Successful State Collaboration Between
EHDI and IDEA Part C:
Strategies, Resources and Upcoming Activities

2024 EHDI Conference

Agenda

- Introductions and Review of Agenda

- Overview of the National Early Hearing Detection and Intervention (EHDI) Outcomes Committee

- Initial Discussion

- Examples of Successful Collaboration

- Planning Agenda and Collaboration Meetings

- Continuation of Discussion

- Next steps

Presenters

* Stacy Callender, Mississippi State Department of Health

* Marcia Fort, North Carolina EHDI Coordinator

* Judy Juengel, Wyoming Part C Coordinator

* Evelyn Shaw, Early Childhood Technical Assistance Center (ECTA)

* Sharon Walsh, The Center for IDEA Early Childhood Data Systems (DaSy)

Let's See Who Is Here

Raise Your Hand As Many Times As You Want

- Do you work with the EHDI program? The Part C Early Intervention Program?

- Do you work at the state level? Local level? National level?

- Are you an administrator? Provider?

- Are you a family member?

- Do you work with a family association?

- Who did we miss?

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National Early Hearing Detection and Intervention (EHDI) Outcomes Committee

- Formed in April 2016. Meets monthly.

- Initially a partnership between CDC/NCBDDD and the ECTA Center at the FPG Institute at UNC Chapel Hill, with the addition of the DaSy Center in 2018.

- Members include EHDI and Part C state coordinators and/or staff, CDC/NCBDD EHDI Program, HRSA, and OSEP, NCHAM, Hands & Voices FL3 Center, ODDACE Center, and ECTA and DaSy staff.

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Initial Committee Work

CDC Requests

- Identify outcomes data EHDI programs could collect, including from Part C

- Identify challenges with collecting Part C data for EHDI reporting

- Review and make recommendations about modifications, additions and/or recommendations to the functional standards related to Part C

Priorities Committee Identified:

- What data can/cannot be shared? How can states share data without parental consent?

- Part C data systems vary greatly from state-to-state, including the types of data collected and how data are stored

- Need for increased communication among federal agencies (OSEP, HRSA, and CDC)

- Need for greater understanding of each other's program (especially at provider level)

Committee Work and Achievements 2016-Present

- Supported the understanding of data elements collected by EHDI and Part C programs, caveats in sharing data between the programs that could address specific Functional Standards

- Identified challenges and strategies to support data sharing, including examples of successful state data sharing efforts between Part C and EHDI

- Facilitated solutions, within the privacy regulations, for data sharing between Part C and EHDI

- Provided focused presentations: Data Sharing. Part C eligibility definitions, outcomes research on young children who are deaf or hard of hearing

- Provided recommendations to the CDC Functional Standards Committee on programmatic goals subsumed under Goal Statement 4 (4.6-4.8, 4.10-4.13)

- Promoted and facilitated continued collaboration between federal and state partners

- Detailed strategies that support data sharing

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EHDI Outcomes Committee Products

- Developed **guidance** from state EHDI and Part C to local agencies regarding the importance of data sharing, why it is needed and strategies for sharing data

- Developed a **data sharing agreement checklist**

- Developed a **data sharing agreement template**

- Collected (and continues to collect) **data sharing agreements** (with state consent) and provides a central location for posting these agreements with NCHAM

Early Hearing Detection and Intervention Program (EHDI) and Early Intervention:

Data Sharing Partnerships Improve Systems

Data Sharing Agreement Template: Examples from the Early Hearing Detection, and Intervention Program (EHDI) and Early Intervention Programs

Data Sharing Agreement Checklist: Early Hearing Detection, and Intervention Program (EHDI) and Part C

Additional Resources
The National Center for Hearing Assessment and Management (NCHAM) provides additional information regarding data sharing agreements and memoranda of understanding between Part C and EHDI programs, as well as examples of state data sharing agreements.

https://ectacenter.org/topics/earlyid/ehdi.asp

EHDI Outcomes Committee Work 2023 to Present

- **Partnership agenda/discussion guide**
  - Continuum tools – steps from a cooperative relationship to a partnership
  - Address critical versus desirable topics
  - Use the anecdotes of successful collaborations work and how theses states resolved obstacles/barriers
  - Include a Q&A
- **Examples of Successful Collaboration**
  - Inspire other programs,
  - Give solid examples of collaboration between EHDI and Part C, and
  - Provide resources through the identified successful states

Discussion Questions

- What collaborations are you involved in and what ideas can you share?

- What successes have you experienced in collaboration between EHDI and Part C?

- What are some challenges you experience in collaboration between EHDI and Part C?

