National Center on Deaf-Blindness

Early Identification and Referral Self-Assessment Guide

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Preface

The Self-Assessment Guide is designed to be a tool that utilizes a data-based decision making process model to assist Deaf-Blind Projects in the analysis of current early identification and referral efforts and determination of specific strategies to implement to improve efforts at local and state levels.

Overview of the Self-Assessment Guide Process:

- **Step One** will require users to systemically analyze Deaf-Blind Child Count data and current early identification and referral efforts. Projects will be guided through a process to assess Part C, medical and other systems in their state; to reflect on the results and to determine whether underlying issue(s) exist related to under-identification, under-referral or both.
- **Step Two** will require users to carefully scrutinize their current situation; identify the state system(s) and issue(s) with the highest potential for change, (based on feasibility and likelihood of impact); and create an action plan identifying strategies to address any issues identified through the assessment.
- **Step Three** will entail implementation of the action plan with technical assistance, as needed, from NCDB.

Part 1 – Review of Data

Part 1 contains five sections. It is intended to help projects take a systematic look at their child count data and decide whether the need exists to implement strategies to improve early identification and referral efforts. There are no specific established standards against which to judge whether a state has a low birth-2 Deaf-Blind Child Count. Instead, in each section we provide guidelines, based on a 5-year trend, that you can use in making this judgment. *Please be aware, however, that all these data should be interpreted with caution. This holds particular relevance when numbers are very small, as a difference of one or two children can greatly affect results.*

We have intentionally provided a number of ways for projects to look at their data. Analysis from more than one perspective allows you to take a broad view and create a reliable snapshot of the situation in the state. The process allows you to probe deeper as you move through it. Depending on individual state circumstances, certain sections may prove more helpful than others. If you have questions about a particular section(s) and its significance please contact us.

Part 1: Section A

Current birth through 2 Deaf-Blind Child Count in comparison with state's Federal Part C Count

In looking at the past five years of data (see Table 1 below) you will see that nationally the proportion of children on the Deaf-Blind Child Count for ages birth through 2 compared to the Federal Part C Count ranges from 0.16% to 0.17%. That is, for the past 5 years there have been between 1.6 and 1.7 children on the National Deaf-Blind Child Count ages birth through 2

for every 1000 children on the Federal Part C Child Count. Using this range can be instructive if there is a significant discrepancy in the state, or if the proportions are fairly consistent.

Compare the state's proportion to the national proportion. Are they similar? Are they very different? The range at the national level is very small and it is likely that state to state proportions will fluctuate quite a bit and thus the range will be larger at the state level. If the average proportion over the 5 years is less than 0.10%, (approximately 1 standard deviation below the 5 year mean) the current Deaf-Blind Child Count for children birth through age 2 might be proportionately low in comparison with the state's overall Part C Count.

Table 1. Proportionality of State Birth through 2 Deaf-Blind Child Count to Part C Count

Year	National Deaf-Blind Child Count (0-2)	Federal Part C Count	National Deaf-Blind Proportion	State Deaf-Blind Child Count (0-2)	State Part C Count	State Deaf-Blind Proportion
Average						
Range						

Part 1: Section B

Current state birth through 2 Deaf-Blind Child Count in comparison with the National Deaf-Blind Child Count data

Another way to look at these numbers is to compare the state's Deaf-Blind birth through 2 count to the state's entire Deaf-Blind Child Count and see how this ratio compares to the rest of the country.

On average, over the past 5 years just fewer than 6.0% of the children on the National Deaf-Blind Child Count have been ages birth through 2 years of age. Compare the state's proportion to the national proportion. Are they similar? Are they quite different? The range at the national level is again very small and it is likely that state to state proportions will fluctuate and thus the range will be larger at the state level. However, if the average proportion over the 5 years is less than 3%, (approximately 1 standard deviation below the 5 year mean) the current count for children birth through age 2 might be proportionately low in comparison with other state and National Deaf-Blind Count data.

Table 2. Proportionality of State Birth through 2 Deaf-Blind Count to National Birth through 2 Deaf-Blind Count

Year	National Deaf-Blind Child Count (0-2)	Total National Deaf-Blind Child Count	National Proportion (0-2)	State Deaf-Blind Child Count (0-2)	Total State Deaf-Blind Child Count	State Proportion (0-2)
Average						

Part 1: Section C

Current birth through 2 Deaf-Blind Child Count in comparison with a state's overall Deaf-Blind Child Count age distribution

There may be many reasons why the state's distribution is different from the national distribution. We would suggest that you also look at how the state Deaf-Blind Child Count is distributed across the various age ranges. Table 3 below provides *Equal Distribution* numbers and *National* data across all age ranges in which you can compare your state data to. Certainly an equal distribution is not likely, though some reasonable distribution might be expected. Even if you feel comfortable that the birth through age 2 count is satisfactory, looking at the overall distribution might point out other matters to consider.

