

Supporting Parents

Same Needs, New Normal

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Learning Outcomes

Participants will be able to...

- identify effective practices in providing parent supports.
- determine needs and topics to address in parent support groups.
- describe components of parent groups to use in their own work.

Disclosures

Meredith Berger

Non-Financial

Children's Hearing Institute-Medical
and Educational Advisory Board

NYS EHDI Advisory Committee

Financial

Employed by Clarke Schools
for Hearing and Speech

Jackie Garcia

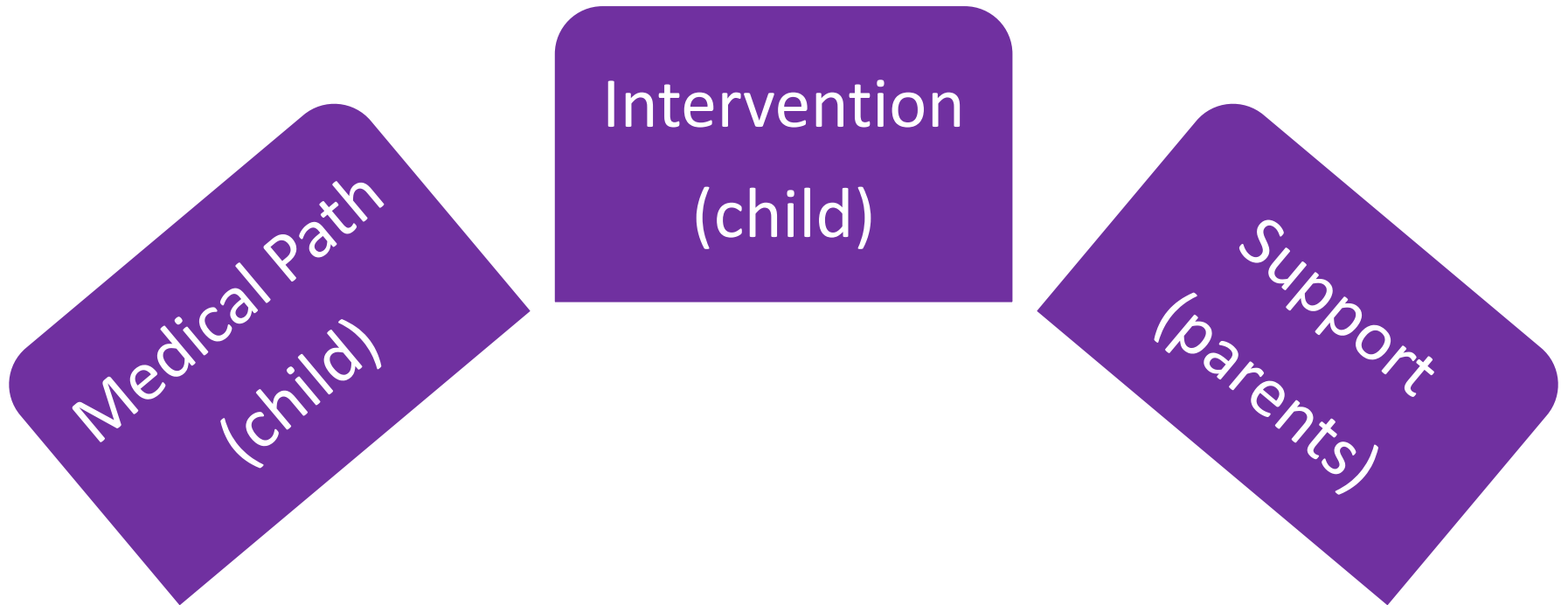
Non-Financial

None

Financial

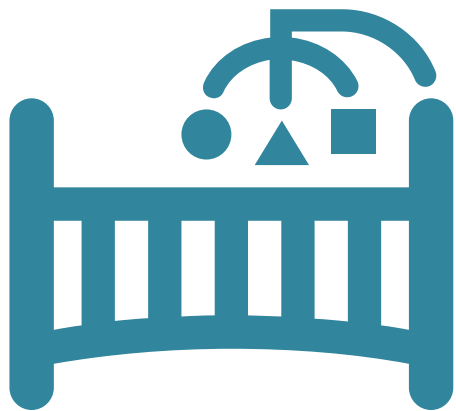
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In the beginning...

