



Health Experiences of Individuals with Intellectual Disabilities Using Photovoice

Megan Gray, OTS, Amanda Malzacher, OTS, Brittany St. John, OTR/L, Libby Hladik, MSOT, Savanna Lurie, Karla Ausderau, PhD, OTR/L



OCCUPATIONAL THERAPY PROGRAM, DEPARTMENT OF KINESIOLOGY, UNIVERSITY OF WISCONSIN-MADISON

Introduction

- Individuals with intellectual disability are at an increased risk for health disparities.^{1,2,3}
- The personal accounts of individuals with intellectual disability are necessary to illuminate facilitators and barriers to health promotion to address these disparities.
- The photovoice method highlights important perceptions and experiences, with participants making decisions throughout all aspects of the process.⁴
- The objective of this qualitative study is to understand how individuals with intellectual disability participate in and access health promoting occupations using photovoice methodologies.

Methods

Using photos, interviews, and focus groups, participants (*n* = 10) answered three guiding questions:

- 1) What does it mean to be healthy?
- 2) What do you like to do to be healthy?
- 3) What makes it hard to be healthy?

Stages of Data Collection

Stage 1: Photovoice training
Camera orientation, project scope, brainstorming session

Stage 2: Photo collection
Take photos with researcher, narrative description of photos

Stage 3: Caption interviews
Semi-structured interviews to develop caption explaining why participants took each photo

Stage 4: Focus groups
Share photos and captions with other participants, share experiences

Stages of Data Analysis

Stage 1: Data Management
Organize photos and transcribe interviews.

Stage 2: Independent Analysis
Independent Analysis of data to identify preliminary themes

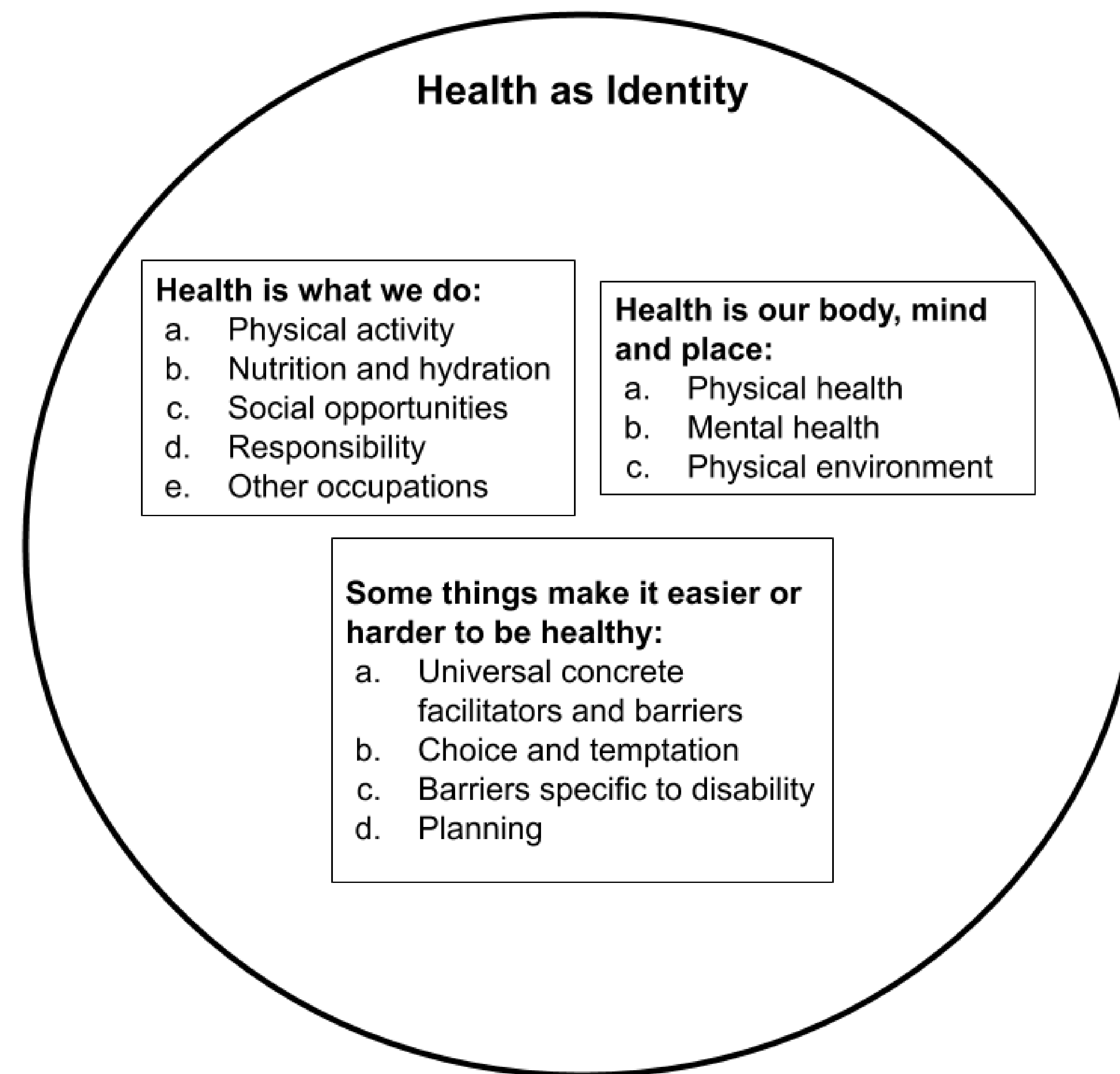
Stage 3: Team Analysis
Team shares themes, develops and consolidates common themes.

