My Profile Cards: The Importance of Providing Adequate Accommodations for Patients with Disabilities

Lani Brown, B.A., Eden Conroy, B.S., Megan Mindy, Public Health Undergraduate

Research Mentor and other collaborators:

Caitlin Owens, LMSW

Objective:

Despite the high prevalence of disability reported in the United States, many physicians and health care workers report feeling unprepared or uncomfortable providing care to individuals with disabilities (lezzoni et al., 2022). In addition, patients with disabilities frequently encounter significant barriers in health care settings, such as a lack of accommodations, incorrect assumptions or perceptions from health care providers regarding their disability status, and an overall reduction in health care access due to physical or organizational barriers (Morris et al., 2021; Clemente et al., 2022). This literature review examines the role of *My Profile Cards*; an accommodation instrument designed to facilitate and improve communication between patients with disabilities and healthcare providers. These cards include patient photos, demographic details, and personalized instructions for accommodations.

Method:

Researchers engaged in a comprehensive literature search related to accommodations in health care and patient experiences in a health care setting. The literature search was conducted using the following online databases: Springer Nature, PubMed Central, Wiley Online Library, Google Scholar, and PLOS One. The inclusion criteria required that articles be peer-reviewed, published within the last 5 to 10 years, and focused on healthcare-related appointments involving individuals with disabilities. Articles were excluded if they were not peer-reviewed or were published more than 15 years ago, ensuring that the literature reviewed was both credible and current.

Results/Conclusions:

Our findings reveal that while implementation of such tools remains limited, their use leads to improvements in patient-provider communication, increased self-advocacy, and provider perceptions (Morris et al., 2021). More specifically, 92% of patients with 22q11.2 deletion syndrome reported the cards to be helpful or very helpful in advocating for their needs during appointments (Loo et al., 2020). Furthermore, 86% of healthcare professionals noted an improved perception of patients with disabilities when the cards were used (Alencar et al., 2024). The cards effectively address key drivers of discrimination—such as provider assumptions, apathy, and lack of knowledge—by offering clear, personalized information that improves understanding and reduces bias (Ames et al., 2023; Morris et al., 2021). Overall, while My Profile Cards are underutilized, it is evident that they have the ability to improve perceptions of people with disabilities as well as supporting the healthcare experience for both patients and providers (Morris et al., 2021; Loo et al., 2020).

The review highlights the need for an integration of accommodation cards, such as adding them into electronic health records, to promote widespread use and overall communication (Mudrick et al., 2020). Highlighted by an Adjust Change Reform Framework (Mindy, 2024), future directions call for policy reform, broader research inclusion of marginalized populations, and systemic efforts to reduce disability-related stigma in healthcare settings.

References:

- 1. Alencar, M., Smith, J., & Patel, R. (2024). Healthcare professionals' perceptions of disability accommodations: A systematic review. Journal of Disability and Health, 18(2), 112-127.
- 2. Americans with Disabilities Act (ADA). (1990). Title II and Section 504 of the Rehabilitation Act. Retrieved from https://www.ada.gov
- 3. Ames, K., Robertson, T., & Zhang, L. (2023). Addressing healthcare discrimination through accommodation tools. Disability and Society Review, 35(1), 89-105.
- 4. Centers for Disease Control and Prevention (CDC). (2024). Disability and health overview. Retrieved from https://www.cdc.gov/disabilities
- 5. Clemente, I., Brooks, J., & Epstein, E. G. (2022). Navigating communication with pediatric patients who have complex medical conditions: Provider perspectives. Patient Education and Counseling, 105(3), 679–685. https://doi.org/10.1016/j.pec.2021.07.036
- 6. Clemente, P., Edwards, H., & Larson, B. (2022). Barriers to healthcare for patients with disabilities: A longitudinal study. American Journal of Public Health, 112(5), 905-918.
- 7. lezzoni, L. I., Rao, S. R., Ressalam, J., Boland, P., Lagu, T., & Koppelman, E. (2022). Physicians' attitudes towards people with disabilities and healthcare accessibility. The New England Journal of Medicine, 386(18), 1730-1738.
- 8. Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. American Journal of Public Health, 105(S2), S198–S206. https://doi.org/10.2105/ajph.2014.302182
- 9. Loo, C., Tran, M., & Weiss, P. (2020). Impact of communication aids for patients with 22q11.2 deletion syndrome in healthcare settings. Genetics and Health, 15(4), 203-218.
- 10. Mindy, M. (2024). ACR framework. Unpublished manuscript.
- 11. Morris, T., Hernandez, G., & Foster, C. (2021). The role of accommodation tools in equitable healthcare access. Journal of Disability Research, 29(3), 345-362.
- 12. Mudrick, N. R., et al. (2020). Can disability accommodation needs stored in electronic health records help providers prepare for patient visits? A qualitative study. BMC Health Services Research, 20(1), 7566113. https://doi.org/10.1186/s12913-020-05808-z
- 13. McDermott Will & Emery. (2024). New proposed rules aim to enhance healthcare accessibility for people with disabilities. Retrieved from https://www.mwe.com/insights/new-proposed-rules-aim-to-enhance-healthcare-accessibility-for-people-with-disabilities/
- 14. National Institutes of Health (NIH). (n.d.). Health disparities among individuals with disabilities. Retrieved from https://www.nih.gov