

Feasibility of Telehealth Caregiver Group Intervention for Behavior Difficulties in School-Age Children with Down Syndrome

Allison Meyer, PhD^{1,2}, Rebecca Bernstein, BA¹, Maritza Cobian, PhD^{1,2},
 Kristine Wolter-Warmerdam, PhD ABD, MA¹, Francis Hickey, MD^{1,2}

¹The Sie Center for Down Syndrome, Children's Hospital Colorado, Aurora CO

²Department of Pediatrics, University of Colorado School of Medicine, Aurora CO



Background

- Children with Down syndrome (DS) often have significant behavior difficulties that interfere in their own and their family's lives with some studies estimating more than 90% of children have a challenging behavior weekly or daily
- To address behavior difficulties in DS, interventions such as ABA therapy are often recommended. In addition, school-age children often access additional therapy services including speech, occupational, physical therapies
- Additional accessible intervention options that support a whole-child perspective on behavior in DS are needed

Objectives

- To evaluate the feasibility and acceptability of a caregiver telehealth group to address behavior difficulties in school-age children with DS
- To explore change in caregiver strategy-use after group participation

Methods

Participants

- 30 school-age children (54.8% male) with DS seen at a multidisciplinary DS clinic
- Mean age=7.7 yrs (SD=1.9), range=5-12 yrs
- Caregiver reported concerns for behavior such as aggression, elopement, refusal, and non-compliance
- 61.3% (n=19) English-speaking caregivers; 38.7% (n=12) Spanish-speaking or multilingual caregivers
- Can access a virtual telehealth service (i.e., Zoom)

Measures:

- Feasibility and acceptability: Caregiver survey completed via REDCap (within 6 weeks after last group session)
- Exploratory measure: Caregiver reported strategy use pre-treatment and post-treatment (within 6 weeks of last session)

Intervention

Group Format

- Group was provided in English or Spanish
- Six visits over 8-12 weeks via telehealth
 - Individual intake session with psychologist
 - Four 90-minute group sessions with up to 4 families
 - Session 1:* Learning style of DS; common behavior difficulties; understanding behavior difficulties in DS using iceberg (see Figure 1)
 - Session 2:* Caregiver focused strategies to support behavior
 - Session 3:* Use of consequence-based strategies; child-focused strategies to increase skills
 - Session 4:* Role of emotion regulation in behavior; wrap-up
 - Individual follow-up with psychologist