In addition to looking at the state's distribution against the national distribution, look for patterns that may appear and that seem unusual, such as three to four times as many children at ages 3-5 than 0-2. Obviously if there are few or no children in the 0-2 age range, concern is in order. There are no set criteria to help in making a judgment as to whether the state's 0-2 Deaf-Blind Child Count is proportionally low compared to the overall distribution. One rule of thumb might be that if the entire state Deaf-Blind Child Count is skewed toward older children and there are relatively fewer children at ages birth through 2 and ages 3-5, then the current count for children birth through age 2 might be proportionately low in comparison with the state's overall Deaf-Blind Child Count. If you are seeing a shift in population over time toward the older age groups, this might also be an indication that for some reason early identification and/or referral efforts may not be as effective as you might like them to be.

Table 3. Proportionality of State Birth through 2 Deaf Blind Child Count with Overall Deaf-Blind Count Age Distribution

Year	Total State Deaf-Blind Child Count	State 0-2 Deaf-Blind Count (3 years)	State 3-5 Deaf-Blind Count (3 years)	State 6-11 Deaf-Blind Count (6 years)	State 12-17 Deaf-Blind Count (6 years)	State 18-21 Deaf-Blind Count (4 years)
Equal Distribution		***13.6%***	***13.6%***	***27.3%***	***27.3%***	***18.2%***
Percent of Total						
Percent of Total						
Percent of Total						
Percent of Total						
Percent of Total						
State Average Percent of Total						
Percent of Total (National)						
Range Across Past 5 Years (National)						

Part 1: Section D

Percent change in numbers of children on the Deaf-Blind Child Count from ages birth-1, 1-2, and 2-3

A final analysis of state and national data looks at the jumps that might exist from one age to the next, and especially at the Early Intervention (EI) to Early Childhood Special Education (ECSE) transition at age three. As you can see from Table 4 below, the national data indicate a significant increase for children under one year of age to one year olds, and a much smaller increase from one year olds to 2 year olds and again in the transition year from EI to ECSE.

Compare the state's jumps from age to age with the national data. Are they similar? Are they quite different? The range at the national level is relatively small across years (except at the first jump) and it is likely that state to state proportions will fluctuate and thus the range will be larger at the state level. If the state data indicate that there is a large jump between two and three year olds – much larger than the 20% increase at the national level, this could indicate issues related to referral by Part C. Similarly, if the state data indicate that there is a large jump between infants birth to age one and one year olds, – much larger than the nearly 170% increase at the national level, this could indicate issues of identification and/or referral.

Table 4. Population Jumps From Birth Through Age Three

	Column A	*Column B*	*Column C*	*Column D*	*Column E*	*Column F*	*Column G*
Year	**Under 1 year**	**1 year olds**	**% Change**	**2 year olds**	**% Change**	**3 year olds**	**% Change**
National Average							
State Average							

Part 1: Section E (Optional-Strongly Recommended)

Additional analysis of other factors that may affect current birth through 2 Deaf-Blind Child Count

Within any state there may be more specific issues that warrant investigation. You may want to consider geographic distribution, etiology, a particular demographic category or any other factor(s) that you think important. For example you may suspect that referrals are coming primarily from major urban areas in the state. You may wish to focus on historically challenging locations such as rural/isolated areas, tribal lands or inner cities; or find a way to align with existing efforts in the state to identify and provide support to families living in poverty or children

living in foster homes. You may also feel that a comparison to a select group of states, rather than national data, would be useful.

If you decide to analyze additional factors it may be helpful to construct a table to collect and summarize such data. NCDB can assist you in gathering categorical information from the Deaf-Blind Child Count or the federal Special Education Child Count. Other state-specific demographic information may need to be generated by tapping into other data sources within the state. Please contact us if you would like assistance.

Two examples are provided below. The first table has region as the main geographic category. (Alternative categories might include: county, LEA, etc.) The second table is an example using race/ethnicity data to make comparisons.

Table 5: Example Table for Geographic Data – By Region

Region	State Part C Count	State Part C Percentage	State Deaf-Blind Child Count (0-2)	State Deaf-Blind Percentage (0-2)
Region 1				
Region 2				
Region 3				
Region 4				
Region 5				
Region 6				
Region 7				
TOTAL				

Table 6: Example Table for Race/Ethnicity Data

Race/Ethnicity	State Part C Count	State Part C Percentage	State Deaf-Blind Child Count (0-2)	State Deaf-Blind Percentage (0-2)
American Indian or Alaska Native				
Asian				
Black or African American				
Hispanic/Latino				
White				
Native Hawaiian/Pacific Islander				
Two or more races				
TOTAL				

Part 2 – Determination of Need for Improvement

In this part you will review the results of Part 1 to determine whether there is a need for improvement of identification and/or referral of children birth through age 2 within the state.

