

Integrating Stakeholder Participation for Production and Dissemination of Research Findings

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PURPOSE: Individuals with IDD have unique and often complex healthcare needs, including an increased risk of numerous secondary conditions (Havercamp & Krahn, 2019) that contribute to significant health disparities. However, they are commonly excluded from health research opportunities that may begin to address these disparities (McDonald et al., 2018). It is critical that individuals with IDD and their caregiving communities are provided inclusive research opportunities to address these existing practices and resulting consequences, as well as inform future research and policy decisions to mediate the effects of health disparities. The purpose of this study is to identify and describe ways for integrating stakeholders within the larger research process to produce and disseminate scientific research.

DESIGN: A prospective study of stakeholder engagement was implemented to identify meaningful and appropriate stakeholder integration into the production and dissemination of research results.

METHOD: Three co-researchers with IDD were identified to participate in producing and disseminating the results of a larger research project. Participants assisted with development of a manuscript on health disparities and advocacy work for people with IDD and integrated in multiple aspects of the manuscript production. Co-researchers were interviewed on effective inclusion mechanisms that were implemented throughout the process and interviewed after manuscript completion. Virtual meetings were held to discuss the research process and co-construction of a manuscript that integrated the co-researcher ideas, lived experiences and feedback through an iterative process.

RESULTS: Co-researchers identified general and unique ways to support their communication and learning styles to allow for their participation. They also identified unique aspects of the manuscript production that were the best match for their personal skill sets. Unique strategies will be outlined in the presentation. In addition personal health stories and case examples were developed and integrated into the manuscript. Co-researchers highlighted their personal experiences with health disparities research and how they advocated for changes to their healthcare provision as well as educating their personal doctor and legislators. In addition, co-researchers supported the development of an “easy read” format that provided an accessible format of the finalized manuscript for accessible dissemination. Co-researchers overall were very satisfied with their participation in the manuscript development and identified it as an important part of participating in the overall research process.

CONCLUSION: This project highlights the collaborative work between researchers and self-advocates with IDD. Self-advocates have a role in the research process, including the production and dissemination of research findings. Three co-authors with IDD participated in the co-construction of a manuscript on inclusive health-promoting interventions. Details regarding the co-construction of the manuscript and perspectives from self-advocates with IDD will be included. The Easy Read Article Summary will be introduced as a collaborative tool to be integrated in the scientific community to promote accessible research dissemination. Impact Statement Inclusion of individuals with IDD in research production and dissemination is critical to ensure research priorities remain client-centered and stakeholder voices are represented. The Easy Read Article Summary provides an opportunity for accessible research dissemination and must be a top priority in occupational therapy research dissemination.

References

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