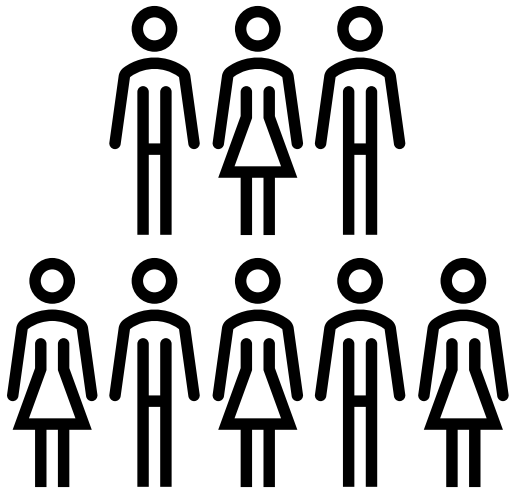


Initial Reactions

- Surprise? Shock? Stress? Confusion? Isolation?
- Falsely reassured by screener.
(Fitzpatrick et al., 2008, 2016)
- Multiple systems > huge learning curve



Parent to Parent Support

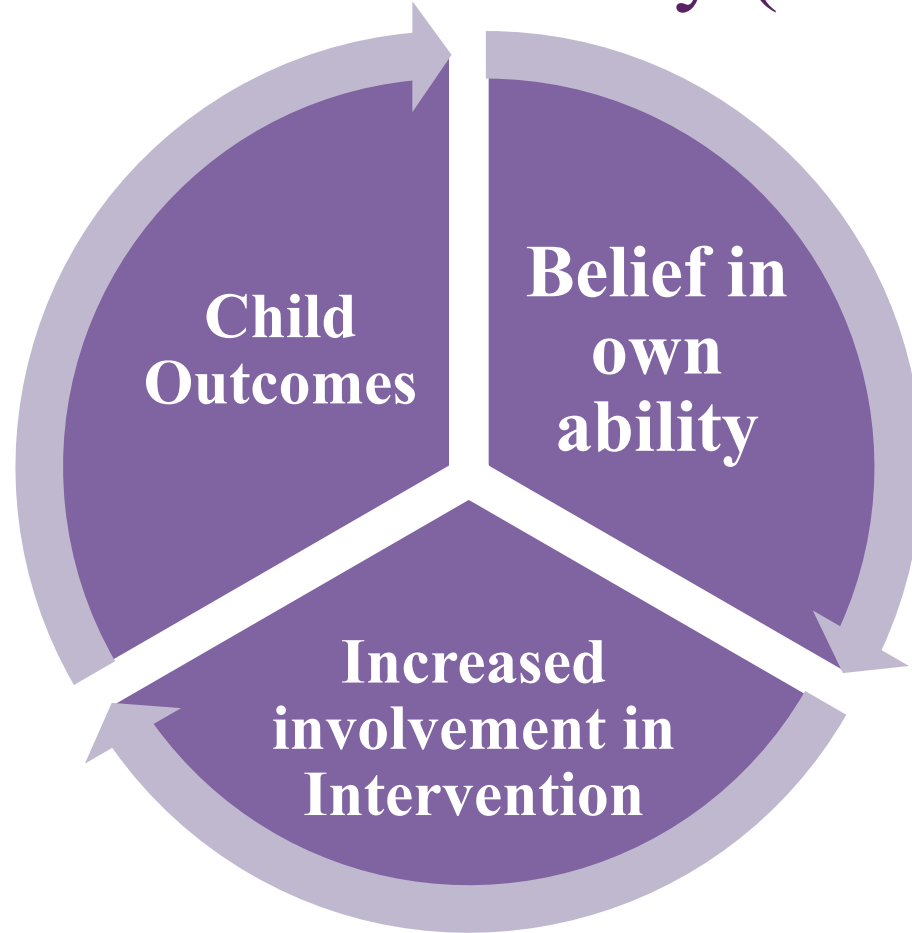


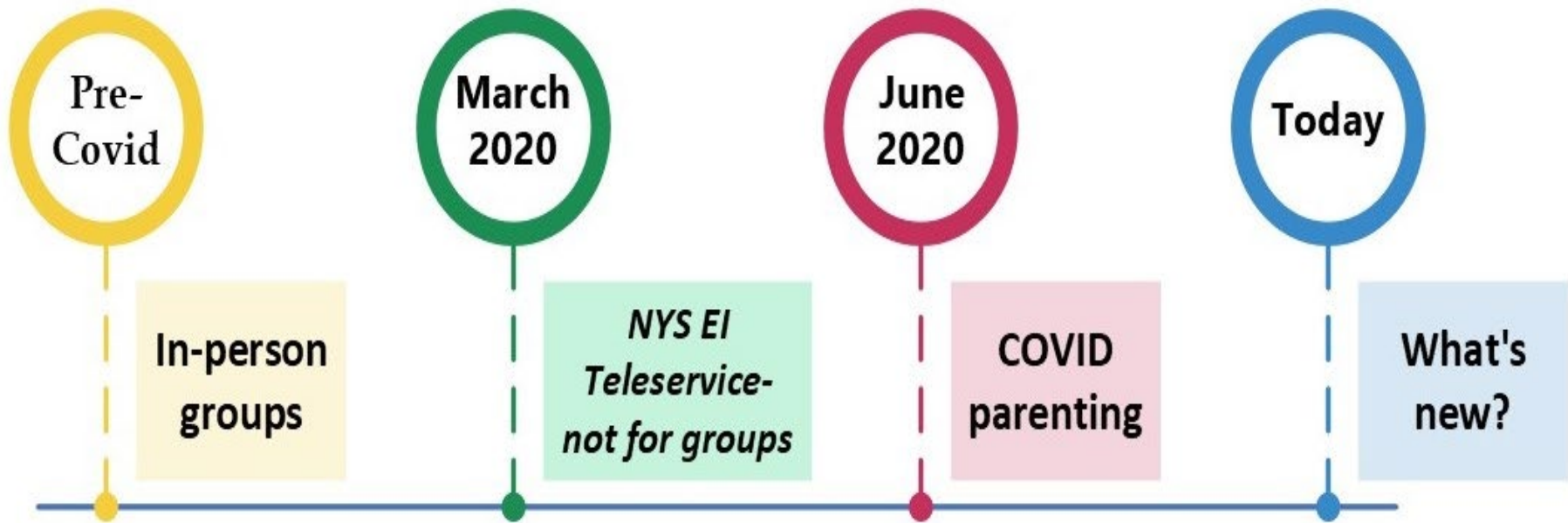
Parents benefit from connecting with other parents...

- For empathetic support, knowledge, and skills to facilitate the navigation of this new experience. (Henderson et al., 2016)
- Other parents of D/HH children are in the best position to offer advice and support (Mehta et al., 2019)
- As part of their support system, to accrue the necessary knowledge and experiences to be effective parents to their D/HH (Moeller et al., 2013)

Parental Self-Efficacy is tied to parenting and child outcomes. (Ambrose et al., 2020)

Parent Self-Efficacy (PSE)







1st Meeting


Before...

- Emailed parents of infants under a year
- Sent initial date/time to meet. (babies optional)
- Agenda included discussing times/dates that would work for the future*** NY was on lockdown

During...

- Initial group: 4 families (babies < 6 mo)
- No real agenda, “figure it out together”
- Started with parents introducing themselves and describing their child (age, HL, amplification)
- Parents guided future meeting topics-starting with hearing each other’s journey

Weekly format

- Met weekly. Both parents often joined.***
- Group expanded 4  10 families

Format:

- Intro: Parent & baby names, baby age, degree of HL & amplification, celebration!!!
- Recap of previous week's topic and updates.
- Current topic
- Topics-parents suggested for next week.