Reflection Question:

Does it seem that the Deaf-Blind Child Count for age groups less than three is lower than it should be?

To assist in answering this question, identify which of the following indicators are present in the state:

Indicator	Yes	Possibly	No
Current Deaf-Blind Child Count for children birth through 2 is proportionately low in comparison with the state's federal Part C Count. *(See Section A)*			
Current Deaf-Blind Child Count for children birth through 2 is proportionately low in comparison with the state's overall Deaf-Blind Child Count. *(See Section B)*			
Current Deaf-Blind Child Count for children birth through 2 is proportionately low in comparison with other state age distributions and National Deaf-Blind Child Count age distribution data. *(See Section C)*			
The state % change in Table 4, Column C is significantly greater than the national % change in Table 4, Column C. *(See Section D)*			
The state % change in Table 4, Column E is significantly greater than the national % change in Table 4, Column E. *(See Section D)*			
The state % change in Table 4, Column G is significantly greater than the national % change in Table 4, Column G. *(See Section D)*			
(Optional) Current Deaf-Blind Child Count for children birth through 2 as measured by state identified categories is proportionately low. *(See Section E)*			

If you answered YES or POSSIBLY to any of these indicators then complete Parts 3, 4 and 5.

Part 3 – Review of State Systems

The following issues and contexts were identified during a 2009 focus group of individuals from eight state deaf-blind projects. While in and of themselves they may or may not be important in the effective identification and referral of young children who are deaf-blind or at risk, each was identified as a potentially important variable. Since the creation of the guide, these have been validated by users as still being important.

Think about the following questions and record your answers. If you're unsure of an answer now is the time to investigate how the state operates. Referring back to your answers will be helpful later in the process.

System: Deaf-Blind Project

1. Where is your project housed? (e.g. SEA, IHE, State School, other?)
   If your project is housed at an agency that does not necessarily have close ties with other state agencies within the EI system, this could result in under-referral if significant measures have not been taken to establish those ties.

2. To what degree is your project involved in the state's overall early identification efforts?
   If your project is involved in the state's overall identification efforts, you are more likely to be in the position to make others aware of deaf-blindness and its risk factors. If you are not involved, you may be less likely to advocate these issues. As a known entity you are also more likely to receive referrals.

3. Does your project staff have early intervention expertise? Do you have access to early intervention expertise?
   Having someone on project that knows infants and toddlers and how to relate to families, service providers, administrators, etc. is important. Providing this will build trust and confidence and contribute to cooperation in identification and referral.

4. Does any member of your project staff belong to the state Interagency Coordinating Council (ICC)? Any other state boards and organizations focused on early intervention?
   Being an active member of the state early intervention community develops awareness and visibility which can facilitate identification and referral.

System: State Part C Program

1. Where is the state Part C Program housed? (e.g. SEA, Health division, other state agency?)
   The location of your project and the Part C Program affect the level of effort required to develop relationships with Part C leadership.

2. How is the Part C Program in the state organized and what service delivery models are used? (e.g. one state-wide program, county or regional programs operating independently)
   How the state Part C program is set up affects the efforts required to develop relationships and provide awareness training or materials. A Part C Program that has adopted a medical model will also require a different approach than an educational/developmental model.

3. How strong is your project's relationship with the state's Part C Program(s) and Director?
   This may be the single most important factor for ensuring appropriate referrals to your project. A strong working relationship will ensure awareness, visibility and a voice at the table.

4. Has your project collaborated with the state's Part C Program now or in the past? In what ways?

System: Medical Community

1. Where are the Neonatal Intensive Care Units (NICUs) in the state located? What is your project's relationship with them?
   NICUs are an important target audience for disseminating information regarding deaf-blindness and related etiologies to improve identification and referral to Part C and/or your project. A critical role in the NICU is that of Case Care Manager or Social Worker who is responsible for working with parents to coordinate services with other programs.

2. What is your project's relationship with hospitals and medical centers serving young children with disabilities and health challenges? (e.g. pediatric intensive care units, developmental clinics)

3. What is your project's relationship with medical specialists in the state? (e.g. neonatologists, pediatricians, geneticists, pediatric audiologists and ophthalmologists)
   Developing a relationship with the medical community can be challenging, but can contribute to raising awareness about deaf-blindness and associated etiologies to improve/increase appropriate identification and referral to Part C and/or your project.

4. Has your project collaborated with the medical community in the state? In what ways?

System: Early Hearing Detection and Intervention (EHDI) Program

Note: If you need assistance answering the following questions go to:
http://www.cdc.gov/ncbddd/hearingloss/ehdi-programs.html

1. Is there an EHDI Program established in the state? If so, where is it housed? Is it active statewide?

2. How strong is the program? (National indicators include: screening over 70% of newborn infants and a loss to follow-up rate of less than 50%).

3. How is the program administered? Who does EHDI refer a family to for additional assessments and/or services in your state?