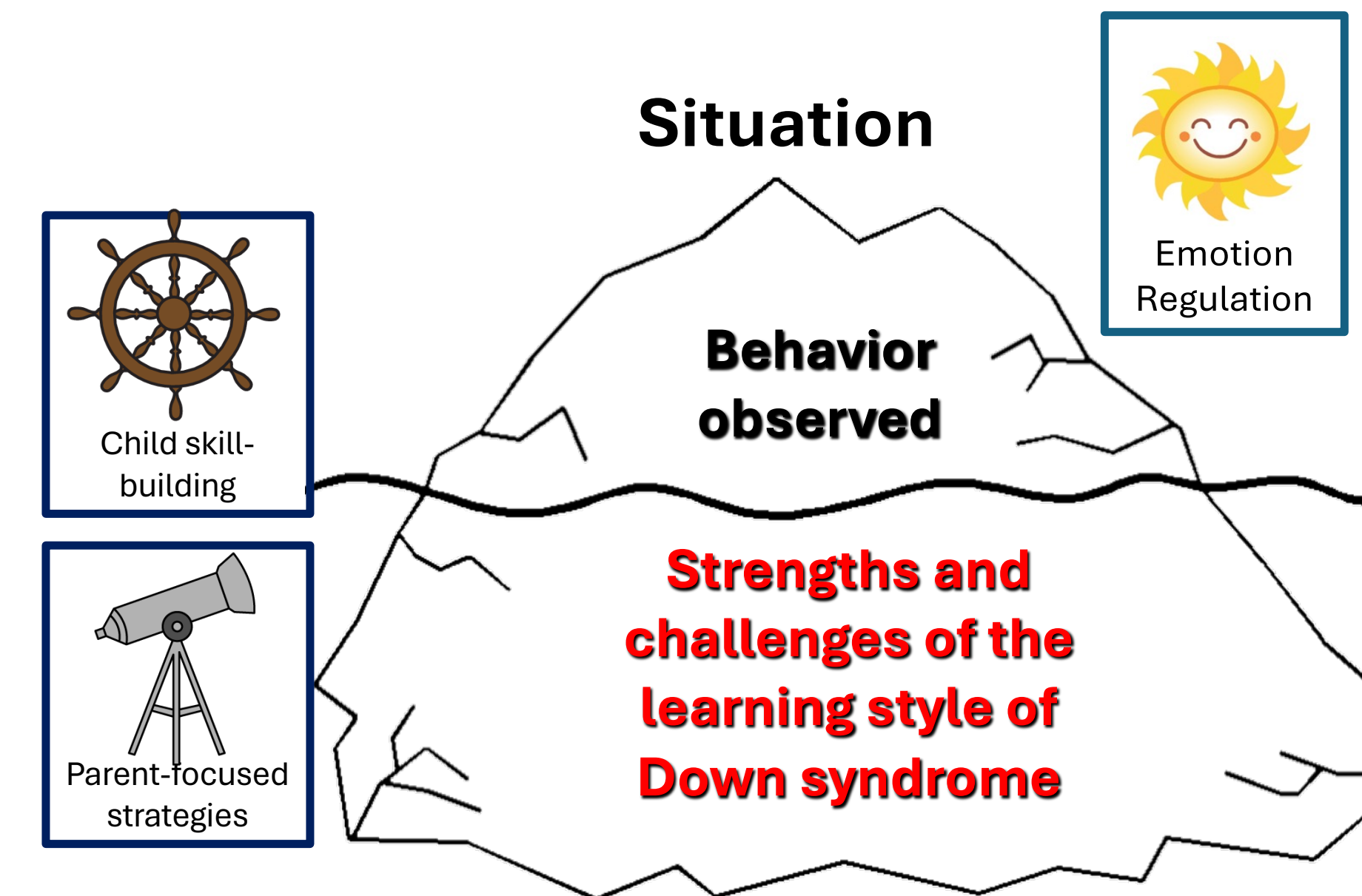


Figure 1: Iceberg model used throughout group sessions to understand behavior

Results

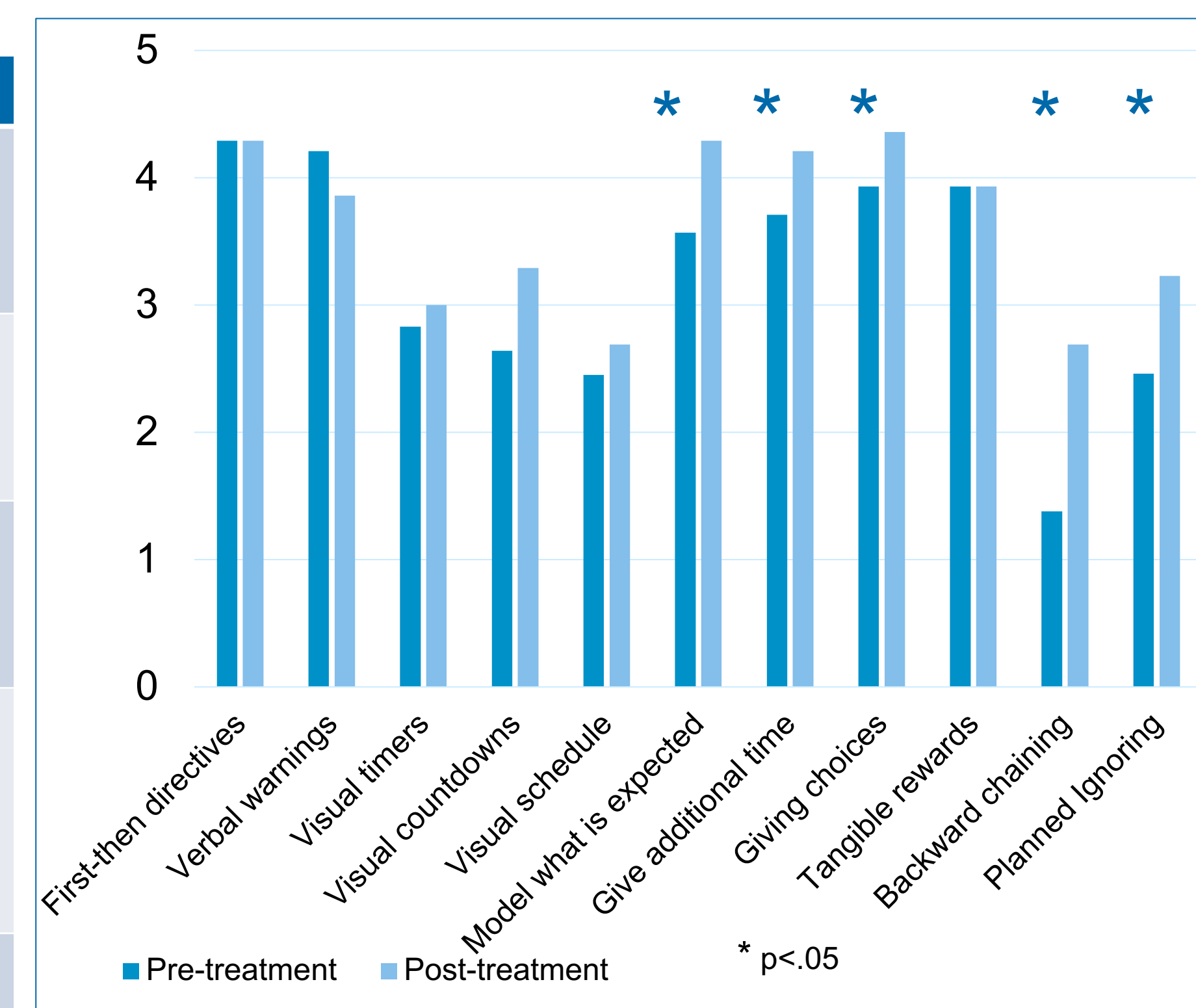
Feasibility and Acceptability

- On a scale of 1 (*Strongly disagree*) to 4 (*Strongly agree*), overall ratings were high and suggest this type of group is feasible and acceptable to families of school-age children with DS to address behavior concerns (see table below)
- Independent samples t-tests indicated no significant differences between parents that participated in Spanish vs. English groups

Question	English	Spanish	p
The strategies discussed in this group were helpful for my family.	3.47 (.52)	3.25 (.50)	.48
I was able to teach my child strategies to decrease difficult behaviors.	3.33 (.49)	3.25 (.50)	.78
I would recommend this group to others who have children with similar needs.	3.67 (.49)	3.50 (.58)	.62
The format of 4 group sessions with 1-2 individual follow-up sessions was appropriate.	3.60 (.51)	3.25 (.50)	.27
The telehealth format of this group worked well for my family.	3.69 (.48)	3.50 (.58)	.58

Use of Strategies

- Caregivers rated their use of strategies on a scale of 1 (*Never*) to 5 (*Always*) pre- and post-treatment
- Paired samples t-tests indicated significant increase in use of several caregiver-focused strategies



Conclusions

- English and Spanish-speaking caregivers report that a parent-coaching telehealth group to support behavior difficulties in their child with DS is helpful and feasible
- There was significant improvement in caregiver-use of several strategies. It is particularly notable that caregivers readily incorporated strategies that could be used across environments and without additional materials (i.e., giving processing time, modeling, planned ignoring, etc.). However, results should be interpreted with caution as it does not account for repeated measures across participants