****lockdown/WFH for many*

Parent-Generated

Topics

- Types of Amplification
- Retention
- Audiological testing
- Reading an ABR/Audiological report
- Talking about the diagnosis with family/friends
- Considerations for future children
- Self- Advocacy

Speakers

- Older D/HH students at different ages
- Parents of older (6+) D/HH children
- D/HH Adults
- Audiologist
- Music Therapist
- Other Clarke staff



Being a parent of a child with hearing loss is wonderful. It can also be isolating. Having access to a group of people who are in the same or similar situation at the same time has been a tremendous comfort. I know that when I have a question during the week about something [my child] is experiencing or about how to help her learn or have better access to sound, I can bring that question to the group. Most of the time, someone has the answer.

This group changed everything about how we thought about and dealt with [our child's] hearing loss. It gave us a support group of parents who were going through the same situation as us...The support from this group extends well beyond just support for hearing loss...The peer-to-peer learnings and support are so powerful. It has given us strength and made us less emotional about [our child's] hearing loss.

My son was diagnosed with severe to profound sensorineural hearing loss at birth and it was a complete nightmare until I found Clarke... This parent group session is where I found hope. We learned so much about the development, the progress that could be made and how we can help guide our child to succeed. Having other parents to communicate with and lean on for support and share similar experiences gave me confidence, made me feel I wasn't alone, and gave me courage to face my child diagnosis.

Once, after I pointed out the sound of a passing bus to [my child], and an acquaintance from the community (after several months of seeing [my child] wearing her aid) asked me “can she hear?” It was discussions we had in baby group - about what audiograms mean, what kids can/can’t hear with or without their devices, how the general public often perceives (and misunderstands) “deafness” - that prepared me to answer both calmly and confidently.

Virtual Parent Groups 2.0

September 2021-July 2022



Clarke Schools
for Hearing and Speech

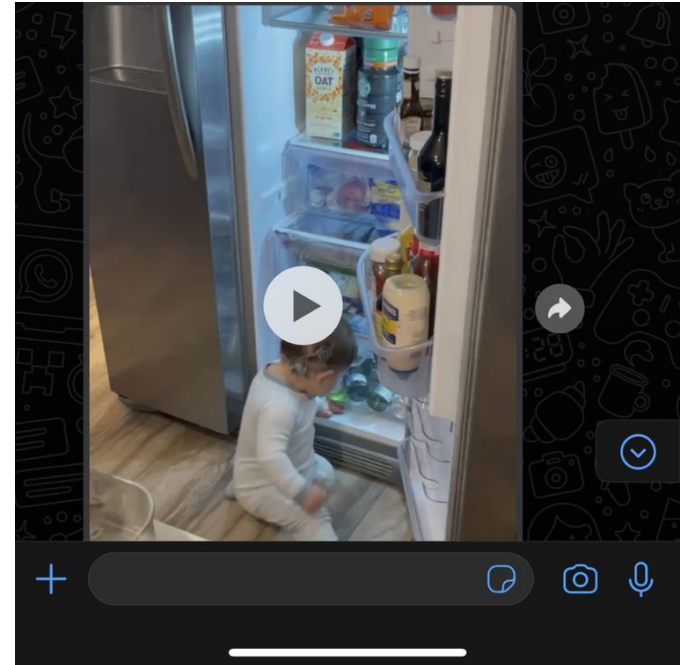
What changed?

