

A Decade of Reach Out and Read Implementation in a Pediatric Down Syndrome Clinic

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Background of ROR in a DS Center

- Reading aloud between parents and children is a strong predictor of emergent literacy and important method to increase language development.
- Reach Out and Read (ROR) program was established to promote literacy development by incorporating books into routine pediatric healthcare and encourage families to read together.
- Our research shows that children with DS benefit from this early literacy promotion in a medical setting.
- In 2015, the Sie Center for Down Syndrome (DS) was the first DS clinic in the U.S. to implement the ROR program. We report on the program's milestones, modifications made, and lessons learned, revealing the unique impact of the ROR program in a pediatric DS clinic

Program Participation

- In 10 years of ROR at the Sie Center, we have distributed:
 - 2,581 books** to **1,164** unique children
 - 2024 (n=**295**); 2023 (n=**247**)
 - Books in **8 languages** including: Dari, Rohingya, Vietnamese, Kinyarwanda, Portuguese, and Farsi
 - Our total collection includes books in 23 languages
- Diverse group of patients participating in ROR, including children with:
 - Autism (n=**101**; 8.7%)
 - Hearing impairment (n=**660**; 56.7%)
 - Vision impairment (n=**866**; 74.4%)

Ten Years Later – What we Have Learned

Program Expansions for a Pediatric DS Clinic

Age of program participation

- 2015-2020 ROR program ages: **6 months to 5 years**
- Our program broadened the age range to include **infancy to age 6 years** in 2021
 - Goal was to introduce reading aloud as a developmental tool starting at an earlier age and better address the neurodiversity in our patient population.

Talking points to families

- Before ROR participation, many caregivers had a limited view on literacy achievement in DS. Since partnering with ROR, we:
 - Share our **research** regarding the positive impact of a ROR program with our population.
 - Model** shared reading and discuss the benefit of early reading aloud.
 - Share learning and bonding opportunities beyond reading (face-to-face time, sound of voice/listening skills, learning facial cues, and time spent together).



Target **content books** for our unique population – many with co-occurring conditions

- Include autism, visual and hearing impairments, dyslexia, ADHD, executive functioning, and sensory integration disorder.
- Distribute books with relatable content such as touch and feel books, books with music, books that address feelings or the challenges of making friends.



Adding books like "Sensory Ninja" based on needs of our patients

Collaborative effort in clinic

- Our multidisciplinary providers include the child's ROR book **in the visit**.

Distribution of books to siblings

- Collection of gently used books that we distribute to siblings.
 - Siblings can be a **role model** for the enjoyment of reading and encouraging shared reading.

Building Literacy Through Partnership

- Established meaningful partnership with the **National ROR Organization**.
- Sie Center representation on the **ROR Board of Directors**.
 - Establish a working partnership for our clinic.

Implications

- Building stronger families through reading** - ROR promotes healthy family routines such as reading together, reduced screen time, and supported sibling bonding through enjoyed reading aloud to their brother/sister.
- Promoting cultural connection** - Having books available in many languages was crucial in respecting and helping parents communicate with their child with DS.
- Program modifications** - Target unique needs of this population to support overall child development in children with DS.
 - Book selection** - Ten years later, in partnership with ROR, we are still able to make modifications to book selections, age ranges, etc. for this program to work successfully with our patient population.
- Family engagement** – Educating caregivers and families about the importance of reading aloud starting at a very early age.



Disclosures

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