Implications

- Caregiver satisfaction and change in caregiver behavior can be provided through a *brief* telehealth intervention (8 hours or less)
- Empowering caregivers to feel confident managing their child's behavior and emotion regulation needs can support increased access to the community and decreased need for additional intensive therapies
- Additional studies are needed that evaluate change in caregiver strategy use, change in child behavior, and inclusion emotion regulation in conceptualizing behavior, and expands access to families that speak a wide range of languages
- Limitations:
 - Small sample size, particularly with post-treatment measures for Spanish-speaking families
 - Limited to those that can access telehealth

References

- Patel, L., Wolter-Warmerdam, K., Leifer, N., & Hickey, F. (2018). Behavioral characteristics of individuals with Down syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, 11(3), 221-246.
- Will, E., & Hepburn, S. (2015). Applied behavior analysis for children with neurogenetic disorders. In *International review of research in developmental disabilities* (Vol. 49, pp. 229-259). Academic Press.
- Neil, N., Amicarelli, A., Anderson, B. M., & Liesemer, K. (2021). A meta-analysis of single-case research on applied behavior analytic interventions for people with Down syndrome. *American Journal on Intellectual and Developmental Disabilities*, 126(2), 114-141.
- Neil, N., & Jones, E. A. (2018). Communication intervention for individuals with Down syndrome: Systematic review and meta-analysis. *Developmental Neurorehabilitation*, 21(1), 1-12.

Disclosures

The authors declare that they have no conflict of interest with respect to the research, authorship, and/or publication of this article. The authors received no financial support for the research, authorship, and/or publication of this article.