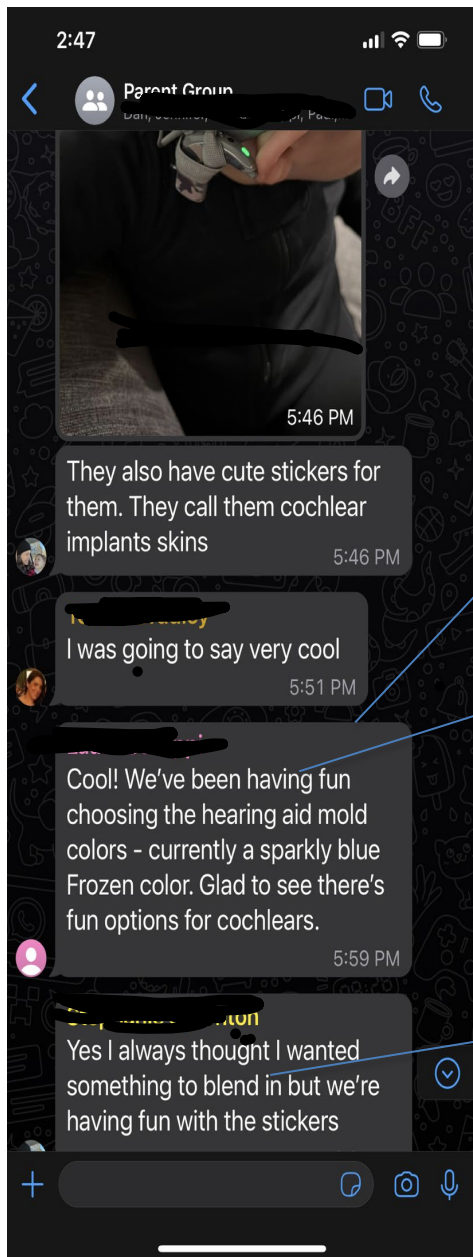
- Multiple groups, based on age of the child.
- Meeting time changed from daytime to evening, after baby asleep.
- “older”/experienced groups-less frequent
- Newer families-more frequent
- WhatsApp
- Topics-SPISE-R
- “Homework”, purposeful follow up
- In-person meet ups

WhatsApp

Just to share a little of our journey, [REDACTED] is finding his voice! He started responding to his name within the first 2 weeks of activation, he understands some things we say like no (surprise surprise) eat, ball, all simple commands, and just the last couple of days he's started saying uh oh, yay with a clap and DADA. He is like a yeti though, can't seem to catch him on camera....until today

8:21 AM





They also have cute stickers for them. They call them cochlear implant skins.

Cool! We've been having fun choosing the hearing aid mold colors-currently a sparkly blue Frozen colors.

Yes, I always thought I wanted something to blend in but we're having fun with stickers



Hey everyone, did your kids have trouble with hearing aids when you first used them? When I first put hers on today she was so freaked out she just screamed and screamed. We turned the decibels way down but she's still very upset by them. Any tips?

Definitely don't be shy about calling the audiologist. Maybe take a video of how quickly she gets upset and email it to the dr. They may be able to observe what's upsetting her or give you tips.

I felt shy about doing that sort of thing but the drs really welcomed it because it helps them better understand if they can see it themselves.

