EHDI and Part C Early Intervention: Lessons Learned About Collaboration and Early Intervention Processes Across the United States

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Early Intervention Systematic Nationwide Analysis of Programs’ Strengths, Hurdles, Opportunities, and Trends (EI SNAPSHOT)

› Funded by the Maternal and Child Health Bureau & Oberkotter Foundation

› One year study looking at
  – Family reports and perceptions
  – Early intervention provider & audiologist reflections
  – EHDI and Part C collaboration
  – Deaf Education personnel preparation programs
  – Publicly available information for families
What is collaboration?

› Networking
  – Aware of organization
  – Loosely defined roles
  – Little communication
  – All decisions are made independently

› Cooperation
  – Provide information to each other
  – Somewhat defined roles
  – Formal communication
  – All decisions are made independently

› Coordination
  – Share information and resources
  – Defined roles
  – Frequent communication
  – Some shared decision making

› Coalition
  – Share ideas
  – Share resources
  – Frequent and prioritized communication
  – All members have a vote in decision making

› Collaboration
  – Members belong to one system
  – Frequent communication is characterized by mutual trust
  – Consensus is reached on all decisions

Why is EHDI and Part C Collaboration Important?

› The Joint Committee on Infant Hearing (JCIH) recommends that “all infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis but at no later than 6 months of age.”
What do we know about EHDI and Part C Collaboration?

› Every state collaborates!
› Each state collaborates differently.
   – State structures
   – Eligibility criteria
   – Data sharing
What do we want to learn through EI Snapshot?

› What are the different ways EHDI and Part C collaborate?
› What are the barriers to collaboration?
› How can we improve collaboration?
› How does the level of collaboration at the Part C and EHDI level impact family and provider perceptions?
Methods

› Review existing data on Part C and EHDI Collaboration.
› Telephone surveys with the EHDI coordinator and Part C coordinator in each state.
› Interviews conducted by Sara Doutre and Diane Behl.
› About 50% completed.
State Governance
Are EI and EHDI programs in the same department or agency?

- 51% Same Agency
- 49% Different Agencies

*Preliminary Results - ongoing data collection in progress
Program Locations

*Preliminary Results - ongoing data collection in progress

<table>
<thead>
<tr>
<th>Category</th>
<th>EL Lead Agency</th>
<th>EHDI Lead Agency</th>
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<tr>
<td>Health</td>
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<td>Other</td>
<td>8</td>
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</tbody>
</table>
Preliminary Results - ongoing data collection in progress
Infant Toddler Coordination Association (ITCA) EHDI Survey, 2008
http://infanthearing.org/privacy/docs/Part%20C%20EHDI%20Survey.pdf

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Eligibility – Are our kids their kids? Are their kids our kids?

State Criteria for Part C Eligibility:
Published Criteria for using Hearing Loss as a Diagnosed Condition to Establish Automatic Eligibility for Part C Services

*Preliminary Results - ongoing data collection in progress
Part C Eligibility for Infants and Toddlers who are D/HH

Criteria to use D/HH as a Diagnosed Condition with Automatic Part C Eligibility

*Preliminary Results - ongoing data collection in progress
What we’re learning from EI SNAPSHOT

› Most states reported that Part C and EHDI staff are active partners with their program, either formally participating on interagency coordinating councils and advisory groups or regularly meeting to collaborate.

› Many EHDI programs automatically refer children who are potentially eligible for EI services to Part C.

› Joint or cross-professional development is present in some states.

*Preliminary Results - ongoing data collection in progress
What we’re learning from EI SNAPSHOT

› Data sharing barriers exist between some EHDI and Part C programs including inability to track and follow up on individual children.
  – Some programs attribute these to HIPAA and FERPA requirements.
  – Programs located in the same agency are less likely to face barriers to data sharing.

› Processes for referring newborns to EI vary by state. The newborn hearing screening program does not always refer directly to EI.

*Preliminary Results - ongoing data collection in progress
What else can you tell us?

Think about the process of moving from hearing screening to early intervention and the state level collaboration in place.

- What is working at the STATE level?
- What are some areas for improvement?
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Next Steps

› Complete the interviews.
› Dig deeper into these data and the connections to the data from the other pieces of EI SNAPSHOT.
› Publish the results.
› Work at NCHAM to develop resources to address the identified gaps.