



# Exploration of the personal care device management needs of children with Down syndrome



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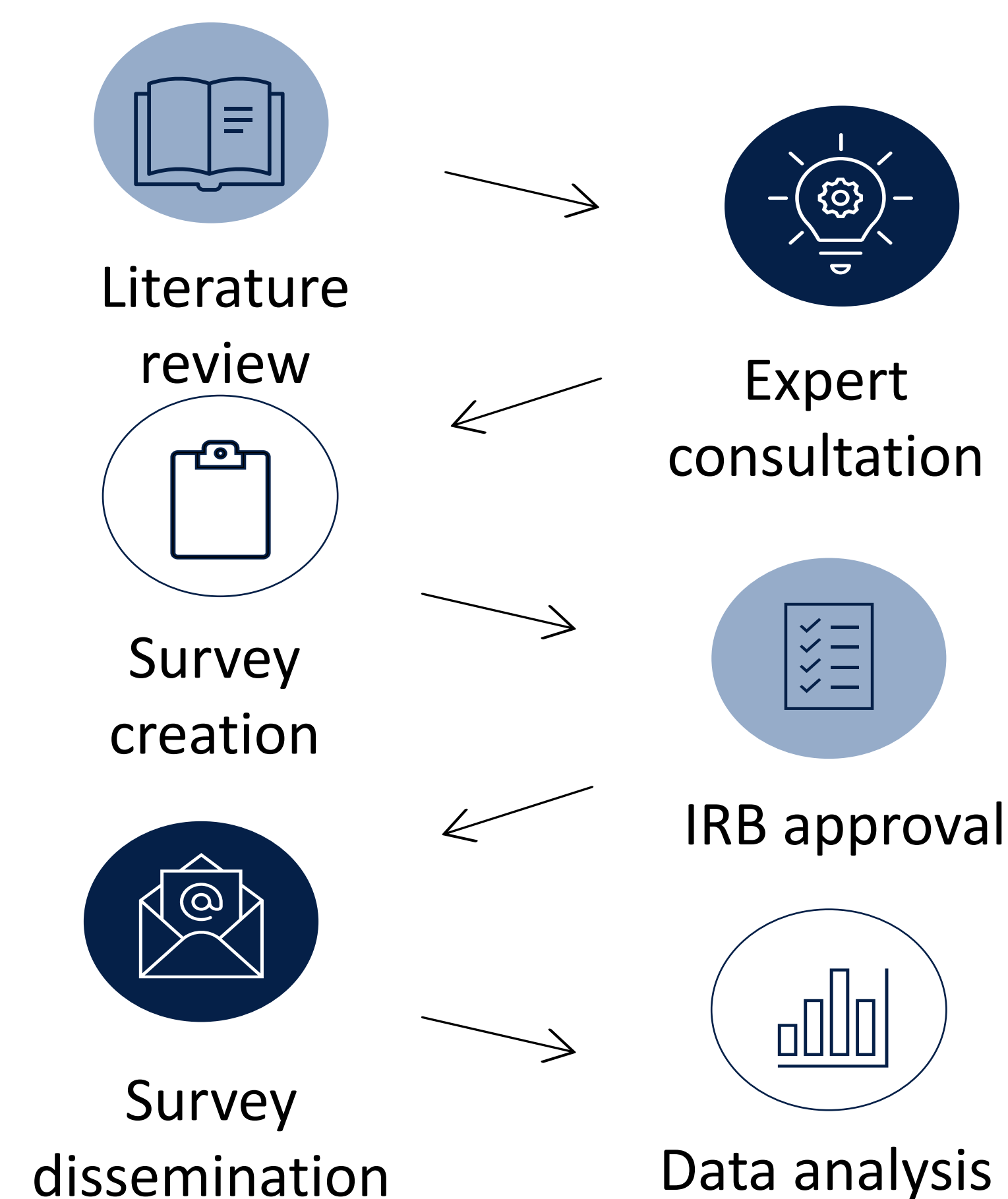
## Introduction

- Personal care device management is defined as access, use, and maintenance of eyeglasses, hearing aids, and CPAP/BiPAP machines (AOTA, 2020)
- Down syndrome (DS) is associated with high rates of:
  - vision problems (60-80%)
  - hearing loss (75%)
  - obstructive sleep apnea (50-79%) (Bull et al., 2022)
- Anecdotally, individuals with DS struggle with equipment use
- Possible reasons for difficulty with equipment adherence include:
  - Physical characteristics of DS leading to poor fit
  - Financial concerns
  - Fear of losing/breaking devices
  - Lack of training/support
  - Decreased understanding of benefits of benefits
  - Sensory sensitivities
  - Anxiety/difficulty with change
  - Behavior (Patel, 2019)

## Research question

What are the barriers and facilitators to access and use of personal care devices for children with Down syndrome?