5:10 PM



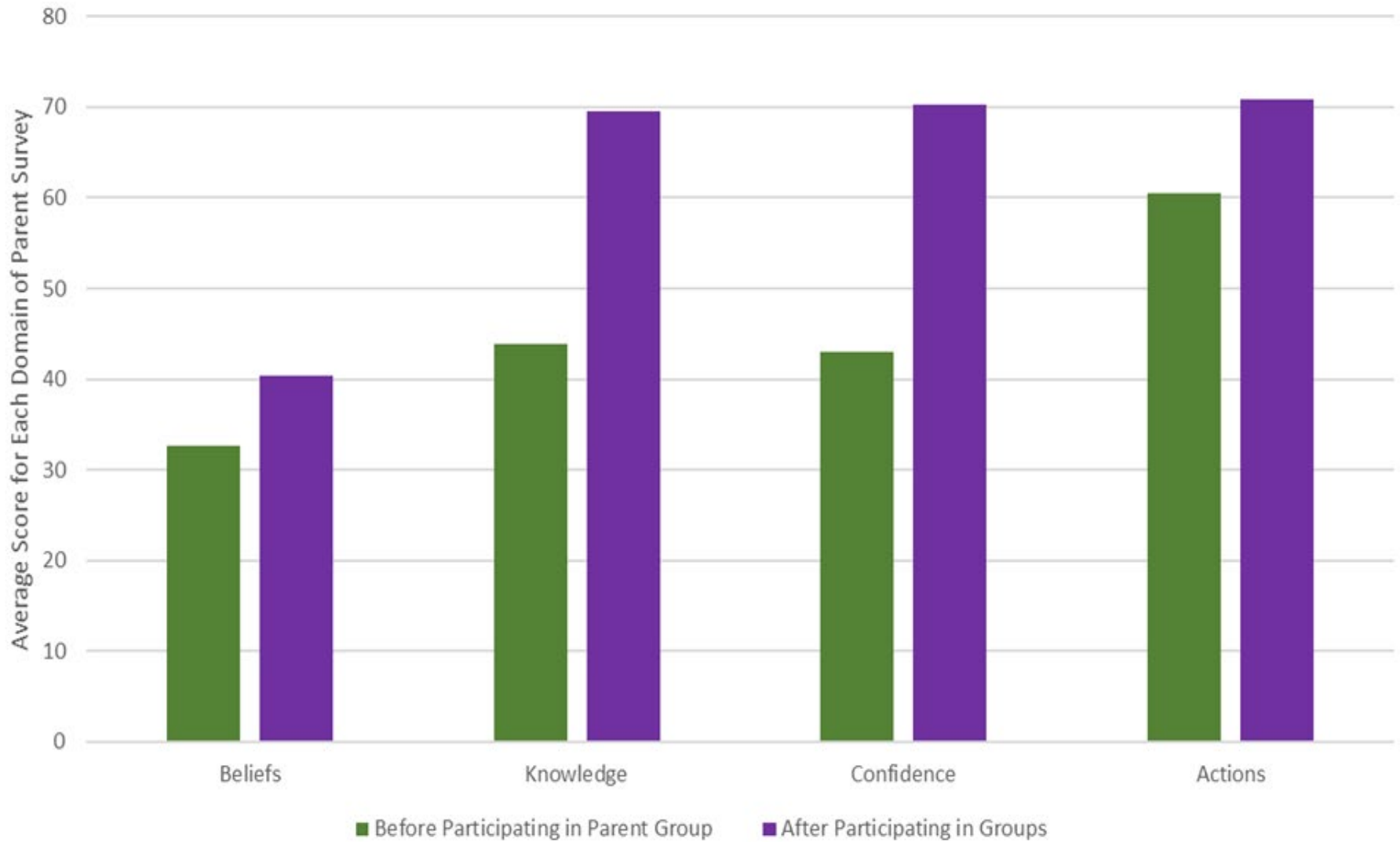
Scale of Parental Involvement and Self-Efficacy–Revised (SPISE-R)

Ambrose, S. E., Appenzeller, M., Mai, A., & DesJardin, J. L. (2020). Beliefs and Self-Efficacy of Parents of Young Children with Hearing Loss. *Journal of Early Hearing Detection and Intervention*, 5(1), 73–85.

Parent Survey:

- 5 section, 4 use a Likert Scale (1-7)
- Parent’s perceptions of their own beliefs, knowledge, confidence, & actions pertaining to supporting their child’s auditory access & spoken language development. And child’s amplification use.
- Adapted it for a pre-/post- survey, included questions about parent goals
- Guided discussions based on SPISE-R

Parents' Feelings of Self-Efficacy Related to their Child's Hearing Needs



What do parents say?