4. Has your project collaborated with the EHDI program? In what ways? Has your project collaborated with those programs that EHDI refers a family to for further assessments and or services?"

System: Other Community Programs (serving children birth through 2)

Note: Depending on how the state is structured, community programs could be agencies that are contracted to supply services through Part C.

1. List below any social service agencies or community organizations you are aware of in the state that serve children birth through two and their families (e.g. Early Head Start, maternal/child health programs, Children's Special Health Care Services, disability specific organizations, outreach programs for children who are blind or have visual impairments or are deaf/hard of hearing).

2. Is there a Babies Count program in the state? If so, how strong is it?
   For assistance go to: http://www.aph.org/advisory/babiescount.html

3. How strong is your project's relationship with other programs in the state focusing on EI/ECSE?
   These agencies and organizations are involved in making referrals to Part C programs and provide another target audience for disseminating awareness materials.

4. Has your project collaborated with any of these programs now or in the past? If so, which ones? In what ways?

Part 4 – Under-Identification Analysis

In Part 4 you will be asked to think about lower than expected birth through 2 child counts that result from under-identification (children whose vision and hearing loss have not yet been identified).

This part contains three sections. Each section includes examples, reflection questions and indicators designed to assist you in thinking critically about your project's efforts.

- *Section A* assists in determining if under-identification is an issue within the state.
- *Section B* provides initial analysis of the causes of under-identification and assists in determining whether sufficient indicators are present to address the under-identification through collaborative activities with Part C, medical providers, EHDI and/or other community programs.
- *Section C* provides additional analysis of the causes of under-identification and utilizes your data analysis to identify potential systems to target.

Please spend time thinking about and discussing these questions with others on your project staff if possible.

Part 4: Section A

Determining if low deaf-blind child counts are due to *under-identification* of children with deaf-blindness

Examples of under-identification include children whose vision and hearing loss have not yet been identified due to:

- the existence of serious medical complications that take precedence
- suspicion or identification of hearing loss without consideration of vision loss
- suspicion or identification of vision loss without consideration of hearing loss
- lack of service provider knowledge related to specific conditions associated with vision and hearing loss
- lack of qualified personnel with training specific to deaf-blindness available in birth through 2 systems to identify/evaluate vision and hearing loss

Under-Identification Systems Assessment

Reflection Question: Does it seem that low birth through 2 child counts are due to children with both hearing and vision loss not being identified as deaf-blind?

To assist in answering this question, indicate your response to the statements below:

Indicator	Yes	No
Children birth through 2 referred to the Deaf-Blind Project often lack complete documentation of hearing and/or vision loss.		
There is a significant increase on the child count for children between the ages of birth-1 to 1-2, and 1-2 to 2-3? ***(Refer to Part 2 on page 9. If you checked YES or POSSIBLY to any indicator(s) then check YES here.)***		

If you checked YES to the indicator above please identify which of the following indicators are present:	Yes	No	Unsure
• Of the children accounting for this increase, a review of records/available information show that prior to being on the Deaf-Blind Child Count a number of the children were not receiving **Part C services.**			
• Of the children accounting for this increase, a review of records/available information show that prior to being on the Deaf-Blind Child Count they were receiving **Part C services** but hearing and/or vision loss was not identified and therefore not referred to the Deaf-Blind Project ***earlier***.			
• Of the children accounting for this increase, a review of records/available information show that prior to being on the Deaf-Blind Child Count they were receiving **medical services** but hearing and/or vision loss was not identified and therefore not referred to the Deaf-Blind Project ***earlier***.			

- If you checked "**Yes**" to any of these indicators then low deaf-blind child counts may be due to under-identification of children who are deaf-blind. **Please complete Sections B and C if one or more indicators are present.**

- If you checked "**Unsure**" to any indicators, then low deaf-blind child counts may be due to under-identification and you will need to investigate the issue more thoroughly. Sections B and C may help with this or you may wish to include an item in your Action Plan related to gathering more information.

Part 4: Section B

Analysis of systems involved in identifying young children with vision and hearing losses

Part C Program

Reflection Question: Does it seem that the state's Part C program is adequately identifying children with combined hearing and vision losses?

To assist in answering this question, complete the grid below:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
The Part C program considers (or screens for) vision loss when there is suspicion or identification of hearing loss.				
The Part C program considers (or screens for) hearing loss when there is suspicion or identification of vision loss.				
The Part C program considers hearing and vision losses when specific conditions associated with those losses are present. (e.g. CHARGE, asphyxia, CMV)				
The Part C program has resources to complete evaluations and referrals for evaluation of vision loss.				
The Part C program has resources to complete evaluations and referrals for evaluation of hearing loss.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with the Part C program in the state may already be effective in addressing under-identification.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage Part C program personnel in making a determination if more or different collaboration activities would be helpful.

Medical Community

Reflection Question: Does it seem that medical community providers (hospitals, developmental clinics and/or medical specialists) in the state are adequately identifying children with combined hearing and vision losses?

