



The Impact of Educational Resources for Caregivers of Children with Down Syndrome

Samantha Hilyer, OTD; Chris Eidson, PhD, MS, OTR/L, FAOTA

Department of Occupational Therapy | University of Alabama at Birmingham

Madison Gaston, OTR/L | UAB Sparks Center for Pediatrics

Introduction

- Every year, one in 775 babies are born with Down syndrome, making it more common than any other chromosomal condition (*About down syndrome, n.d.*).
- Medical conditions associated with Down Syndrome include congenital heart defects, hearing loss, eye problems, and many others (Bull et al., 2022).
- Also, children diagnosed with Down Syndrome often face milestone delays in areas such as: (Baumer et al., 2024)
 - ADLs
 - IADLs
 - School based tasks
 - Sensory processing
- These delays can lead to a decrease in quality of life, due to the associated medical conditions as well as delays, for the individual and an increase in caregiver stress.
- There is a great need for easily accessible and readable resources to prevent further milestone delays, but barriers can make it difficult for families.
- These barriers include:
 - Readability (Schmidt, 2022)
 - Ease of access to local healthcare professionals (Alabama Department of Public Health, 2025)
 - Negative initial diagnosis experience (Artal et al., 2024)
- The purpose of this project is to create a resource for caregivers of children with Down syndrome to address care giving concerns through increased carryover of milestone development in the home and knowledge of care needs.

Methods

- Project implemented at UAB Civitan-Sparks Lifespan Down Syndrome Program, comprised of interdisciplinary team members, caregivers, and children with Down Syndrome.
- Participants were recruited through the Down Syndrome Program caregiver email group and social media group through an anonymous link.
- Creation of Resource:
 - Designed based on input from caregivers
 - 5th grade reading level
 - Non-serif print for visibility
- Resource was made available through printable PDF format and distributed between surveys through email and social media groups.
- Resource topics:
 - Personal hygiene
 - School based tasks
 - Caregiver resources
- Qualtrics survey (pre-test/post-test)
 - Statement of consent
 - 5-point Likert scale
 - Multi-select, multiple choice, and open-ended questions