The group has been a lifeline. Becoming a new parents
We did not know anyone with hearing loss or
and the children have especially during these more times) is
anything about parenting a child with hearing
is what's typical a child hearing, and what's impacted by the
loss. The group has given us a community, a
navigating loss. We've over things we've been eating, to sleeping,
safe space to listen and learn from each other as
feel dignified, to doctors, linguists, and it's been helpful to
the health as well as professional advice on the way to find for
some with other people in the hearing world. This is not a
thriving, both fighting. We are building a team. This
that saved us tons and "figuring" way that is different
than others. We know that our children will thrive but
there are setbacks that we know we have others to
lean on, vent to, and learn from. We have been able to
see how far we have come



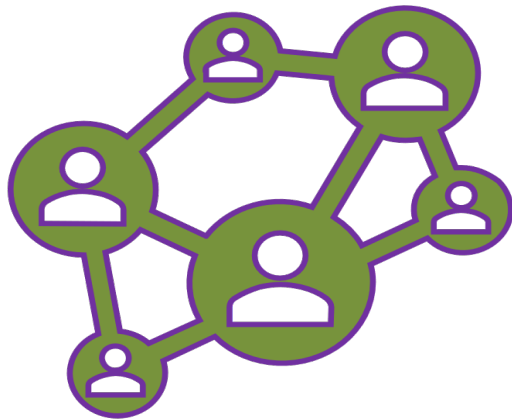
Successes

- A safe space/safety net
- Attendance
- Both parents involved
- Parents sharing tips for advocacy
- Use of WhatsApp
- Deep relationships developed, outlasting the group
- PSE!!

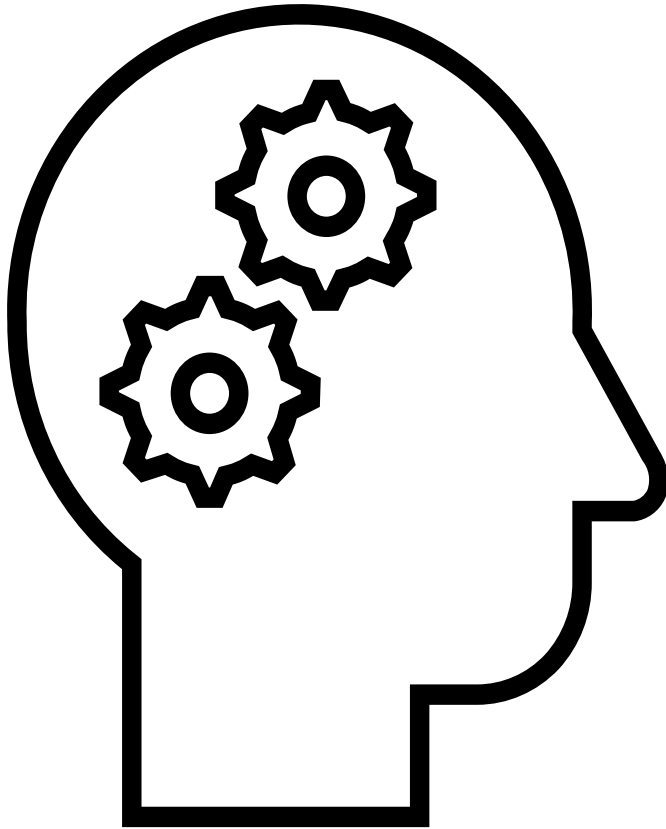


Planning Considerations

- Identification of initial schedule
- Staff (nighttime commitment)
- 8+ people talking online-choppy conversation
- How to replicate the ease of in-person convos
- Workshop vs parent support



Planning Considerations



- Parents not seeing other babies (what's typical?)
- Age /developmental differences-different stages
- Composition of group-age? HL type? Early/late?
- Late starters
- Participant limits

Next Steps

- Spanish groups
- Targeted groups (i.e. microtia/atresia, late id)
- Refine pre-/post-survey
- Balance parent support groups with workshops
- Replicate for preschool and older (especially those who missed EI)



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References

- Ambrose, S. E., Appenzeller, M., Mai, A., & DesJardin, J. L. (2020). Beliefs and Self-Efficacy of Parents of Young Children with Hearing Loss. *Journal of Early Hearing Detection and Intervention*, 5(1), 73–85.
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