To assist in answering this question, complete the grid below:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
Providers consider (or refer or screen for) vision loss when there is suspicion or identification of hearing loss.				
Providers consider (or refer or screen for) hearing loss when there is suspicion or identification of vision loss.				
Providers consider hearing and vision losses when specific conditions associated with those losses are present. (e.g. CHARGE, asphyxia, CMV)				
There are resources available for providers to complete evaluations and/or referrals for evaluation of vision loss.				
There are resources available for providers to complete evaluations and/or referrals for evaluation of hearing loss.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with medical community providers in the state may already be effective in addressing under-identification.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage medical community providers in making a determination if more or different collaboration activities would be helpful.

EHDI Program

Reflection Question: Does it seem that the state's EHDI program is adequately identifying children who also have vision loss?

To assist in answering this question, complete the question grid below:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
State EHDI program staff are aware of/knowledgeable about risk factors and conditions associated with combined vision and hearing loss.				
State EHDI program staff considers (or refers) for vision loss when hearing screening indicates hearing loss.				
State EHDI program staff considers the combination of hearing and vision losses when specific conditions associated with those losses are present.				
There are programs and/or properly trained professionals available for the state EHDI program to refer to for screening or evaluation of vision loss.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with the EHDI program in the state may already be effective in addressing under-identification.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage EHDI program personnel in making a determination if more or different collaboration activities would be helpful.

Community Programs

Reflection Question: Does it seem that community programs that serve children birth through 2 in the state (e.g., Early Head Start, Children's Special Health Care Needs, disability specific organizations, outreach programs for children who are deaf/hard of hearing or blind/visually impaired) are adequately identifying children with combined vision and hearing losses?

To assist in answering this question, complete the grid below:

Indicator	Yes	If Yes, Which Ones?	No	Unsure
Staff from community programs serving children birth through 2 are aware of/knowledgeable about risk factors and conditions associated with combined vision and hearing loss.				
Community programs serving children birth through 2 consider (or refer) for vision loss when suspicion or identification of hearing loss is present.				
Community programs serving children birth through 2 consider (or refer) for hearing loss when suspicion or identification of vision loss is present.				
Community programs serving children birth through 2 have authorization/resources to make referrals for evaluations for hearing and vision loss.				
Community programs serving children birth through 2 directly evaluate and identify children who are deaf-blind.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with the community programs in the state may already be effective in addressing under-identification.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage community program personnel in making a determination if more or different collaboration activities would be helpful.

Part 4: Section C

Thinking about potential systems and underlying issues to target in addressing *under-identification*

This section is intended to begin the process of narrowing your potential targets for action to improve efforts of early identification. You will need to refer to Part 4: Section B to complete the table on the following page.

Six potential explanations related to under-identification are listed in the left hand column. For the systems you identified in Section B as potential collaborative partners, indicate the response (**Yes, No, Unsure**) that best describes each system's typical response to each item. The category of "Medical Community" has been broken into two separate systems to assist you in narrowing your focus of attention and better align with existing evidence-based practices and materials.

If you discover that it is difficult to determine an answer this is a good time to gather additional information about particular systems within the state and the types of practices used to identify children with vision and hearing losses. This could be done by contacting representatives from particular systems and/or enlisting assistance from a small work group that represents some, or all, of the systems you thought about in Part 3. One state found it helpful to complete this section with the help of their Advisory Board.

When finished, tally the number of "Yes" responses for each system and write the number in the bottom row (**Total**). The systems with the most "Yes" responses are the likely systems to target.

You may also tally the number of "Yes" responses for each potential explanation across systems and write the number in the far right column. If no system(s) emerges as a clear target, then the potential explanations with the most "Yes" responses may serve as a starting point instead. If there are several "Unsure" answers indicated then more information gathering may be a potential action item.

Table for Part 4: Section C

Potential Explanations for Under-Identification	Potential System(s) to Target					Potential Issue(s) to Address	
	Part C Early Intervention Program	**Hospitals and Medical Centers** (e.g. Intensive Care Nurseries, Pediatric Intensive Care Units, Developmental Clinics)	**Medical Specialists** (e.g. Developmental Pediatricians, Geneticists, Audiologists, Ophthalmologists)	**EHDI (Early Hearing Detection and Intervention)** (Includes Newborn Hearing Screening and Follow-up Programs)	**Community Programs that serve children birth through 2** (e.g. Early Head Start, Maternal/Child Health, Outreach Programs)	✓ **CHECK** (Indicated by several YES responses)	**Priority** (Rank checked boxes)
The existence of serious medical complications takes precedence and referral or screening for vision and/or hearing loss is not completed.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Referral or screening for vision loss is not automatically considered when there is suspicion or identification of hearing loss.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Referral or screening for hearing loss is not automatically considered when there is suspicion or identification of vision loss.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Lack of knowledge related to specific conditions associated with vision and hearing loss prevents providers from considering hearing and vision losses, conducting screenings and/or making appropriate referrals when associated conditions are present.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Evaluations or referrals for evaluation of vision loss are not completed because of lack of resources available in birth through 2 systems to identify/evaluate vision loss.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Evaluations or referrals for evaluation of hearing loss are not completed because of lack of resources available in birth through 2 systems to identify/evaluate hearing loss.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
TOTAL							

Part 5 – Under-Referral Analysis

In Part 5 you will be asked to think about lower than expected birth through 2 child counts that result from under-referral (children who have been identified with vision and hearing loss but not referred to the Deaf-Blind Project).

