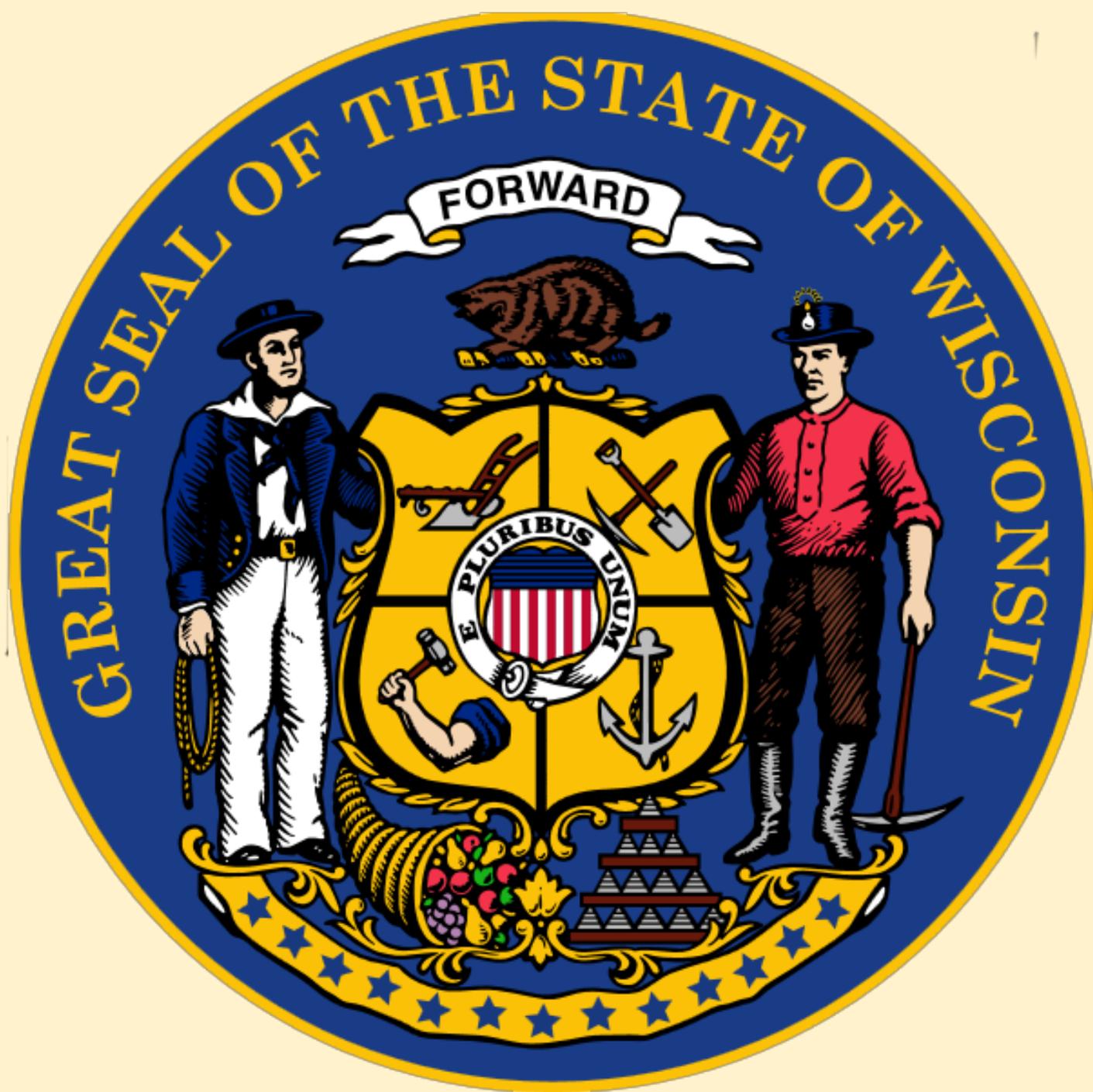


Moving Forward: Wisconsin Sound Beginnings (WSB) Parents Reaching Out

Presented by: Connie Stevens and Jeanne Gustafson
2020 National EHDI Conference in Kansas City, MO





WSB Parents Reaching Out

- We reach out to every family whose child under age 3 has been identified with compromised hearing and referred to Part C early intervention called the Birth to 3 Program.
- How did we get to this point?
- By moving forward through changes.
- Staff creating and agreeing to...