Results

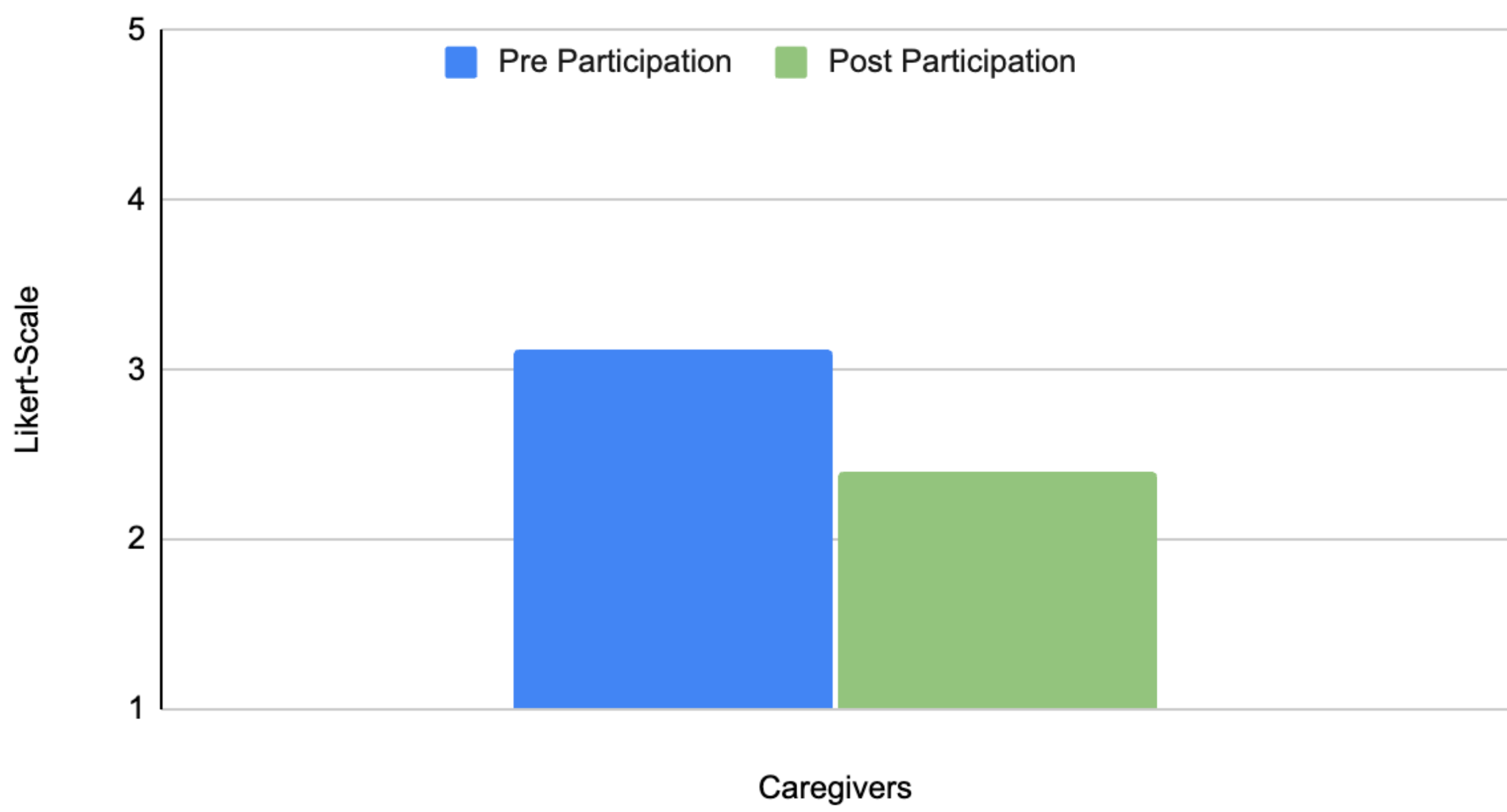
Pre-Survey

- 79 responses
- Caregiver knowledge, stress level, confidence, and resource organization preferences
- 15 questions including Likert-scale, multichoice, and open-ended

Post-Survey

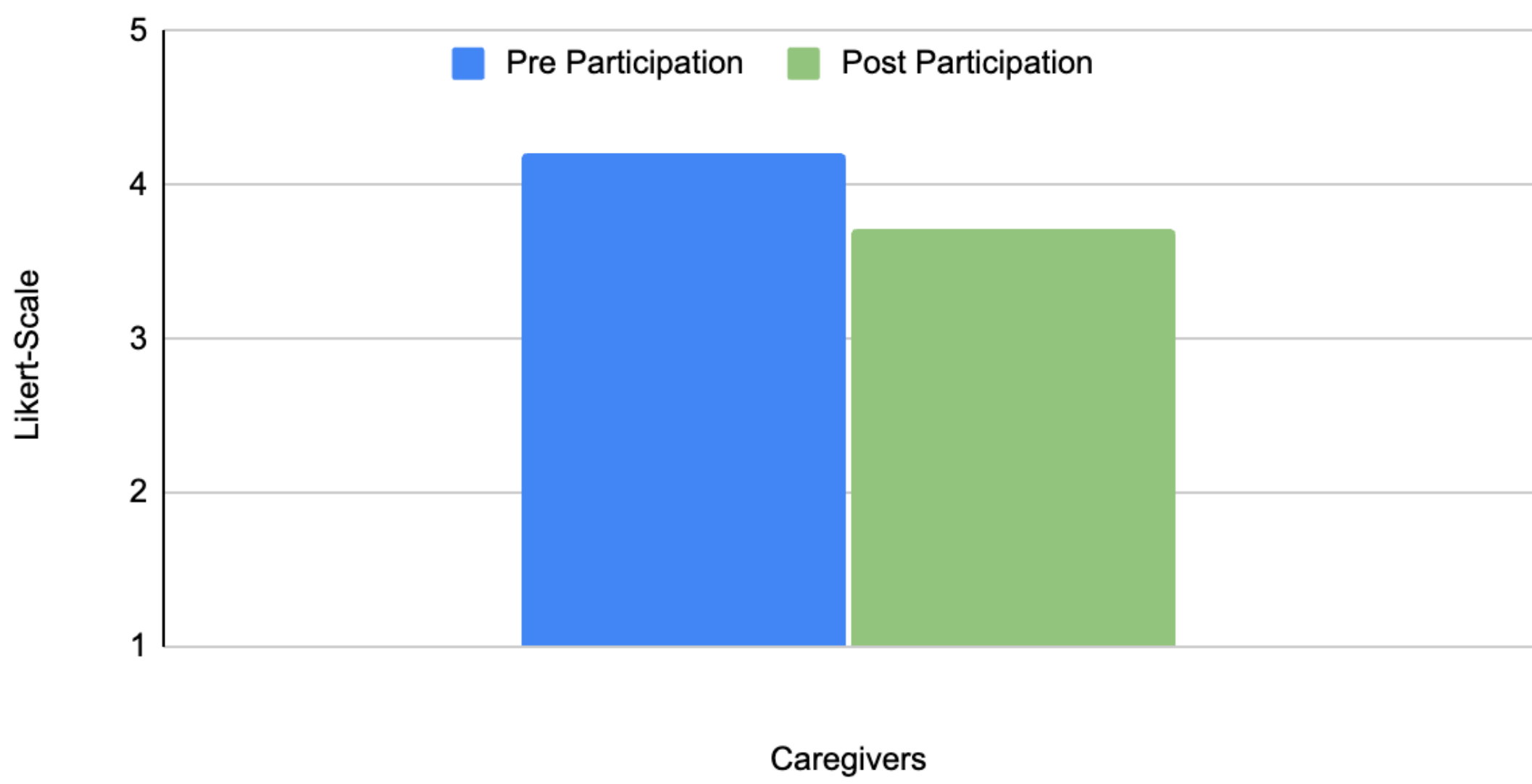
- 5 responses
- Caregiver knowledge, stress level, confidence, and perspective on resource effectiveness
- 8 questions including Likert-scale, multichoice, and open-ended