This part contains three sections. Each section includes examples, reflection questions and indicators designed to assist you in thinking critically about your project's efforts.

- *Section A* assists in determining if under-referral is an issue within the state.
- *Section B* provides initial analysis of the causes of under-referral and assists in determining whether sufficient indicators are present to address the under-referral through collaborative activities with Part C, health care providers, EHDI and/or other community programs that serve children birth through 2.
- *Section C* provides additional analysis of the causes of under-referral and utilizes your data analysis to identify potential systems to target.

Part 5: Section A

Determining if low deaf-blind child counts are due to *under-referral* to your project

Examples of under-referral include children who have been identified with combined vision and hearing losses but not referred to your project due to:

- lack of awareness that the project exists
- lack of awareness about services that the project can provide
- lack of understanding or value of services that the project can provide
- severe health problems seem to take precedence over early educational needs
- complexity of referring a child to the project
- concerns about HIPPAA/FERPA impact on sharing information
- lack of knowledge about the developmental and educational implications of deaf-blindness

Under-Referral Systems Assessment

Reflection Question: Does it seem that low deaf-blind child counts are due to children identified as deaf-blind not being referred to your project?

To assist in answering this question, identify which of the following indicators are present in the state:

Indicator	Yes	No
Few referrals are received from the Part C program.		
Few referrals are received from medical providers.		
Few referrals are received from state Early Hearing Detection and Intervention (EHDI) Program.		
Few referrals are received from other community programs serving children birth through 2.		
Child count from ages birth-1 to 1-2, and/or 1-2 to 2-3 increases significantly. ***(Refer to Part 2 on page 9. If you checked YES or POSSIBLY to any indicator(s) then check YES here.)***		

If you checked "**Yes"** to the indicator(s) above please respond to the following items:	Yes	No	Unsure
• Of the children accounting for this increase, a review of records/available information show that prior to being on the Deaf-Blind Child Count a number of the children were receiving **Part C services.**			
• Of the children accounting for this increase, a review of records/available information show that prior to being on the Deaf-Blind Child Count they were receiving **Part C services** and hearing and vision losses were identified.			
• Of the children accounting for this increase, a review of records/available information show that prior to being on the Deaf-Blind Child Count they were receiving **medical services** and hearing and vision losses were identified.			

- If you checked "**Yes**" to any indicator(s) then low deaf-blind child counts may be due to under-referral of children who are deaf-blind. **Please complete Sections B and C if one or more indicators are present.**

- If you checked "**Unsure**" to any indicator(s) then low deaf-blind child counts may be due to under-referral but you will need to investigate the issue more thoroughly. *Sections B and C* may help with this or you may wish to include an item in your Action Plan related to gathering more information.

Part 5: Section B

Analysis of systems involved in referring young children with vision and hearing losses to Part C and/or the Deaf-Blind Project

Part C Program

Reflection Question: Does it seem that the state Part C program is adequately referring children with combined hearing and vision losses?

To assist in answering this question, indicate which of the following statements your project staff suspect might be occurring:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
The number of referrals currently coming from the Part C program has potential to increase.				
The Part C program identifies children with vision and hearing losses and refers children to your project in a timely manner.				
The Part C program has access to the resources needed to complete evaluations for hearing and vision losses.				
The Part C program personnel can be accessed for training and technical assistance.				
State resources, agencies or groups exist to effectively facilitate reaching/partnering with the Part C program for referral.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with the Part C program in the state may already be effective in addressing under-referral.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage Part C program personnel in making a determination if more or different collaboration activities would be helpful.

Hospitals and Medical Centers

Reflection Question: Does it seem that hospitals and medical centers are adequately referring children with combined hearing and vision losses?

To assist in answering this question, indicate which of the following statements your project staff suspect might be occurring:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
The number of referrals currently coming from hospitals and medical centers (as indicated earlier) has potential to increase.				
Hospitals and medical centers identify children with vision and hearing losses and refer children on to Part C or to your project in a timely manner.				
Hospitals and medical centers have access to the resources needed to complete evaluations for hearing and vision losses.				
Personnel from hospitals and medical centers can be accessed for training and technical assistance.				
State resources, agencies or groups exist to effectively facilitate reaching/partnering with hospitals and medical centers for referral.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with medical community providers in the state may already be effective in addressing under-referral.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage medical community providers in making a determination if more or different collaboration activities would be helpful.