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Workgroup 1 -Partnership agenda/discussion guide

Group 1: Collaborative Meeting Guidance

- The goal for this workgroup is to create guidance around collaborative meetings (who, what, how, data process)

- Not one meeting, but a series of meetings

- For each meeting type, the guidance will provide:
  - Purpose of meeting
  - Pre-meeting activities (e.g., who to invite and what to share prior to the meeting)
  - Sample agenda (e.g., discussion topics and activities)
  - Post-meeting activities (e.g., next steps for follow-up)

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Collaboration Continuum

Derived from http://www.waitakere.govt.nz/ourpar/pdf/potentialofpartnership.pdf and
Hands & Voices: The Partnership Continuum – Team Reflection and Planning for the Future

Coexistence	Networking	Cooperation	Collaboration	True Partnership
No systematic connections between programs and personnel	Programs and personnel share information and communicate about program-specific activities	Programs and personnel engage in formal interactions, typically on specific or time-limited activities or projects	Programs and personnel engage in long-term, ongoing formal interactions around shared goals	Programs and personnel engage in integrated interactions, activities, and projects around shared goals, resources, and decision making
1	3	5	7	9

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Group 1: Collaborative Meeting Guidance

- Collaborative Meeting Types:
    - Understand Programs and Systems
    - Improve the Referral Process
    - Plan for and/or Expand Hearing Screening for Children Up to Age Three
    - Decrease the Loss to Follow Up Rate
    - Increase Identification of Children with Late Onset Hearing Loss
    - Implement Professional Development for Healthcare and Intervention Providers
    - Improve Coordination of Services
    - Share Data on Outcomes
    - Use Data to Drive Improvement Efforts

- Meeting Purpose & Expectations
  - Purpose, Outcomes, When this meeting would be helpful
- Partners to Invite
  - Consideration and possible attendees
- Preparation
  - Soliciting input, sharing information, preparing for the meeting
- Meeting topics
  - Sample agenda, discussion questions, and activities
- Next steps

MEETING TEMPLATE 1
Collaborative Meeting to Understand Programs and Systems
(Mary Ellen Whigham)

What is the purpose and expected outcome of this meeting?

Meeting Purpose
This collaborative meeting is an
systems to ensure all parties un
services and scope, and their p
(DHH).

Meeting Outcome
The main outcome is for all par
programs, personnel, and oper

When would this meeting be h

This collaborative meeting may
Coordinator) or program perso
initiated, or a program or part o

Who are the best partners to i

Considerations
- What are the key programs
- Who has a key role in those
- Who are champions for the
- Who is knowledgeable abou
- Who can leverage their pro
- Who is or will be impacted
- Who has access to potential

Possible Attendees
- EHDI Coordinator and other
- Family Based Organizations
  and other parent leaders.
- Part C Coordinator and othe
- Healthcare providers (e.g., A
- Head Start/Early Head Start
- Home Visiting program repr
- Other Community partners

What preparation is needed before the meeting?

Soliciting Input
- Ask invited participants to identify other key p
  other relevant participants.
- Determine what participants already know or
  systems through a brief survey or needs asse

Sharing Information
- Share a draft agenda and ensure each program
  describe their program or role.
- Share relevant documents from each participa
  statements, description of services or support

Preparing for the Meeting
- Decide whether the meeting will be in person, virtual, or hybrid.
- Arrange communication access for all particip

What topics to discuss during the meeting?

Program Overview
- What is the name, purpose, and organization
- What are the guiding regulations or national s
- What privacy rules or regulations apply to you
- What is the funding source(s) and limitations?
- What are the general procedures for each pro
- On a chart from birth to school age, where do
  families?
  - *Optional Timeline Activity: Draw a timeline*
    "SCHOOL ENTRY". Provide each participati
    or sticky notes. Have them place them indi
    role will interact with children and families

Screening and Diagnosis
- Review the following:
  - JCIH recommendations (1-3-6)
  - ASHA/AAA professional practice guideline
  - State rules for screening and diagnosis
  - Rules/protocols for other screening partne
    nurses)
  - Grant requirements and activities
- What screenings procedures are used? When? By whom?
- What diagnostic procedures are used? When? By whom?

Other
- What, if any, misconceptions exist about EHDI and Part C that need to be addressed and
  how can that be accomplished?
- What, if any, overlapping responsibilities and shared goals can be identified?

How will the participants move forward?

Next Steps
- Who else needs to be at the table?
- What additional communication or messages are needed?
- What resources we can share now or send later?
- Where are things going well? Where are the bottlenecks?
- What overlapping responsibilities and shared goals can be worked on collaboratively?
- What strategies might we implement first?
- What is the timeframe expected for addressing agreed upon actions?

