



Together We Can
Do So Much

The unique collaboration
in Oregon between
EHDI and Hands & Voices



“Alone we can do so little. Together we can do so much.”
-Helen Keller

Participants will:

- List two defining features that make the Oregon EHDl and GBYS - Hands & Voices collaboration unique.
- Describe ways in which both entities and families benefit from the collaboration.
- Summarize considerations for a strong parent-serving organization and EHDl partnership in your state.



EHDI

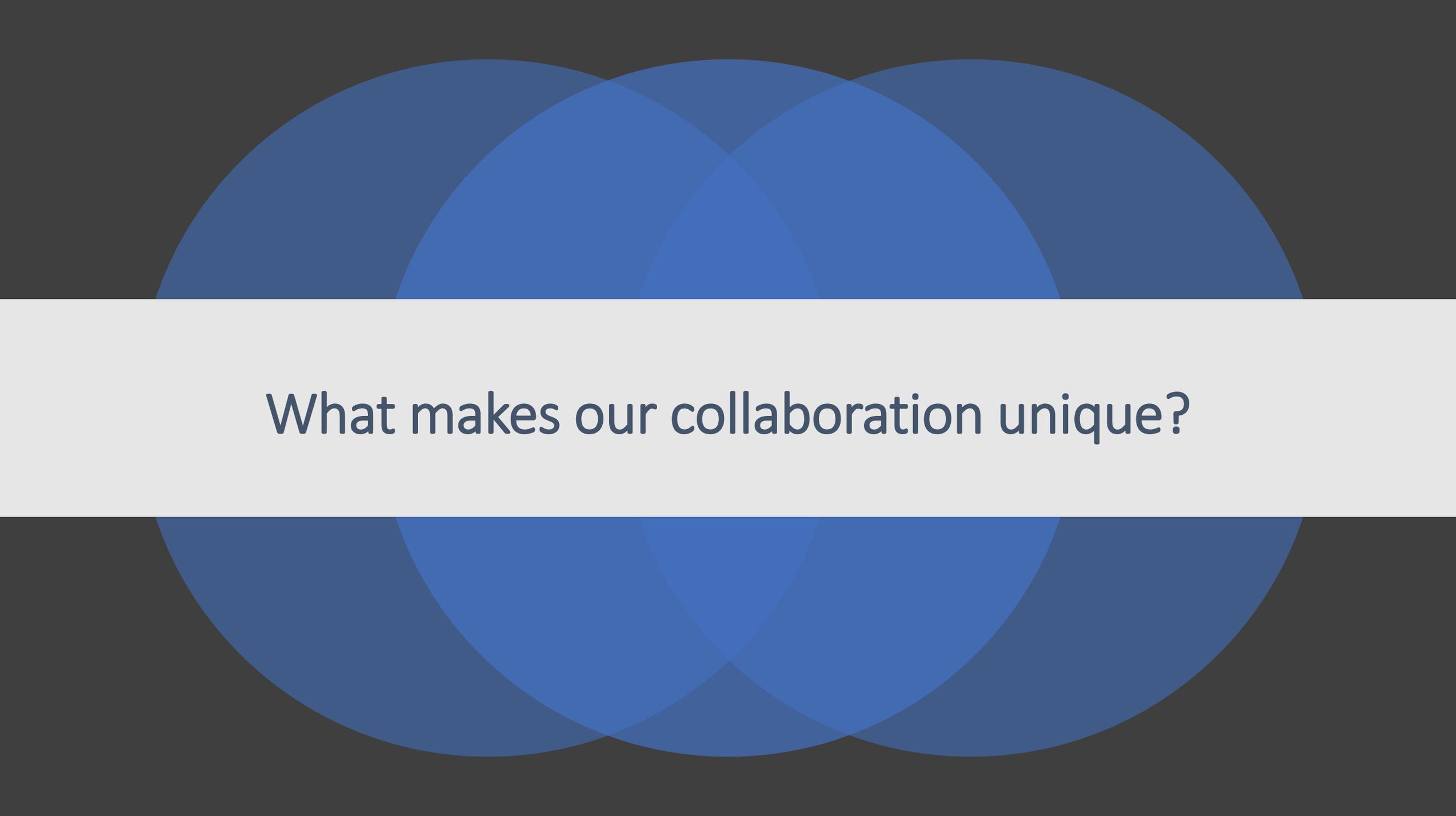
- Public health program in state agency
- Active surveillance
- Data collection, analysis, evaluation
- Educate the public and providers
- Mobilize partnerships
- Policy development
- Promote and enforce legal requirements (screening!)
- Workforce development



