



## **Part C / EHD Leaders Discussion Guide**

As outlined in the Notice of Funding Opportunity HRSA-20-047, all current recipients of funding for the Early Hearing Detection and Intervention Program are required to address the following two requirements (as well as others):

1. “Facilitate improved coordination of care and services for children who are DHH and their families through the development of mechanisms for formal communication, training, referrals, and/or data sharing between the state/territory EHD Program and the Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.”
2. “Develop a state/territory plan to expand infrastructure, including data collection and reporting, for hearing screening for children up to age 3 by the end of year 2. This plan should outline the resources, key stakeholders, partnerships, and services necessary to implement the plan.”

The importance of collaboration between EHD and Part C is underscored by the fact that Part C represents a potential system in which children who remain unidentified as being deaf or hard of hearing may be identified as a result of interacting with Part C and subsequently begin to access supports and services. It is estimated that 3-6 children per 1000 may have late onset hearing loss identifiable subsequent to the newborn period. Additionally, there may be children who were lost to follow-up from newborn screening or children with congenital hearing loss who did not receive newborn screening for various reasons. Children in any of these circumstances will benefit from closer collaboration between Part C and EHD.

We recognize that each state and territory is unique—some already have very close working relationships between EHD and Part C and some do not. Regardless of where you are in developing an effective working relationship between your EHD and Part C programs, we suggest you consider arranging time for one or more discussion(s) between leaders in state EHD and Part C early intervention programs as a way of strengthening your collaborative activities to improve outcomes for infants and young children who are deaf or hard of hearing. Select whichever of the following questions are relevant for your situation or add others that are more appropriate. Please let us know if these discussions are useful and if there is anything we can do to help.

## Potential Questions State ELDI and Part C Coordinators Can Discuss

### State Part C Demographics and Statistics

1. How many children have been served by Part C in our state during the past year (or other relevant time period for which there is available data)?
2. What statistics exist about previously or currently served children with respect to:
  - Ages
  - Primary disability/diagnosis the determined eligibility
  - Whether the child's disability/diagnosis was known prior to referral to Part C or a consequence of the Part C evaluation process?
  - Regarding children served by Part C who are deaf or hard of hearing:
    - How many were referred to Part C as a result of newborn screening/diagnostics?
    - How many were referred to Part C because of an explicit concern about a possible hearing loss?
    - How many were referred to Part C about non-hearing related concerns but were then identified as deaf or hard of hearing?
    - What types of services are provided to children who are deaf or hard of hearing?

### Hearing Related Part C Practices

Consider this scenario. A child is referred to Part C without specific mention of concerns about a possible hearing loss. The child may or may not have other developmental delays or established conditions that deem the child eligible according to state Part C eligibility criteria. If such a child has an unidentified hearing loss, how likely is it that the child's hearing status will be determined and considered during the Part C eligibility-determination process and/or at any other point during which the child interfaces with the Part C system? Here are some specific questions to help ELDI and Part C leaders explore ways for such children to more likely be identified by the Part C system.

1. How is a determination of hearing status incorporated into Part C eligibility determination and in-take processes?
  - How often does this occur?
  - When does this occur in the timeline?
  - Who may be responsible for this?
  - Is hearing status determined for all children or for a subset of children considered for or deemed eligible for Part C services?
  - What criteria are used for determining when hearing status should be established for a given child?
  - What are the hearing loss criteria for eligibility (degree, laterality)?

