

# Bridging the Information gap between HIPAA and FERPA through a Parent Consent Form

Office Newborn Screening, Arizona Department of Health Services  
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Ensuring infants and toddlers with hearing loss are enrolled in Early Intervention Services timely

## Objectives

1. Identify Challenges & Barriers related to EHDI being able to capture Part C enrollment information
2. Strategize on how to reach an agreement to exchange patient identified EHDI information to meet the 1-3-6 goals.
  - Meet with Part C program to clarify their responsibility to AzEHDl
  - Meet with state legal representatives to identify required language
3. Develop a consent form for exchanging data while meeting both HIPAA and FERPA requirements
  - Worked together on creating the form
  - Modified an existing Part C consent form
  - Informs parent of purpose of the consent
  - Only requests minimal amount of personal information
  - One time consent



## Barriers

- Educational rights VS. medical rights
- AzEHDl (ADHS) and Part C are not within the same agency
- Lack of a shared data system
- Delays in receiving EI enrollment information



ARIZONA DEPARTMENT OF ECONOMIC SECURITY  
 Arizona Early Intervention Program (AzEIP)

**CONSENT TO SHARE EARLY INTERVENTION RECORDS AND INFORMATION**

I, \_\_\_\_\_, give my informed consent for the Arizona Early Intervention Program (AzEIP Team-based service provider and/ or ASDB Service Coordinator) to release and share information (in writing and/or conversation) regarding:

Child's full name \_\_\_\_\_ Date of birth \_\_\_\_\_

To the person/agency:  
 Arizona Department of Health Services/ Office of Newborn Screening (fax number: (602)-364-1495)

For the purpose of:  
 Sharing AzEIP Referral Date: \_\_\_\_\_  
 Sharing Initial IFSP Date: \_\_\_\_\_

As part of newborn screening, the Arizona Department of Health Services receives hearing screening information for all children in Arizona. This information is used to identify newborns or infants who are referred to the Arizona Early Intervention program who have been diagnosed with a hearing loss and have an initial IFSP. This helps ensure infants and their families receive the necessary resources and supports.

Annually, the information on the number of children with an identified hearing loss, including those who were referred to AzEIP and had an IFSP, is reported to the Center for Disease Control. Only aggregate numbers are shared; personally identifiable information is never released.

I have read and understand the conditions of this release. I understand that I have agreed to disclose the information only to the person/program listed above, and that the person/program may not disclose personally identifiable information to anyone else without my prior written consent. This is a one-time consent to share this information and is valid for 6 months.

Print or type Full Name of Parent(s)/ Responsible Party \_\_\_\_\_ Relationship to Child \_\_\_\_\_

Signature of Parent(s)/Responsible Party \_\_\_\_\_ Date \_\_\_\_\_

**This form is only to be used to send Early Intervention referral and enrollment information to the Arizona Department of Health Services, Office of Newborn Screening.**

Equal Opportunity Employer/Program • Under Titles VI and VII of the Civil Rights Act of 1964 (Title VI & VII), and the Americans with Disabilities Act of 1990 (ADA), Section 504 of the Rehabilitation Act of 1973, the Age Discrimination Act of 1975, and Title II of the Genetic Information Nondiscrimination Act (GINA) of 2008, the Department prohibits discrimination in admissions, programs, services, activities, or employment based on race, color, religion, sex, national origin, age, disability, genetics and retaliation. The Department must make a reasonable accommodation to allow a person with a disability to take part in a program, service or activity. For example, this means if necessary, the Department must provide sign language interpreters for people who are deaf, a wheelchair accessible location, or enlarged print materials. It also means that the Department will take any other reasonable action that allows you to take part in and understand a program or activity, including making reasonable changes to an activity. If you believe that you will not be able to understand or take part in a program or activity because of your disability, please let us know of your disability needs in advance if at all possible. To request this document in alternative format or for further information about this policy, contact your local office, TTY/IDD Services: 7-1-1. • Free language assistance for DES services is available upon request. • Disponible en español en línea o en la oficina local.

## Using the Form

Using the form is simple:

- ASDB/Part C has the parent sign at initial IFSP meeting
- The Referral and IFSP date are entered
- Part C Faxes the completed form to ADHS
- ADHS Reconciles and enters in the EHDl database

## Lessons learned

It takes time for Part C to incorporate into system every day process

- Had to ask parents of older kids at home visit o sign consent to capture prior enrollment/IFSP to complete missing data elements in the EHDl database
- Helps us to identify providers not reporting to the EHDl program and/or to Early Intervention
- Help facilitate enrollment where needed

## Measures of Success

- Found cases that were potentially LTFU in the EHDl database
- Improved collaboration between Part C and EHDl
- Clarified a consistent definition of IFSP date versus enrollment date

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