

Safety, Choice, & Autonomy for People With Intellectual and Developmental Disorders & Their Caregivers During the COVID-19 Pandemic

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PURPOSE: Adults with intellectual and developmental disabilities (IDD) often experience challenges in employment, housing, and accessing safe and quality services; this has been further exacerbated by the ongoing COVID-19 pandemic. The purpose of the study was to understand how adults with IDD who receive state-funded adult long-term care (LTC) services report their safety and ability to make choices during the COVID-19 pandemic, as compared to their caregivers.

DESIGN: Participants were over 18, living in Wisconsin, and receiving LTC supports. The survey was available for a person with IDD or an individual who could report on their behalf; 88% (n=181) of respondents were caregivers and 11% (n=23) were adults with IDD. The average age of survey respondents was 29 and the sample was largely male (58.3%; n=99).

METHOD: This study is part of a larger study surveying a state-level sample of adults receiving LTC. The original data set surveyed eligible participants over several time periods, the first data collection beginning in 2017. The sample included in this presentation will focus on data collected during 2021 (n=206). Respondents for the survey included both adults with IDD living in Wisconsin receiving LTC and/or their care partner or another individual who is able to report on their behalf. Respondents were asked a series of multiple choice questions, including their perceived safety and ability to make choices, through an online survey.

RESULTS: Preliminary results show that the majority of adults (67%; n=151) did not report safety concerns. Those that did report concern reported they felt the most unsafe at home. When asked to describe more specifically, there were discrepancies in answers between surveyed care recipients and their care partners. The top reported concern was the physical environment for care recipients and concerns about being alone for care partners. Questions regarding choice and autonomy revealed that the majority of respondents (56.8%; n=125) reported having some to no control over their lives. Additional findings related to choice, autonomy, and safety will be discussed, specifically focusing on the comparison between survey results for care recipients compared to their care partners.

CONCLUSION: Self-determination is a highly discussed topic for adults with intellectual and developmental disabilities, especially when focusing on concerns regarding autonomy, choice, and safety. The ongoing COVID-19 pandemic is exacerbating existing challenges related to self-determination for this population, therefore, it is even more important that occupational therapists and researchers are dedicating efforts to prioritizing the needs of this population. This study illuminates concerns regarding autonomy, choice, and safety during COVID-19 as it is directly linked to improved health and well-being. This study will continue to forward innovative occupational therapy intervention ideas and areas for research to address an existing gap in the literature on self-determination in the midst of a global pandemic. This study will also propose next steps for addressing self-determination during COVID-19, prioritizing the lived experiences and contributions of self-advocate researchers, and provide examples for accessible and inclusive dissemination of this work. The role of occupational therapists in supporting community-dwelling adults with ID receiving LTC services and supports, especially in response to the COVID-19 pandemic, will be identified. This work will substantially impact occupational therapy practice by providing clear recommendations to address historically disadvantaged and marginalized individuals.

References

- Dodds, R. L., Maurer, K. J., Montgomery, L. S., Cutting, S., & Jilek, C. (2022). Self-advocate perspectives on COVID-19 in Urban Los Angeles: impacts on autonomy and access to supports. *Journal of Intellectual & Developmental Disability*, 1-14.
- Linehan, C., Araten-Bergam, T., Baumbusch, J., Beadle-Brown, J., Bigby, C., Birkbeck, G., Bradley, V., Brown, M., Bredewold, F., Chirwa, M., Cui, J., Godoy Gimenez, M., Gomiero, T., Kanova, S., Kroll, T., MacLachlan, M., Mirfin-Veitch, B., Narayan, J., Nearchou, F., Nolan, A., ... Tossebro, J. (2020). COVID-19 IDD: A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers. HR
- Sheppard-Jones, K., Avellone, L., Rumrill, P., & Seward, H. (2021). Impact of COVID-19: Considerations for individuals with developmental disabilities across major life domains. *Journal of Vocational Rehabilitation*, 54(1), 5-13.
- Vicente, E., Mumbardó-Adam, C., Guillén, V. M., Coma-Roselló, T., Bravo-Alvarez, M. A., & Sánchez, S. (2020). Self-Determination in People with Intellectual Disability: The Mediating Role of Opportunities. *International journal of environmental research and public health*, 17(17), 6201. <https://doi.org/10.3390/ijerph17176201>