2. How is hearing status determined for a child?
  - What method(s) are used for determining the hearing status of a child?
  - What follow-up protocol(s) are used as a part of this process?
  - What data are collected, reported and shared and with whom are data shared? Is the data individual or aggregate?
  - If hearing is one of multiple disabilities, how is the “primary” disability determined? If hearing loss is a secondary disability, is it reported and/or counted in statistics?
3. To what degree are the practices for determining hearing status variable from one local program to another in the state?
  - In what ways might practices vary?
  - What factors contribute to any variability that may exist? (staffing, resources for accessing equipment, training, available audiological services, etc.)
4. Are there state-level recommendations, guidance, requirements, or regulations regarding the determination of hearing status of children being considered for enrollment in Part C that local programs are aiming to achieve?
  - What, if any, data collection, oversight or accountability efforts accompany such recommendations?
5. Children 0-3 years of age are prone to ear infections that can disrupt or slow standard procedures for determining hearing status. What steps, if any, are taken to ensure that children who require intermediary medical assessment and/or treatment for middle ear conditions receive a determination of hearing status after a temporary/fluctuating middle ear condition is resolved?
  - What happens if the process of addressing middle ear conditions exceeds the 30-day window required by Part C from the time of in-take to eligibility determination and IFSP development?
  - Are there any steps taken to ensure that the hearing status of these children continues to inform the child’s eligibility for and/or nature of services the child receives through Part C?
6. To what degree are the answers to the above questions different if a child is referred to Part C with a specifically mentioned concern about hearing status?
7. What data are currently available on state and local levels regarding the identification of children who are deaf or hard of hearing as a consequence of the Part C eligibility / IFSP development processes (as opposed to the newborn screening process)?

- How does the Part C identification rate of children who are deaf or hard of hearing in your state compare to the estimates of 3-6 per thousand subsequent to the newborn period?
  - Are identifications of children who are deaf or hard of hearing reported to the EHDI system and, if so, how?
  - What state Part C eligibility criteria apply to children who are identified with a hearing loss?
    - Degree of hearing loss
    - Uni-lateral versus bi-lateral
    - Permanent versus temporary
8. From what other sources does Part C obtain referrals of children with hearing screening or evaluation results such as Early Head Start, health care providers, etc.?
- Is there a formal connection or agreement between Part C and any such providers or programs to ensure timely referral and follow-up?
  - Are Part C hearing results reported to the referring source?
  - Is there data reflecting these types of referrals to Part C?
  - What type of data are shared (individually identifiable, numerical only, aggregate)?
9. What terminology pertaining to the identification of children who are deaf or hard of hearing through the Part C process should be discussed and understood by all parties, including professionals and family members such as:
- Hearing loss/impairment
  - Type/degree/laterality of hearing loss
  - Hearing threshold
  - Deafness
  - Hard of hearing
  - Assessment
  - Evaluation
  - Screening
  - IFSP
  - Service Coordination
  - etc.
10. What are the most common questions providers within each program/system have about the other system or that families have about these two systems (EHDI and Part C) that need to be addressed?
- What, if any, misconceptions exist about the relationship between EHDI and Part C that need to be addressed and how can that be accomplished?

## Information Sharing Opportunities

1. What mechanisms are used to share resources or learning opportunities with local Part C staff?
  - Do you use eblasts?
  - Do you have regular virtual or live meetings?
  - Are there state conferences/workshops?
  - How is social media used?
  - Is there a website/bulletin board or other online presence that local providers access for this purpose?
2. Has there been any training or technical assistance activities on the topic of hearing, hearing criteria or hearing evaluation that you are aware of?
  - If so, who was involved?
  - What was the nature of it?
  - Who was the provider of the services?
3. What meeting opportunities (either virtual or live) exist for Part C in the state?
  - Who organizes these?
  - What opportunities exist for sharing and/or gathering information as a part of these meetings?
  - Is there any data collection planned whereby information about current hearing screening and follow-up practices could be collected?
  - If we wanted to collect information about current practices and/or needs pertaining to hearing evaluations, what would be the best mechanisms to consider?
4. Are there any local Part C programs in the state that are viewed as leaders or models for others?
  - What hearing evaluation methods are currently being used by these programs?
  - How might initial collaborations with model programs lend to an expansion of evidence-based practices across other local programs?
5. Are there data sharing agreements or established means for creating them?
  - How might newborn screening and diagnostic data be shared with Part C?
  - How might Part C data be incorporated into the EHDI Tracking and Surveillance system?