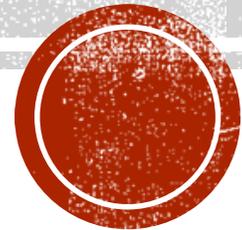


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**“NO! YOU CAN’T HAVE IT”:
PROBLEMATIZING CHOICE IN INSTITUTIONALIZED ADULTS
WITH INTELLECTUAL DISABILITIES**

Khalilah R. Johnson, PhD, OTR/L
Institute for Inclusion, Inquiry, and Innovation & Department of Occupational Therapy
Virginia Commonwealth University



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OVERVIEW

- Background and brief literature review
- Guiding research question
- Institutional ethnography
- Research site and participants
- Methods and analyses
- Meal time negotiations
- Implications for practice and research

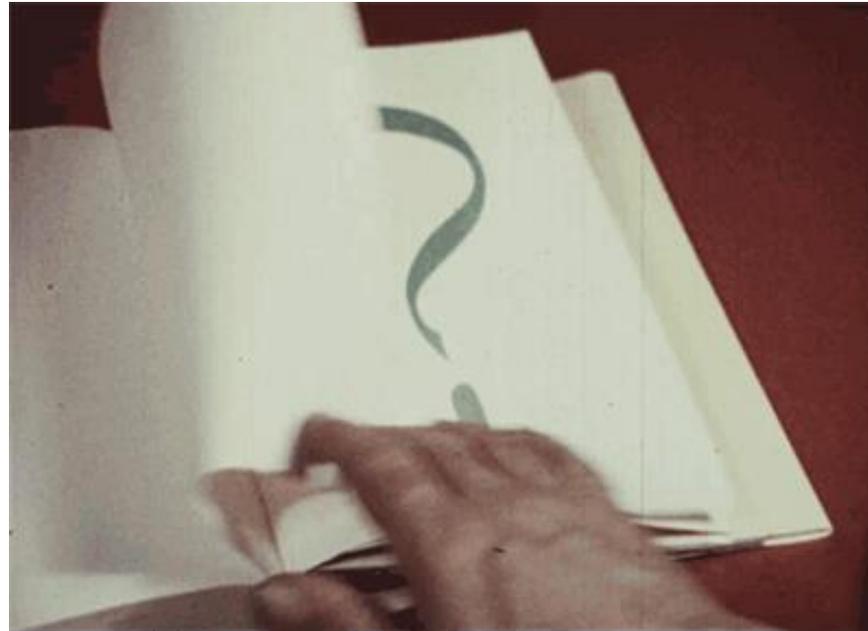


BACKGROUND

- **Adults with ID have fewer opportunities to make choices and are often denied opportunities to live their lives according to their preferences.**
(Johnson & Bagatell, 2018; Ward & Stewart 2008; Wehman, 2015; Wehmeyer & Abery, 2013; Wehmeyer, 2013)
- **Adults with profound ID are able to display distinct preferences and may become more self-determined if provided adequate supports.**
(Katz & Assor, 2007; Lohrmann-O'Rourke & Browder, 1998; Ward & Stewart, 2008)
- **Staff often face challenges with incorporating activities according to the interests and preferences of adults with ID.**
(Gray & Muramatsu, 2013; Johnson & Bagatell, 2017)
- **Direct care is affected by the types of services, personnel and management. Coupled with the lack of opportunities for self-determined choice-making, this may translate into practices that marginalize adults with ID.**
(Mansell et al., 2008)



How do meal time intervention plans become embodied restrictive practices?



INSTITUTIONAL ETHNOGRAPHY

- Social theory and methodology aimed to reveal the social practices and discourses that textually mediate how choice-opportunities emerge.
(Smith 2005, 2006)
- People function in the everyday world as social beings and that engagement is relational and purposefully coordinated through *work*.
(Campbell & Gregor, 2004; Smith, 2005)
- *Work* is the paid and unpaid activities that people perform every day.
(Smith, 2005)
- Human action is organized occurs through “ruling relations” – the concerted integration of extra-local texts (printed and electronic) that mediate and socially organize participation in daily life.
(DeVault, 2006)
- Exposes the *problematic* – the major issue under investigation



RESEARCH SITE

- The ***Community Center for Developmental Disabilities*** (CCDD) is an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)
 - Services: psychological and psychiatric care, nursing, occupational therapy, physical therapy, speech and language services, vocational training, and 24-hour custodial care.
- Residents and staff participants were recruited from ***Hope House***
 - Oldest residential facility at the CCDD.
 - Hope House is designed to resemble a conventional home; however, the facility contains artifacts that are characteristically institutional including hospital and adult crib beds and industrial-style bathrooms.



PARTICIPANTS

- Residents with ID
 - 4 men
 - 3 women
 - Severe and profound IDD
 - Minimal to total assistance; ambulatory and wheelchair users
 - Average age – 39 years
 - Average number of years in Hope House – 23 years
- Staff Members
 - 3 administrators
 - 5 direct care staff
 - 7 women
 - 1 man
 - Average age – 35 years
 - Average number of years employed at Hope House – 6 years, 8 months



METHODS & ANALYSES

- Participant-observation
 - Morning and night-time routines, meals, social and leisure activities, special events, daily charting, team conferences, and staff meetings.
- Interviews
 - 5 direct care staff and the shift supervisor completed formal individual interviews. Each individual interview ranged in length from 15 to 60 minutes. One group interview with 4 direct care staff and the shift supervisor convened for 45 minutes.
- Text analysis
 - Programmatic policies and procedures which participants stated were important to their work were identified through informal and formal interviews, and functioned as the lens through which to examine and document the organization of meal times.
- Narrative analysis
 - Meal time narratives were extracted from the field notes and analyzed through an iterative and reflexive process to contextualize and give meaning to what was happening during meal time exchanges between staff and residents.

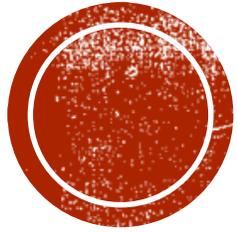


EXAMPLE FROM MEAL TIME NARRATIVES



The Phantom Meal Plan





Why does this matter?

IMPLICATIONS FOR PRACTICE & RESEARCH

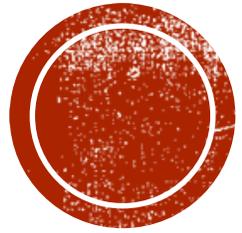
- Ongoing research in relation to institutionalized persons with ID
- Expanding the conceptualizations of nonverbal choice-making and its impact on person-centered practices
- Need for critical examination of national and state-level policies governing ICFs/IID
- Staff training in recognizing the various ways adults with ID may communicate through nonverbal, emblematic gesture vocabularies



LIMITATIONS

- Small sample size limits inferences.
- Knowledge gleaned is not transferrable to the experiences of staff and residents in similar facilities.
- Capturing the experiences of participants who are nonverbal or use non-symbolic forms of communication is challenging.





Questions?

Johnson, K., & Bagatell, N. (2018). No! You can't have it: Problematizing choice in institutionalized adults with intellectual disabilities. *Journal of Intellectual Disabilities*. Advance online publication. <https://doi.org/10.1177/1744629518766121>

Email: KJohnson84@vcu.edu

Twitter: @OccScienceBae