Medical Specialists

Reflection Question: Does it seem that medical specialists in the state are adequately referring children with combined hearing and vision losses?

To assist in answering this question, indicate which of the following statements your project staff suspect might be occurring:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
The number of referrals currently coming from medical specialists has potential to increase.				
Medical specialists identify children with vision and hearing losses and refer children on to Part C or to your project in a timely manner.				
Medical specialists have access to the resources needed to complete evaluations for hearing and vision losses.				
Medical specialists can be accessed for training and technical assistance.				
State resources, agencies or groups exist to effectively facilitate reaching/partnering with medical specialists for referral.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with medical specialists in the state may already be effective in addressing under-referral.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage medical community providers in making a determination if more or different collaboration activities would be helpful.

EHDI Program

Reflection Question: Does it seem that the state's EHDI program is adequately referring children with combined hearing and vision losses?

To assist in answering this question, indicate which of the following statements your project staff suspect might be occurring:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
The number of referrals currently coming from the state EHDI Program has potential to increase.				
State EHDI program identify children with vision and hearing losses and refer children on to Part C or to your project in a timely manner.				
State EHDI program personnel can be accessed for training and technical assistance.				
State resources, agencies or groups exist to effectively facilitate reaching/partnering with the EHDI program for referral.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with the EHDI program in the state may already be effective in addressing under-referral.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage medical community providers in making a determination if more or different collaboration activities would be helpful.

Community Programs

Reflection Question: Does it seem that community programs that serve children birth through 2 in the state (e.g. Early Head Start, Children's Special Health Care Needs, disability specific organizations, outreach programs for children who are deaf/hard of hearing or blind/visually impaired) are adequately referring children with combined hearing and vision losses?

To assist in answering this question, indicate which of the following statements your project staff suspect might be occurring:

Indicator	Yes	If Yes, Is It Adequate? (Explain Briefly)	No	Unsure
The number of referrals currently coming from community programs serving children birth through 2 has potential to increase.				
Community programs identify children with vision and hearing losses and refer children on to Part C or to your project in a timely manner.				
Community programs serving children birth through 2 have authorization/resources to make referrals for evaluations for hearing and vision loss.				
Personnel from community programs serving children birth through 2 can be accessed for training and technical assistance.				
State resources, agencies or groups exist to facilitate effectively reaching/partnering with social service agencies for referral.				

Next Steps:

- If you checked "**Yes**" to all of the indicator(s) then collaborative activities with community programs in the state may already be effective in addressing under-referral.
- If you checked **any other response**, then additional collaborative activities may be constructive.
- If further investigation is necessary, you may wish to engage community programs in making a determination if more or different collaboration activities would be helpful.

Part 5: Section C

Thinking about potential systems and underlying issues to target in addressing *under-referral*

This section is intended to begin the process of narrowing your potential targets for action to improve efforts relating to under-referral. **You will need to refer to Part 5: Section B to complete the table on the following page.**

Seven potential explanations related to under-referral are listed in the left hand column. For the systems you identified in Section B as potential collaborative partners, indicate the response (**Yes, No, Unsure**) that best describes each system's typical response to each item. This information will be useful as you begin to make decisions related to systems to target and strategies to implement as you develop an Action Plan. As in Section B, we have broken out "Medical Providers" into two separate systems to assist you in narrowing your focus of attention and better align with existing evidence-based practices and materials.

When finished, tally the number of "Yes" responses for each system and write the number in the bottom row (**Total**). The systems with the most "Yes" responses are the likely systems to target.

You may also tally the number of "Yes" responses for each potential explanation across systems and write the number in the far right column. If no system(s) emerges as a clear target, then the potential explanations with the most "Yes" responses may serve as a starting point instead. If there are several "Unsure" answers indicated then more information gathering may be a potential action item.

Table for Part 5: Section C

Potential Explanations for Under-Referral	Potential System(s) to Target					Potential Issue(s) to Address	
	Part C Early Intervention Program	**Hospitals and Medical Centers** (e.g. Intensive Care Nurseries, Pediatric Intensive Care Units, Developmental Clinics)	**Medical Specialists** (e.g. Developmental Pediatricians, Geneticists, Audiologists, Ophthalmologists)	**EHDI (Early Hearing Detection and Intervention)** (Includes Newborn Hearing Screening and Follow-up programs)	**Community Programs serving birth through 2** (e.g. Early Head Start, Maternal/Child Health, Outreach Programs)	✓ **CHECK** (Indicated by several YES responses)	**Priority** (Rank checked boxes)
Potential referrers do not refer because they are unaware of the existence of your project.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Potential referrers do not refer because they are unaware of the services offered by your project.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Potential referrers do not refer because they do not value services offered by your project.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Potential referrers do not refer because they have low expectations of children who are deaf-blind and have multiple disabilities (may not see the advantage of early intervention).	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Potential referrers do not refer because severe health problems seem to take precedence over early educational needs.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Potential referrers do not refer because they are reluctant to "label" a child as deaf-blind and referring would necessitate a label.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Potential referrers do not refer because they do not recognize deaf-blindness as a unique disability and do not understand the importance of referral.	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE	YES NO UNSURE		
Total							

Part 6 – Developing an Action Plan

Step 1: Complete the Decision-Making Matrix.

