

# How to Support Cohesion Between Family Based Organizations and EHDI



# Participants will:

- ✓ List three defining areas that contribute to the success of FBO and EHDl program collaboration in Oregon.
- ✓ Describe ways in which both entities and families benefit from the collaboration.
- ✓ Summarize opportunities to develop and/or enhance a strong parent-serving organization and EHDl partnership in your state.



# Our Elemental Qualities

## Oregon EHDI

- Oregon Health Authority > Public Health Division > Maternal and Child Health > EHDI
- Approximately 3.0 FTE
- EHDI legislation
- Home grown data collection system in Claris / FileMaker Pro
- In house informatics/data system development expertise
- Regular and extensive data analysis
- Experience working with family serving and CYSHN entities

## Oregon Guide By Your Side

- GBYS Program led the creation of Chapter
- Board: D/HH adults, educators, parents
- Funding sources / resources: EHDI HRSA funds and donations, no other grants currently
- Regional guides – matched to EI D/HH specialized service regions (Regional Inclusive Services)
- Birth to 21, community-building events, relationships (Family Camp)
- Frequent parent guide team meetings, annual in-person meetings, autonomy

coherence  
relationships  
heart  
community  
intentions  
connection

data  
vast-deep  
harmonious  
understanding  
partnership  
supportive

# The Nuts and Bolts of How We Work in Oregon

- Have a contract, updated annually
- Quarterly Advisory Committee meetings w/ GBYS updates
- Annual GBYS training – standing EHDI invitation
- Direct and opt out referrals
- Data access and information sharing
- EHDI-created reports for QA and monitoring, HSFS reporting
- Emails for family support coordination
- Limited additional reporting required
- Special projects: FEHDI, D/HH adult to family support workgroup, etc.

# Organizational and Interpersonal Relationships

- History
- Shared vision
- Commitment
- Autonomy
- Close collaboration




# Details of Contract Statement of Work

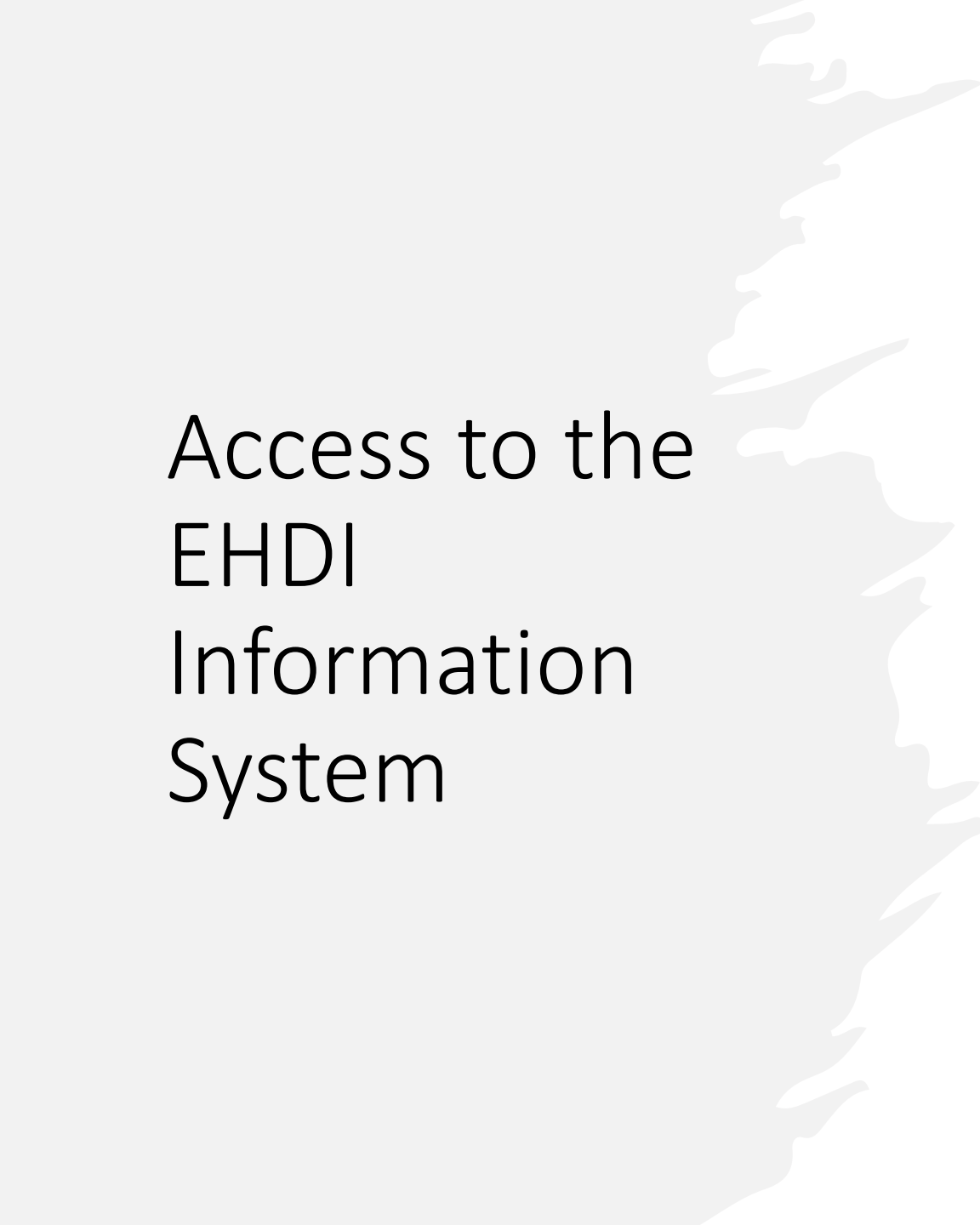
- Family contact expectations
- Participate as member of Advisory Committee
- Collaborate to increase family participation
- Leadership training for parents
- Consult on family and provider communications
- Events and trainings for families
- Reciprocal invitations
- Ensure all parent guides have required training, background check, confidentiality agreement, etc.