Stage 4: Member Checking
Present accessible summary of themes to participants, gather feedback, integrate changes

Results

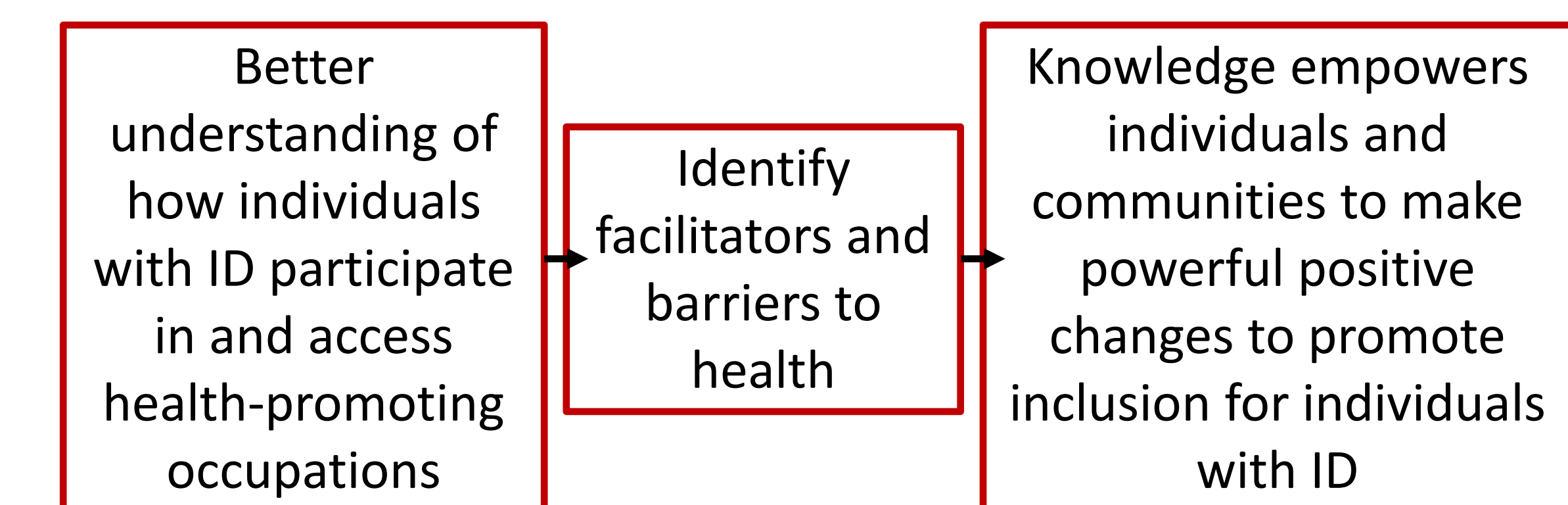
Four themes were found after data analysis:

- 1) Health as identity
- 2) Health is what we do
- 3) Health is our body, mind and place
- 4) Some things make it easier or harder to be healthy



Discussion

- Participants broadly perceived themselves as healthy.
- Participants definitions of health align with the World Health Organization's broad definition.
- Components of health are interconnected. For example, playing team sports provides socialization and physical activity.
- Definitions highlight impacts of social determinants of health.
- Understanding of health-related experiences of people with intellectual disability presents an opportunity for positive change.



- Member checking was an essential component for interpretation of data.

Implications for Practice

- Organizations can use facilitators to health to inform programming.
- Facilitators include planning in ways to make healthy activities easier, personal choices, concrete facilitators such as community resources that are affordable and close, workout and leisure supplies, and more.
- Programs should view health from the holistic perspective described.

Limitations

- Themes revealed only represent experiences of participants.
- Participants live in similar geographic area, may influence results.

Acknowledgments

The authors would like to express their gratitude to participants, lab volunteers, and our generous funding sources, the Society for the Study of Occupation – USA and the Gertrude E. Gaston Endowment in Occupational Therapy Fund at the University of Wisconsin - Madison

References

¹ Krahn, G. L., & Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities*, 27(5), 431–446. <https://doi.org/10.1111/jar.12067>

² Lahti Anderson, L., Humphries, K., McDermott, S., Marks, B., Sisarak, J., & Larson, S. (2013). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *L'état de la science de la santé et le bien-être des adultes ayant une déficience intellectuelle*, 51(5), 385–398. <https://doi.org/10.1352/1934-9556-51.5.385>

³ Young-Southward, G., Rydzewska, E., Philo, C., & Cooper, S. -A. (2017). Physical and mental health of young people with and without intellectual disabilities: Cross-sectional analysis of a whole country population. *Journal of Intellectual Disability Research*, 61(10), 984–993. <https://doi.org/10.1111/jir.12422>

⁴ MacDonald, C. (2012). Understanding Participatory Action Research: A Qualitative Research Methodology Option. *The Canadian Journal of Action Research*, 13(2), 34–50. <https://doi.org/10.33524/cjar.v13i2.37>