## Methods



- Web-based survey available in English and Spanish
- Skip logic determined the number of questions for each respondent based on the equipment prescribed
- Caregivers rated their answers on a Likert scale

## Results

A total of 103 surveys were completed and returned.

Table 1: Child Demographics

	n	%
<b>Age</b>		
≤ 10 years old	61	59.22
> 10 years old	36	34.95
<b>Biological Sex</b>		
Male	53	51.46
Female	48	46.60
<b>Race</b>		
White	33	32.04
Hispanic/Latino	49	47.57
Asian/Pacific Islander	15	14.56
Black/African American	11	10.68
Decline to state	7	6.80
<b>Autism Diagnosis</b>		
Yes	16	15.53
No	80	77.67

Table 2: Caregiver Demographics

	n	%
<b>Language</b>		
English	86	83.50
Spanish	17	16.50
<b>Education Level</b>		
Middle school or lower	10	9.71
High school/some college	31	30.10
College degree or higher	56	54.37
<b>Income Level</b>		
< \$30,000	18	17.48
\$30,000 - \$74,999	34	33.01
≥ \$75,000	44	42.72

Medical Equipment: Prescribed vs. Used

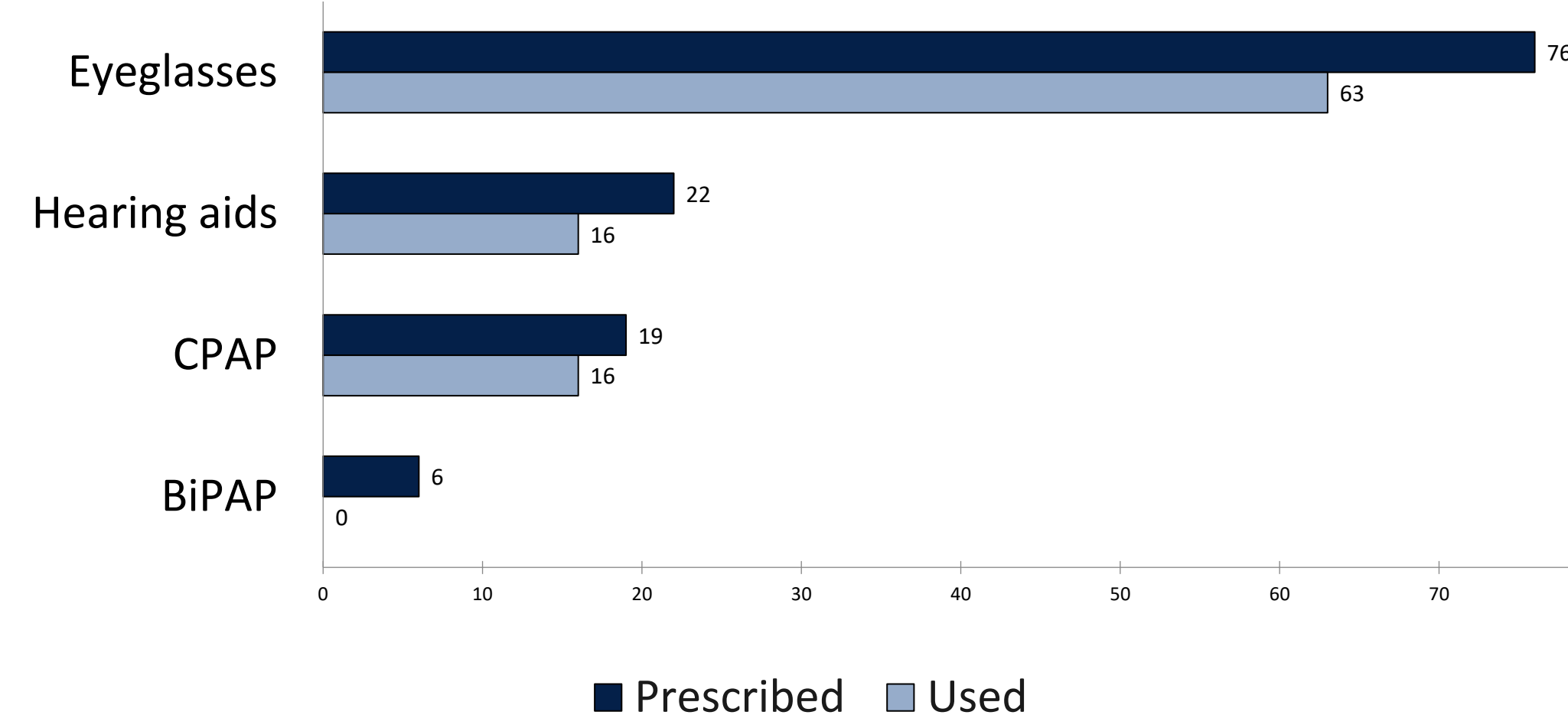


Table 3: Reasons for Non-adherence by Device

Reason	Eyeglasses	Hearing aids	CPAP/BiPAP
It is expensive to obtain/replace equipment (63.2%)	I am concerned my child will damage or lose equipment (61.5%)	My child is sensitive to loud noises (64.7%)	
My child doesn't like having things on their face (55.9%)	My child takes out their hearing aids (61.5%)	My child simply does not tolerate equipment (47.1%)	
I am concerned my child will damage or lose equipment (54.4%)	The process for obtaining equipment was difficult (53.6%)	My child understands the benefits of the equipment (23.5%)	

- 43% of respondents strongly agree or agree with the statement "I wish I had more support in having my child wear their [devices]"
- Tolerance increased with child's age for eyeglasses and CPAP/BiPAP ( $\chi^2(1) = 8.50, p = .004$ ;  $\chi^2(1) = 3.66, p = .056$ )
