

Promoting Family Support in Community-Based Programs for Children with Down Syndrome Ages 0-3: A Needs Analysis



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GiGi's Playhouse Chicago¹

- Achievement Center located on the northside of Chicago that provides free educational, therapeutic, and vocational programs for families and the community.
- Programs offered across the lifespan to allow for a continuum of services through the Playhouse.
- Programs are offered free of cost .

Crawlers & Walkers Program

- Offered once per month, focuses on gross and fine motor skill development through organized play with an emphasis on family engagement; promoted for children ages 0-3 years old.²
- Once children reach the age of 3 years old, program coordinators have seen a decrease in attendance and program retention
- Incorporation of family-centered services for children with disabilities has been shown to increase feelings of family well-being.^{3,4, 5}

Leadership Project Aims

- Investigate ways to support families and caregivers within Crawlers & Walkers
- Develop strategies to meet family needs through the Crawlers & Walkers program
- Implement changes to program structure
- Inform best ways to support family retention in programs 0-3
- Create a sustainable method of program evaluation for future use in Crawlers and Walkers

Methods

Procedures for Data Collection

- Observed and participated in Crawlers & Walkers three times prior to data collection to understand class structure
- Pre-test- 10 question survey, offered in both English and Spanish versions
 - Spanish Translation courtesy of Daniel Garcia, SPT
- Consulted a former parent of the Crawlers & Walkers program (Michael Griggs PT, DPT) regarding the survey format and made appropriate changes
- In-person distribution of surveys, offered in both English and Spanish
- Retrospective parent interview of a family that has aged out of Crawlers & Walkers but still actively participates in GiGi's programs
- Observed additional programming at GiGi's for same age group participants: LMNOP

Procedures for Initial Implementation

- Added structure and variety to Crawler's and Walkers by introducing gross motor, fine motor, and sensory stations.

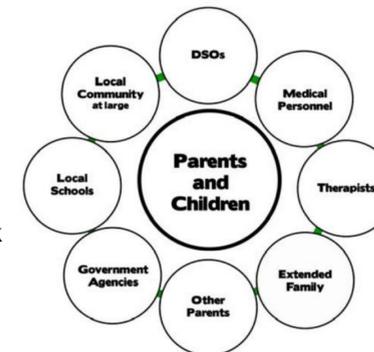
Key Themes

Current Value of Crawlers & Walkers Program

- Parents feel supported with program options offered at GiGi's Playhouse
- Parents feel supported with staff and volunteers at Crawlers & Walkers
- Parents enjoy the unstructured environment and the opportunity to connect with other parents

Areas for Improvement

- Resources for the timing and expectations of developmental milestones
- Additional online services for Crawlers and Walkers—newsletters with latest research
- Implementing a combination of structured time and free time
- Adding a sensory component
- Offering training sessions for parents at GiGi's Playhouse
- Creating a parent directory to facilitate connections of the informal parent network
- Creating an online forum to share relevant information about outside support
- Offering programming more frequently



Informal Parent Network

- Every family noted the value of parent connections within the program
- Research has shown parents of children with disabilities consider this as one of the most important factors when evaluating local communities.⁶

Considerations for Program Improvement

- Offer resources and social media posts in both English and Spanish
- Send email reminders prior to programming
- Expansion of informal parent network (i.e. Facebook groups) Advertise programming to bilingual volunteers
- Create Monthly themes and implement goal-writing on whiteboard prior to each session
- Advertise programming to undergraduate PT and OT students to increase skilled volunteering

References

Available upon request

Acknowledgements

Thank you Evguenia S. Popova, MS, OTR/L and GiGi's Playhouse Chicago for this opportunity. Thank you Michelle Bulanda, PT, DPT, DSc, PCS for her guidance. Thank you Michael Griggs, PT, DPT and Daniel Gracia, SPT for their assistance with survey development.

This work was supported by the Illinois LEND Program [Grant Number: T73MC11047; U.S. Department of Health and Human Services—Health Resources and Services Administration (HRSA)].