Pre and Post Measure of Caregiver Stress



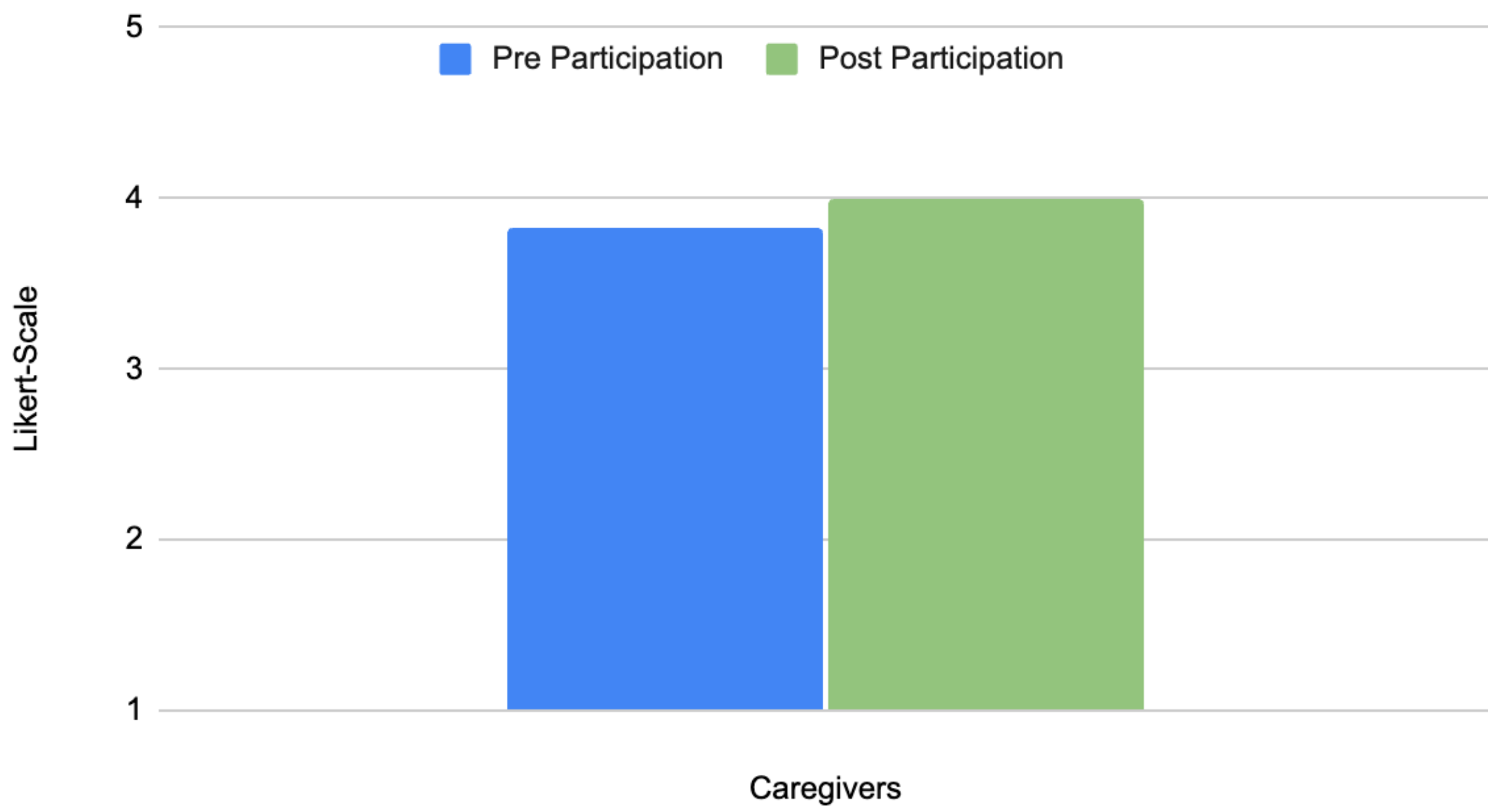
Note. Likert-Scale questions were used to obtain this data, with 1 being not stressed and 5 being very high stress.

