

Reach Out and Read Implementation in a Pediatric Down Syndrome Clinic

Dee Daniels, CPNP, RN, MSN, Kristine Wolter-Warmerdam, PhD ABD, MA,
 Samantha Holland, BS, Fran Hickey, MD

Sie Center for Down Syndrome, Children's Hospital Colorado



Background

- Reading aloud between parents and children is a strong predictor of emergent literacy and important way to increase language development. The 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.
- While significant research has focused on understanding ROR, no studies have specifically evaluated the impact of clinic-based literacy programs on children who have Down syndrome (DS). Many of these studies explicitly exclude children with developmental delays/disabilities despite that, with proper support, most children with DS can read at levels that meet or exceed the abilities of typically developing children matched for mental age.
- To our knowledge, no studies have examined the implementation of clinic-based early literacy programs for children with DS. Limited research exists to describe the early literacy behaviors and environment of young children with DS.

Objectives

This study describes the implementation of the first ROR program in a specialty pediatric Down Syndrome (DS) clinic in the U.S. and contributes to a better understanding of the emergent literacy behaviors, practices, and environment of young children with DS and their families.

Methods

This descriptive study incorporates a retrospective review of a large cohort of children with DS and results from a family literacy survey. Program data and electronic medical records from a full cohort (n=747) of children with DS who participated in ROR between ages 6 months-5 years at the Sie Center for Down Syndrome (SCDS) was evaluated. Additionally, a literacy survey was completed by 209 of the families regarding the home literacy environment, patient's emergent literacy habits and behaviors, and impact of the ROR program.

Reach Out and Read Implementation in Clinic

Overall, the SCDS engaged in **1,477 ROR encounters** with 747 unique patients.

Table 1 Reach Out and Read program participants

Characteristics	ROR Program Patients with DS	
	n	%
Total patients	747	100.0%
Language		
English	620	83.0%
Spanish	109	14.6%
English and Spanish	4	0.5%
Other language	12	1.6%
Unknown	2	0.3%
Book age range		
0-12 months	47/423	11.1%
12-18 months	25/423	5.9%
18-24 months	45/423	10.6%
2-3 years	60/423	14.2%
3-4 years	63/423	14.9%
4-5 years	183/423	43.3%
Insurance type		
Medicaid	368	49.30%
Private insurance	364	48.70%
Other	28	3.70%

Additional information regarding 28.0% (n=209/747) of the clinic's ROR families were gathered through a literacy survey. Forty-five percent (n=94) of these children with DS had an audio or visual impairment.

Table 2 Reach Out and Read literacy survey families

Characteristics	ROR Program Survey Families	
	n	%
Total patients	209	100.0%
Mother's education level		
High school	68	32.5%
Bachelor's degree	74	35.4%
Master's degree	41	19.6%
Doctorate degree	13	6.2%
Other	6	2.9%
Unknown	7	3.3%
Number of child books in the home		
20 or less	20	9.6%
21-50	54	25.8%
51-100	76	36.4%
Over 100	44	21.1%
Unknown	15	7.2%

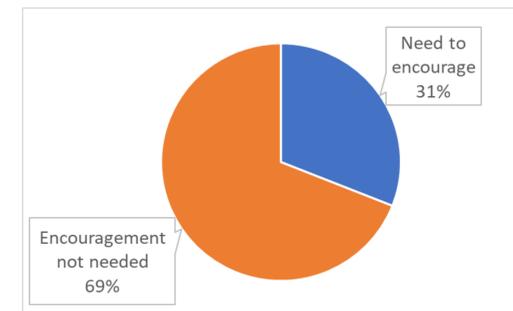
Results

Literacy Behaviors in Children with DS

On average, children with DS participating in ROR began **independently reading at 6.15 years** (SD=1.42). Children with DS most frequently engaged in the following activities when being read to:

- Point at pictures (83.3%)
- Seem to enjoy songs/rhymes (73.6%)
- Look at pictures of other babies or children (65.1%)
- Name pictures (52.6%)
- Move around while you read (45.0%)

Approximately, a third of parents reported needing to encourage their child to participate in reading.



While more children with DS and an audio or visual impairment required encouragement (36.7%) compared to those without (29.6%), this relationship was not significant, $X(1)=1.102, p=0.294$.

Parent Behaviors

- Overall, parents of children with DS participating in the ROR program felt that their **child will read** in his/her lifetime (96.0%).
- A child received more reading time from families each week when the **mother had a college degree** (144.11 minutes \pm 98.02) compared to mothers who had less of an education (109.67 minutes \pm 81.21) (Independent-samples t-test; $p=0.017$).
 - There was no relationship between the number of minutes that a child was read to and the number of minutes that the: 1) parent engages in screen time (television, playing video games, tablet, etc.), 2) parent reads outside of work, and 3) the child engages in screen time (Pearson correlations; $p>0.05$).

Impact of Reach Out and Read

- One-sided Fisher's Exact tests were conducted to compare Child Home Literacy Index scores of active ROR families of children with DS with the active ROR controls without DS.
 - There was a significant difference for:
 - Child's reported favorite activity included books/reading** (DS=25.1%; non-DS control group=87.5%; ($p=0.001$))
 - Five or more books for child at home** (DS=92.3%; non-DS=50.0%; $p=0.003$)
 - Child owns 10 or more books** (DS=90.9%; non-DS=25.0%; $p=0.001$)
 - No difference in bedtime routine includes books/reading, parent reports reading to child, reading aloud 3 or more days per week, and child has access to books in both ROR groups.

Conclusions

- Overall, 96% of parents of children with DS participating in the SCDS ROR program believed their child will read independently in their lifetime.
- Our results indicate that children with DS in our clinic participating in ROR were reading independently on average at 6.15 years of age (SD: 1.25), which is within the scope of when typically developing children begin reading.
- Children with DS, especially those with an audio or visual impairment, may need extra resources and encouragement to engage in reading.
- Our results support the current literature: mothers with a college degree read significantly more per week to their child compared to mothers who had less of an education regardless of both groups participating in ROR.

Implications

- The ROR program is an important clinic-based literacy program for children with DS.
- Children with DS often meet or exceed the abilities of a typically developing children when provided the right literacy resources. Participation in the ROR program during the first 2-5 years of age allows for similar independent reading age achievement compared to typically developing peers.
- Additional support and resources are needed to further encourage enjoyment with reading in this population, especially in children with additional audio or visual impairments, as well as with families with mothers without a college education.
- The ROR program can greatly impact the DS population and other children with developmental disabilities by providing families the resources and structure to encourage literacy.

Disclosures

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