

Presenters:
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While We're Waiting:

Families creating supportive communities while waiting for their child's autism assessment

BACKGROUND:

Family as Faculty (FaF) are family partners who have completed a comprehensive training program that prepares them for partnerships in healthcare and education.

FaF embedded in redesigning ASD assessment process shared their lived experiences of waiting for assessments: feeling confused, scared, frustrated and lacking support.

FaF suggested families need:

- Better info about the diagnostic process
- Resources available while waiting
- Emotional support from peers with lived experience

The goal:

FaF and HB staff co-design a virtual, supportive, community group hosted by FaF, specifically for families awaiting an autism assessment.

THE PROGRAM:

"While We're Waiting"

- 90-min, monthly, virtual discussion for ~10 families, co-facilitated by FaF
- Provides info to families about assessment process
- Creates forum to share resources, stories and experiences, and to ask questions and provide emotional support
- Focus on parents' well-being
- Opportunity for participants to give feedback on the program

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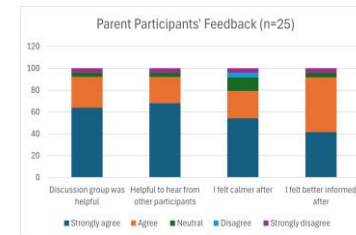


Holland Bloorview
Kids Rehabilitation Hospital



RESULTS:

- 7 monthly sessions run to date
- 109 people registered, 49 attended



IMPROVEMENTS SINCE IMPLEMENTATION

- Increased # of email reminders, which increased number of attendees
- Added video & flowchart to better inform about assessment process
- Added post-session email including resources, link to register for upcoming sessions, and feedback survey

OPPORTUNITIES AND BARRIERS

- Families who registered but did not attend said they were no longer interested (25%), had technology difficulties (25%)
- Existing barriers: access to device, language barrier
- Expand to supportive post-diagnostic communities
- Expand to other programs at Holland Bloorview