A large orange circle on the left side of the slide, partially cut off by the edge.

# Direct referrals for family support

- Referral module created in EHDI Information System
  - Audiologists prompted to refer (not required to refer, though!)
  - Monitoring task at 45 days after identification if no referral to GBYS for reconsideration
  - Referrals are sent with no PHI, only code used to securely access the child's specific record
  - Parent and health care provider(s) receive letter from EHDI with info about GBYS
  - Legal opinion about referring and sharing information
- 
- A decorative graphic in the bottom right corner consisting of several short, thick yellow dashes arranged in a curved, upward-sloping pattern.





# Access to the EHDI Information System

- Supports seamless tracking and communication
- Possible b/c of role-based access to specific cases and fields (minimum data necessary)
- Supported by requirements of parent mentors:
  - Annual trainings –
    - Privacy and Security
    - Mandatory Reporter
  - Background check required
  - Confidentiality waiver signed
  - Training and on-demand assistance
- Legal opinion about minimum data necessary
- Reduces additional reporting burden on GBYS

# Benefits for EHDI

- Personal and community level connections and support for families
- Grounds EHDI program in the family experience
- Ongoing learning about family experience of EHDI system
- Walk our talk: act on our values by investing in community partner and family service
- Case finding for late identified D/HH
- Reinforce messages about importance of early intervention

# Benefits for GBYS

- Majority of infants identified are referred to GBYS
- Access to minimum data necessary for outreach
- Provides data system for documenting guide outreach and engagement with families
- Technical assistance and tailored data system development and modifications
- On-demand reports to guide “next steps” for families, active caseload, FEHDI, etc.
- Opportunity to coordinate with EHDI team



## What We've Learned... and Keep Needing to Practice

- Focus on our shared goals
- Lean into hard conversations
- Keep short accounts
- Value our differences as strengths
- Be willing to redefine the relationship
- Don't make assumptions – communicate!
- Golden and Platinum rules
- Pause, don't be too quick to find fault, give grace
- Consider your needs

# Opportunities to Keep Growing...

- Adequacy of efforts to serve and be responsive to BIPOC families and families who speak other languages - culturally responsive outreach and engagement

| Oregon EHDI          | Diversity and Inclusion Plan   | April 2022   |  |
|----------------------|--|--|--|
|                      |  | -EHDI system partners have increased awareness of D/HH culture and community |  |
| Community Engagement | 1. Review EHDI website and update language and terms for improved accessibility and inclusive terminology  | June 2022 and ongoing  | -Website reviewed, updated and maintained  |
|                      | 2. Review and update EHDI letters and materials for improved accessibility and inclusive terminology   | July 2022  | -Most commonly used letters and materials reviewed and updated   |
|                      | 3. Learn more about implementation of HB 4052 - mobile outreach project - as a vehicle to reach families with hearing screening support.             | July 2022  | -Information gathered and contact person identified  |
|                      | 4. Convene EHDI partners to explore opportunities for increased D/HH adult to family engagement  | Ongoing  | -Ongoing monthly meetings of D/HH Adult to Family Support team   |
|                      | 5. Translate EHDI letters into priority languages based on analysis of the data  | December 2022  | -Most commonly used letters are translated into at least three additional languages  |
|                      | 6. Develop plan to learn more from families or service providers about why families are lost to and/or decline audiology follow-up.                  | June 2024  | -Plan developed<br>-Incentives identified for families to participate<br>-Families identified and recruited<br>-Caregivers participate |
|                      | 7. Develop plan to learn more from families or service providers about why families are lost to early intervention services and/or decline services. | June 2024  | -Plan developed<br>-Incentives identified for families to participate<br>-Families identified and recruited<br>-Caregivers participate |