- No significant differences were detected between equipment adherence and family income, caregiver education level, language of survey completion, or co-occurring autism diagnosis

## Discussion

- More specific training/support for parents of children with DS within interdisciplinary team is needed
- There is an important role for occupational therapy in personal care device management for equipment adherence
- Occupational therapy approaches may include sensory strategies, creation of routine, family training & support, desensitization protocols
- Increasing caregiver and child participation in personal care device management can positively impact occupational performance in other areas such as ADLs, education, and sleep
- The sample was not powered enough to show differences between groups; additional research is needed in this area

## Future steps

- Development of a brief clinical tool to assess adherence to prescribed equipment and specific reasons for decreased adherence
- Creation and implementation of prescriptive desensitization program that uses DS friendly strategies such as parent coaching, visual aids, and video modeling

## References

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, 74, 7412410010. <https://doi.org/10.5014/ajot.2020.74S2001>

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): e2022057010. <https://doi.org/10.1542/peds.2022-057010>

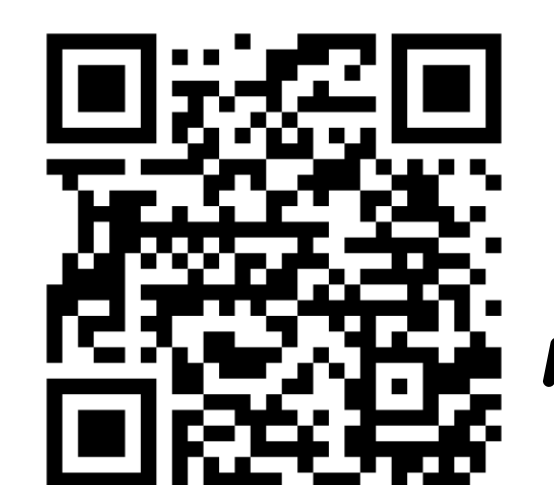
Patel, L. (2019, December). *CPAP, Hearing Aids, and Glasses, Oh my! How to Help My Child to Wear Their Medical Equipment* [Presentation slides]. Global Down Syndrome Foundation. <https://www.globaldownsyndrome.org/wp-content/uploads/2019/12/Desensitization-December-2019.pdf>

## Acknowledgements

Thank you to my mentors for their expertise and support throughout this capstone experience.



Down Syndrome Connection of the Bay Area  
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