Sample Agenda: Understand Programs and Systems

Time	Agenda Topic	Facilitator
	Welcome and Introductions	Host Program
	Brief Program/System Overview	All Participants
	• Lead Organization and Staffing	
	• Key Partners	
	• Workflow/Process/Procedures	
	• Key Outcomes	
	(Optional) Timeline Activity	All Participants
	Screening and Diagnosis	EHDI Personnel
	Early Intervention	Part C Personnel
	Family Support	Family-Based Organization
	Early Childhood/Community Partners	Early Childhood Partners
	Data	
	Personnel	
	Overlapping Responsibilities and Shared Goals	
	Next Steps	

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Workgroup 2 – Examples of Successful Collaboration

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Examples of Successful Collaboration

- Designing a resource containing "gems" of successful state collaboration between EHDI and Part C (including Hands & Voices and others partners as well)

- Will evolve the collection overtime as new examples are available

- Will be posted on a new topical webpage under ECTA, DaSy and NCHAM

- Web design will be searchable by topic and by state

- Always looking for new selections to add

- Please share some and/or contact us

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Training and Technical Assistance

- EHDI, Part C and Hands & Voices provide specialty training in deafness to EI Part C providers

- EHDI and Part C share information about provider training needs, and EHDI providers training to EI providers on late onset screenings

- A Community of Practice of EI providers working with children who are D/HH and their families and community partners specialized in language development, parent supports and Deaf Culture

- A state Training and Technical Assistance Team supports EI providers to enroll in ASL classes and to attend the annual EHDI Conference.

- An EHDI program trains the EI program on the use of the OAE and ABR

- EHDI trains nurses and midwives on how to use the screening equipment and how to refer children to EI

- EHDI and Part C TA and training efforts coordinated through out the year

- Part C TA system consults with family organization director

- EHDI and Part C provide a workshop each year for EI, school for the deaf and blind staff, SLPs, and others who work with DHH children

Referral

- Notifications for referrals via shared data system

- EI referrals may be received directly from a family advocacy program through a business associate relationship

- 100% referral rate to Part C in one state through a parent-driven referral process, initiated by parent support specialists. Referrals required within 72 hours

- Local EHDI coordinators receiving automated referrals *and* coordinating with local Part C programs for referral to EI

Screening/Assessment

- EHDI purchased hearing screening equipment and trained EI providers for home screenings through Part C/ITP.

- Part C provides funding for T & TA on the screening process and EHDI tracks the training and equipment status statewide

- EHDI provides training to EI providers on late onset hearing screenings and data tracking

- In rural areas, funding sources were sought to provide screening equipment to midwives, who then refer to EI

- EHDI supports infant assessments through the use of a mobile bus and tele-audiology

Data Sharing

- Data sharing arrangements address data sharing, security, storage and destruction through contracts, data sharing agreements and parent consent.

- Data are included in an integrated system under certain circumstances.

- Data sharing exists for tracking of newborns to ensure they are enrolled in EI by 6 months of age, dates of IFSPs, dates of service start dates, and EI outcomes.

- Statewide integrated child health information system supports the sharing of EHDI and EI data among authorized users for the purpose of care coordination.

- Child ID numbers are assigned from education to follow children who are deaf and hard of hearing from their initial diagnosis through high school.

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Family Engagement

- Part C, EHDI, and Hands & Voices address training for parents of children who are deaf or hard of hearing, train Part C providers on family engagement. strategies and have developed a Padlet of resources for providers

- Part C programs partner with Hands & Voices for family support.

- The Hands & Voices program has parents sign a consent to share information with Part C, and once the child is enrolled, the Hands & Voices consultant continues to work on family engagement while Part C provides EI services.

Service Delivery and Collaboration Activities

- EI representatives participate in several EHDI stakeholder meetings and groups throughout the state, including regional learning communities, the statewide EHDI advisory group, and the Infant Hearing Screening Advisory Committee.

- The EHDI Coordinator has been appointed to the Part C State Interagency Coordinating Council .

- A collaboration for service delivery includes EHDI, a network for educational services for children birth to age five, and Part C.

- The Part C team collaborates with an SLP experienced in working with infants and toddlers with hearing loss to plan appropriate services. EHDI is a part of the collaborative in a larger work group.

- Services provided by educational entity for all children with hearing loss, in collaboration with Part C.

- Services in EI provide by School for the Deaf and Blind in coordination with the EHDI program.

Challenges

- High turnover

- Navigating data privacy and integration

- Lack of SLPs experienced in working with young children with hearing loss

- Providers have different perspectives on assessments

- Families are at times hesitant to engage with government agencies

- Obtaining a release of information can be a challenge

Tips

- Looking at the collaborations and number of partnerships you have and could have to make things happen.

- Understanding that everyone wants to do the best for families, but they are often limited by the data they can share freely across programs.

- Don't take a passive role in assuming the collaborations and partnerships will develop. You may have to repeat the message several times.

- Don't make assumptions that others know what you do and why you don't do other things.

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Continued Discussion

- What questions or reactions do you have about what you have heard?

- Did anything surprise you?

- What questions do you have for each other?

- What can you do by next Tuesday?

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Closing/Next Steps

Notetaking Sheet

Take a minute to add some items to you note taking sheet

Office of Special Education Programs
U.S. Department of Education