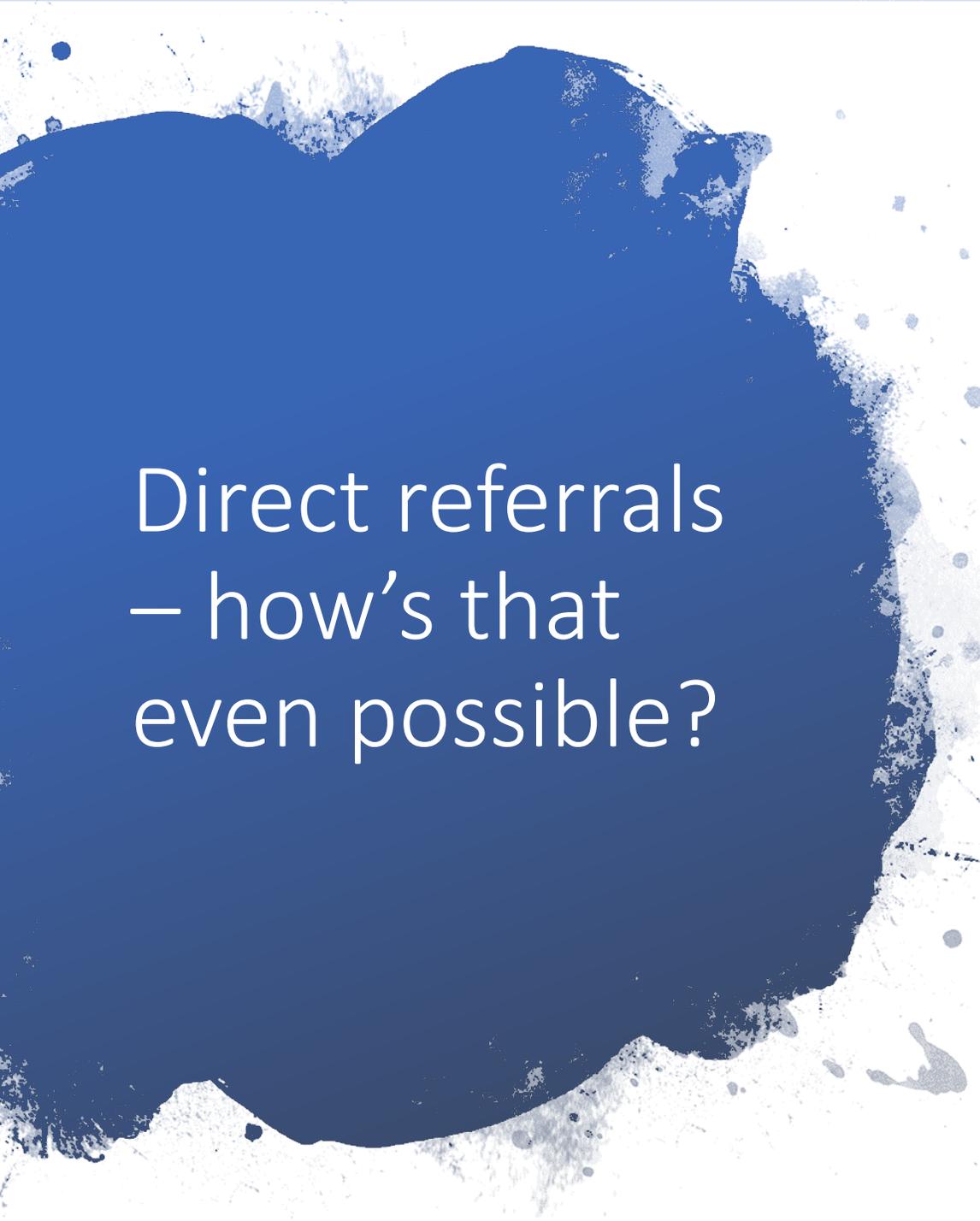
Guide By Your Side

- Family based organization, run by board of volunteers
- Educate parents and care takers
- Unbiased, informational and emotional support
- Emphasis on personal experience
- Training in communication and grief
- Advocacy and support
- Build community connections and fostering relationships