Pre and Post Measure of Caregiver Confidence in at Home Skill Practice



Note. Likert-Scale questions were used to obtain this data, with 1 being not confident at all and 5 being very confident.

Pre and Post Measure of Caregiver Knowledge of Diagnosis



Note. Likert-Scale questions were used to obtain this data, with 1 being not confident at all and 5 being very confident.

Discussion

- Caregivers showed an increase in confidence in skill practice at home after distribution of the survey and an increase in their knowledge of the Down syndrome diagnosis. They also reported a decrease in stress after receiving and reviewing the resource.
- These results can be attributed to the initial survey regarding preferences such as content, language, and organization. As this survey was written based on state literacy levels, 5th grade, this could be a key player in improvement of understanding and confidence.

Limitations

- Lack of required answers to all questions within the initial survey which caused several respondents to decline to answer multiple questions throughout the survey, resulting in 79 participants with an answer frequency ranging from 59-70
- No exclusion criteria questions placed within the survey, as this survey was anonymous, which potentially allowed for individuals outside of the desired population to respond
- Low number of responses to the secondary survey due to technical difficulties with survey distribution

Future Research

- This resource should expand to other age ranges, such as adolescents, to become a lifespan resource for caregivers and individuals with Down syndrome
- Conducting a survey in collaboration with other disciplines would allow for the creation of a more holistic resource to address all areas of concern for caregivers to carry over therapy into their homes.

Conclusion

This study revealed that caregivers are seeking information pertaining to ADLs and how to practice at home as well as associated stories/ charts. Providing a resource to educate caregivers, increasing independence in their child's life roles, is a vital component of milestone achievement. Continuing to expand on this resource and create others like it is the way to see advancements in milestone achievement within this population and highlight the co-occupation of caregiving by decreasing their stress, increasing their knowledge and self-efficacy.

References

- About down syndrome.* National Down Syndrome Society (NDSS). (n.d.-a). https://ndss.org/about#p_71
- Alabama Department of Public Health (ADPH). (2025). *At a glance.* <https://www.alabamapublichealth.gov/ruralhealth/at-a-glance.html>
- Artal, J. M., Randall, L., Rubeck, S., Allyse, M., Michie, M., Riggan, K. A., Meredith, S., & Skotko, B. G. (2024). Parents of children with Down syndrome reflect on their postnatal diagnoses, 2003-2022. *American journal of medical genetics. Part A*, 194(8), e63619. <https://doi.org/10.1002/ajmg.a.63619>
- Baumer, N., DePillis, R., Pawlowski, K., Zhang, B., & Mazumdar, M. (2024). Developmental milestones for children with Down Syndrome. *Pediatrics*, 154(4). <https://doi.org/10.1542/peds.2023-065402>
- Bull, M. J., Trotter, T., Santoro, S. L., Christensen, C., & Grout, R. W. (2022). Health supervision for children and adolescents with down syndrome. *Pediatrics*, 149(5). <https://doi.org/10.1542/peds.2022-057010>
- Schmidt, E. (2022). Reading the numbers: 130 million American adults have low literacy skills. Retrieved from <https://www.apmresearchlab.org/10x-adult-literacy>

Acknowledgement & Contact information

Special Thanks To: Madison Gaston OTR/L

Contact Information: Samantha Hilyer: skhilyer@uab.edu