Decision-Making Matrix

1. In Section C of Part 4 and Part 5 you identified potential explanations for under-identification and/or under-referral and the system(s) that would benefit from additional collaboration. Review those tables and place a check-mark in the table below for those systems for which a need has been identified and potential for positive impact exists. If you have identified more than one issue to address in the tables, the ranking in the right hand column of the charts will assist you in identifying where to focus your efforts.

Sufficient indicators identified in the results of Sections C of Parts 4 & 5	Part C	Hospitals and Medical Centers	Medical Specialists	EHDI	Community Programs
Established a need and potential for positive impact on under-identification:					
Established a need and potential for positive impact on under-referral:					

2. Determine whether you plan to address under-identification and/or under-referral by reviewing the results of your analysis and reflections from Part 4, Section A (pages 15-16) and Part 5, Section A (pages 23-24). (*Note: If there are several responses of* Unsure, *then a first step in your Action Plan might be to gather more information*.)

Indicate Identified Area(s) of Focus Below:

☐ **Under-Identification** ☐ **Under-Referral** ☐ **Both**

3. For the systems identified above, rate from 1 (low) to 5 (high) the items in the first column in the table on the next page. In this section you should review your responses in Part 3 regarding State Systems. This will assist in focusing your efforts in areas that will most likely result in positive outcomes. Sum each column. The system with the highest score represents the system for which there is the highest feasibility for facilitating positive change.

Feasibility and potential for facilitating systemic changes	Part C	Hospitals and Medical Centers	Medical Specialists	EHDI	Community Programs
	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)
Strength of current relationship					
Potential for establishing relationships					
Accessibility of personnel as recipients of training and/or technical assistance					
Potential for collaboration					
Resources or relationships exist to facilitate effective partnering					
Project staff available at level of time/resources needed					
Total					

Step 2: Use information from the Decision Making Matrix to determine which **issue(s) to address** and which **system(s) to target**.

- It is possible that your analysis up to this point will suggest several issues or systems to target. Information from the matrix helps narrow your focus.
- It is strongly suggested that you focus on the system(s) that receive the highest total score on the matrix, even if earlier reflection pointed you in a different direction.

Step 3: Go to the **Toolbox** on the NCDB website to learn more about your targeted system and evidence-based identification and referral practices. These resources have been collected and organized by the Deaf-Blind TA Network to provide information and tips that can help you navigate a selected system and build a base upon which to carry out specific, targeted activities.

Step 4: Develop a **Goal/Outcome Statement**

- As you complete your Action Plan it will be important to design activities that match and support the level of change or outcome you have identified. While identifying your goal(s)/outcome(s) it might be helpful to ask yourself the following questions:
  - What is it you would like to change?
  - Do you want to create a change in knowledge or awareness among administrators, service providers, family members, etc?
  - Do you want to achieve a level of skill acquisition among personnel?
  - Do you want to reach a level of implementation where the goal becomes a common, ongoing practice?

SAMPLE OUTCOME STATEMENTS:

- **Immediate Outcome:** Increase the awareness and knowledge of medical personnel working in NICU Centers throughout (state) regarding the impact of a combined vision and hearing loss on the development of an infant.
- **Long Term Outcome:** Increase the number of NICU personnel identifying infants with a combined vision and hearing loss and making referrals to the state Deaf- Blind Project.

Outcome Statement(s):

Step 5: Think about the **effectiveness of your current early identification and referral efforts** and if/how they will be a part of your Action Plan.

- If your project is currently involved in activities related to the identified issue list them in the table below. Then think about each activity based on what you learned about evidence-based practices using the **TOOLBOX** resources in Step 3. Make any adjustments you think would improve effectiveness.

Current Early Identification and referral efforts:

Activity/strategy	Continue as is	Modify	Discontinue

Step 6: Develop an **Action Plan** using evidence-based practices.

- Download the Integrating Evidence-based Practices into EI&R Action Plan document and print out the sections that correspond to the evidence-based practice(s) you want to implement. Complete each section thoughtfully and carefully.
- Finalize your Action Plan using your own form or the one provided below.

PART 6 – DEVELOPING AN ACTION PLAN

Action Plan

Activity/strategy (Be sure to include those from the previous chart that you will be continuing)	**Steps to take**	**Resources and/or Partners**	**Timeline**