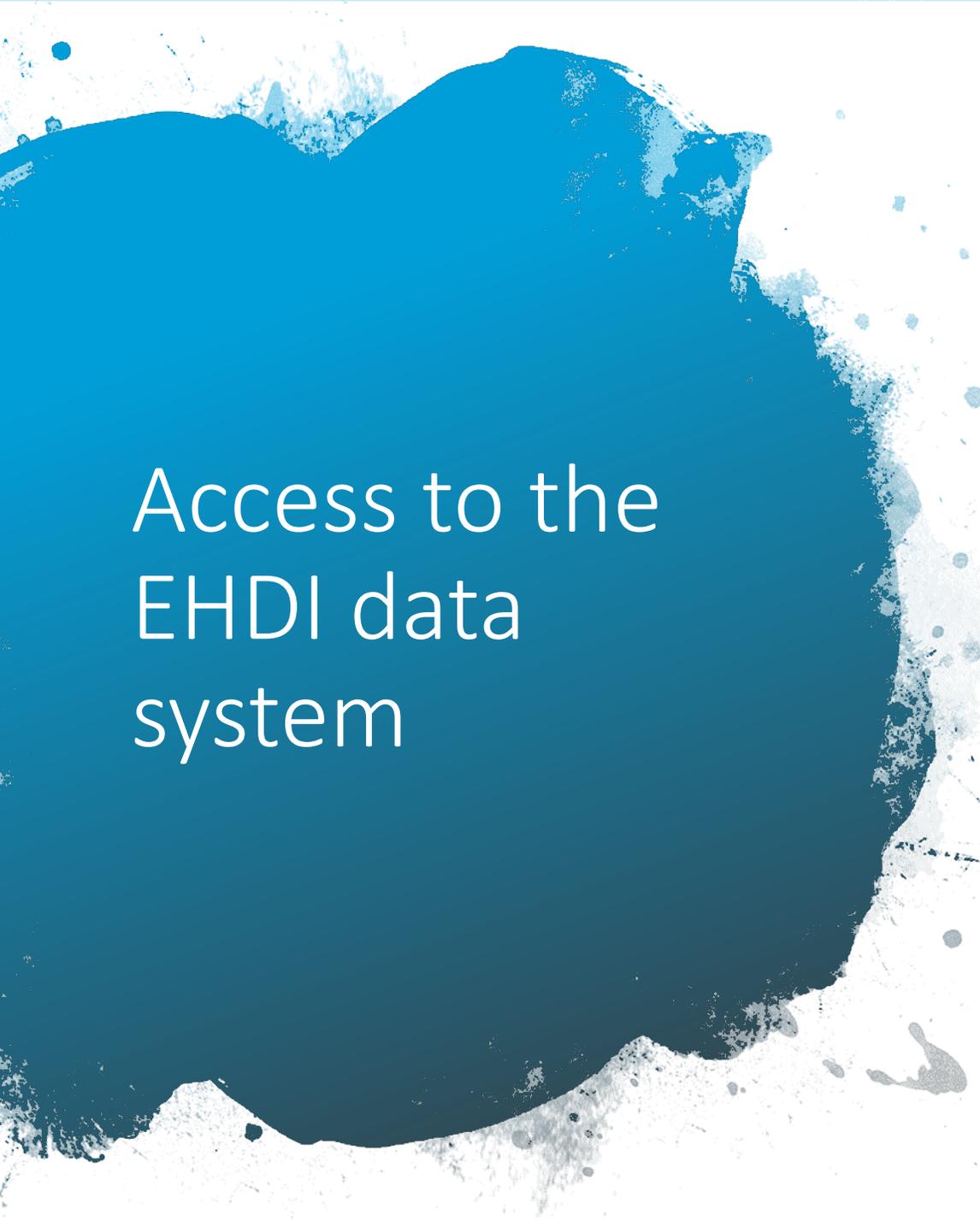


What makes our collaboration unique?