# Opportunities to Keep Growing...

- Adequacy of efforts to serve and be responsive to BIPOC families and families who speak other languages - culturally responsive outreach and engagement
- Quality improvement and using the data system tools
- Levels of service and how to engage the quiet or hard-to-reach families

The screenshot displays the EHDIIIS FEHDI data system interface. At the top, there is a navigation bar with a 'HOME' icon and the text 'EHDIIIS FEHDI'. Below this, there are search fields for 'DOB Search:' and 'Referred to GBYS Coordinator:', along with buttons for 'Run on DOB', 'FEHDI Summary', and 'Run on R...'. The main area contains a table with columns for ClientID, DateofBirth, ChildLastName, ChildFirstName, Scrn TestDate, Initial DX TestDate, Initial Diagnosis, Age Days At IDX, Latest DX Test Date, Latest Diagnosis, and several other columns. A large orange rectangle obscures the 'DateofBirth' and 'ChildLastName' columns for the first 15 rows. A pop-up window titled 'FEHDI Report Summary' is overlaid on the right side of the table, displaying the following data:

| Category   | Value |
|--|-------|
| Total Number in Report   | 83    |
| Total Enrolled in FEHDI  | 40    |
| Total Enrolled in FEHDI 6 mos:   | 32    |
| Total Unable to Contact  | 37    |
| # of families served annually (I know I'd have to add the older kiddos here) |       |
| # of families enrolled by 6 months of age                                    |       |
| # of families contacted but unresponsive                                     |       |
| # of families declined   |       |
| # of families referred but unable to contact                                 |       |

The background table shows the following data for the first 15 rows (with some columns obscured by the orange rectangle):

| ClientID | DateofBirth | ChildLastName | ChildFirstName | Scrn TestDate | Initial DX TestDate | Initial Diagnosis            | Age Days At IDX | Latest DX Test Date | Latest Diagnosis             |
|----------|-------------|---------------|----------------|---------------|---------------------|------------------------------|-----------------|---------------------|------------------------------|
| 891523   |             |               |                | 5/7/2022      | 7/1/2022            | Unilateral permanent hearing | 76              | 7/1/2022            | Unilateral perman            |
| 892648   |             |               |                | 4/30/2022     | 8/5/2022            | Unilateral permanent hearing | 99              | 8/5/2022            | Unilateral perman            |
| 892872   |             |               |                | 5/16/2022     | 5/16/2022           | Unilateral permanent hearing | 17              | 5/16/2022           | Unilateral perman            |
| 893314   |             |               |                | 5/17/2022     | 5/26/2022           | Bilateral permanent hearing  | 23              | 6/29/2022           | Unilateral perman            |
| 894111   |             |               |                | 4/24/2022     | 5-19-2022           | Bilateral permanent hearing  | 28              | 6-8-2022            | Bilateral perman             |
| 894607   |             |               |                | 5/30/2022     | 8/30/2022           | Unilateral permanent hearing | 108             | 8/30/2022           | Unilateral perman            |
| 894769   |             |               |                | 5/17/2022     | 6/28/2022           | Unilateral permanent hearing | 44              | 9/20/2022           | Unilateral perman            |
| 895579   |             |               |                | 5/28/2022     | 1/24/2023           | Bilateral permanent hearing  | 244             | 1/24/2023           | Bilateral permanent hearing  |
| 895919   |             |               |                | 5/24/2022     | 7/12/2022           | Unilateral permanent hearing | 50              | 7/12/2022           | Unilateral permanent hearing |
| 896312   |             |               |                | 5/4/2022      | 6/1/2022            | In process                   | 30              | 7/6/2022            | Bilateral permanent hearing  |
| 896448   |             |               |                | 6/2/2022      | 9/6/2022            | Bilateral permanent hearing  | 98              | 11/18/202           | Bilateral permanent hearing  |
| 896567   |             |               |                | 5/26/2022     | 9/29/2022           | Bilateral permanent hearing  | 128             | 9/29/2022           | Bilateral permanent hearing  |
| 896616   |             |               |                | 6/5/2022      | 7/26/2022           | Unilateral permanent hearing | 53              | 1/20/2023           | Unilateral permanent hearing |

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- D/HH adult to family support plans

3. Tell us about all the types of information and connections that you have needed or wanted for you, your child, and/or your family. Please include both those you wanted/needed and received, and those that you wanted or needed and did not receive. (Choose all that apply.)

- Information about helping my child learn language and to communicate
- Help accessing resources to learn American Sign Language
- Connections to other parents and families of children who are deaf or hard of hearing (D/HH)
- Opportunities for me/my family to connect with D/HH adults
- Opportunities for my child to interact with D/HH peers or adults



It's always important to keep coming back to our  
"WHY"



# Hands & Voices of Oregon Annual Camp



# Contact us:



## **Hands & Voices**

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## **Oregon EHDl Coordinator**

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