WSB mission, values, and guiding principles

<https://www.dhs.wisconsin.gov/newbornscreening/hearing.htm>



Setting the Stage – parent to parent support before Parents Reaching Out

WSB – since 2009 focus was loss to follow up efforts with families, and QI efforts with hospitals, Audiologists, and PCPs. Staff hired through contracts with a county DHS and UW-Madison.

WESP – provided wide variety of supports to families and children, including GBYS program in conjunction with WI Families for Hands & Voices

WI Families for Hands & Voices – chapter created in 2004; provided social opportunities for families and scholarships to attend WESP statewide conference

WSB and Birth to 3 Program – explained power of parent engagement by presenting at and attending Birth to 3 Program regional and state level planning meetings



2017 to 2020 HRSA Grant – EHDI program focus on post-DX parent to parent support

- WESP - funding no longer available for parent to parent support for families with kids under age 3
- WSB – received grant
- “Planful” 3 years:
 - Prepare
 - Perform
 - Perspective – how are we doing?





Safe & Nurturing
Relationship

Resources

Referral

Wisconsin
Sound
Beginnings
Family
Support

Acceptance

Guidance

Empowerment

Engagement

1st year – Collaboration

- Continue contracts with agencies who already employed parents to work with EHDI. Expanded to include a Children's Hospital.
- Strengthen ties with Children and Youth with Special Health Care Needs Program Regional Centers (CYSHCN RC)
 - Attended meetings/trainings to stay informed of new resources
 - Publicized our new efforts in order to work collaboratively
 - Added RC logo to our materials
 - Decided not to follow Parent to Parent model – believe that d/hh is a specialized category and that parents should be paid for their leadership efforts
 - Examined data collection (more on a later slide)



1st year - How did we develop our name?

- Wanted a name which clearly explained what we were doing
- Didn't want to confuse our program with other programs so did internet searches
- Talked with other programs who offered peer support
- Brainstormed with EHDl parent staff and program director, then asked for feedback from other EHDl and CYSHCN staff
- Wanted acronym to be positive and make sense
- Parents Reaching Out – PRO





Wisconsin
Sound Beginnings
Program



parents

Reaching Out



1st year - Protocol development

- Conferred with DHS legal staff
 - PRO support falls within Public Health Authority
 - PRO will ensure that families receive information in order to provide continuous care
- Approval by DHS of:
 - Scripted initial calls to local Birth to 3 Programs to explain PRO
 - Scripted initial communication family attempts
 - Intro card/call/text/questionnaire with no contact letters
- Communicated approved protocol and materials with Birth to 3 and CYSHCN RC partners, pediatric audiologists, WESP, H&V WI chapter, and other non-profits.



1st year - Data Collection planning

- Discussion with partners about where to retain our data.
- Decided to maintain data in existing WSB data system, WE-TRAC
- CYSHCN RC wanted us to share lessons learned
- Developed variables of data we wanted to record and track
- Developed cover sheet to manage info on each family
 - Demographic data
 - Attempts at contact
 - Notes
 - List of resources
- Developed and implemented PRO Case Management area in WE-TRAC



2nd & 3rd years – Perform and Perspective

- Called families and recorded info on cover sheet and in WE-TRAC
- Case conferencing with other WSB Parents
- Reflective consultation
- Reporting on activities and lessons learned
- Developed more avenues of reaching out:
 - Sounding Board Tuesdays
 - Meet & Greets
 - Collaborated picnics with WI H&V



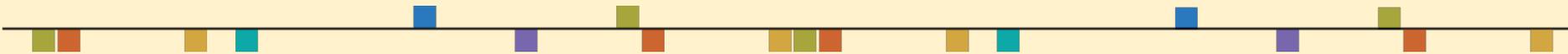
3rd year – Perspective

- Developed data reporting function to:
 - Provide caseload numbers by Parent, Region, Counties
 - Provide lists of closed cases due to no contact at age of 2 ½, thinking parents may be more receptive when kids approaching transition
 - At year 3, we are still counting by hand.
- Assessment:
 - Families/partners participated in a broad survey about EI.
 - DeltaPlus
 - At close-out when children turn age 3.



Parents Reaching Out Effect

“Thanks for reaching out.”



Parents Reaching Out Effect

- Families have expressed appreciation for our service. High consent rate after we talk to them on the phone.
- Many choose listserv in addition to calls so they are kept aware of opportunities. Some only want the listserv.
- Some say to check back when child is older.
- Families who are not reciprocal in our reaching out?
 - Rather than label/code as unresponsive, we could think:
 - They feel comforted.
 - They feel bothered.
 - They feel reminded to take action on something we discussed previously.
 - They intend to return the call/text/email, but life is busy.



WSB Parents Reaching Out

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