Direct referrals – how's that even possible?

- History of GBYS program coordinator role
- Assumption/philosophy of value of parent support for families at a difficult time
- Referral module created in system so audiologists can refer at time of reporting
- Referrals are sent with no PHI, only code used to access the specific record
- Parent and provider receive letter from EHDI with info about GBYS
- Requires trust from audiology community for them to initiate referrals
- Legal opinion about referring and sharing information



Access to the EHDI data system

- Supports a seamless experience for families
- Possible b/c of role-based access to specific cases and fields (minimum data necessary)
- Supported by requirements of parent mentors:
 - Annual trainings – 1) Privacy and Security, 2) Mandatory Reporter
 - Background check required
 - Confidentiality waiver signed
 - Training and on-demand assistance
- Legal opinion about minimum data necessary



Worlds Collide: Working together from very different perspectives

- Find an organization with a shared goal (Hands & Voices near you!)
- Engage in crucial conversations
- Keep short accounts
- Be honest
- Value one another's strengths, differences, and input
- Be willing to redefine the relationship
- Don't make assumptions – communicate!
- Expect and watch for integrity, stewardship, trustworthiness and accountability

Contract Scope of Work

- Family contact expectations
- Participate as member of Advisory Committee
- Collaborate to increase family participation
- Leadership training for parents
- Consult on family and provider communications
- Events and trainings for families
- Reciprocate invitation to OR GBYS annual training
- Collaborate with OCCYSHN on SPoC
- Partner to conduct a parent survey of the EHDI system
- Assess opportunities for Deaf mentor services
- Ensure all parent guides have required training, background check, confidentiality agreement, etc.





Families and Programs Benefit from this
Collaboration





Benefits for Families...

- Authentic connections made by parent guides allows for "filling in the gaps" and "finding" children
- Peer to peer connection supports healthy emotions, which in turn creates compliance within systems (home visits, phone calls, texts)
- Early Intervention is explained by parent guides clearly and positively to every family
- Support network for families is created

You have inspired me beyond belief to think...that bringing people together IS possible.

I plan to meet with some of my Deaf friends and explore hosting Family Nights for all families with Deaf children [and] adults where all modes of communication are welcome. Seeing all those children play together at camp reminded me of playing with...Deaf kids I met when I was young. If we can do more of those things, we can bridge the gap between the Deaf and hearing communities...

I'm also playing with the idea of hosting a Women's ASL Night...having a space open to all...to get together and heal through sharing language and stories and art.

I don't plan on having children but I feel causes like these are why I'm meant to be living right now, to help people connect and heal!! I want you to know that whatever ideas I come up with are stemmed in part from some of the life changing moments I experienced at the camp you hosted. Thank you very much for your efforts.

- **Nicole Aubuchon, ASL Interpreter at
GBYS Summer Camp**

Benefits for EHDI

- Authentic parent voice
- Community level connections and support for families
- Grounds the program in the family experience
- Actualize our values through investment in community partner and family service
- Case finding for late onset and progressive losses
- Reinforce messages about importance of early intervention
- Collaborator in reaching and supporting families

Benefits for GBYS

- Facilitated referrals by audiologists to GBYS program
- Access to minimum data necessary for outreach
- Platform to document guide contacts in EHDI IS
- No need to duplicate data entry
- Technical assistance re: data system development and modifications
- On-demand reports to guide “next steps” for families, active caseload, etc.
- Opportunity to coordinate with rest of child’s EHDI team



Considerations for a strong parent-serving
organization and EHDI partnership



Considerations

- Values
- Data system protections
- Legal review
- Personnel requirements
- Contract
- Trust
- Communication

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