

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

Office of Newborn Screening, Arizona Department of Health Services
 Authors: Fran Altmaier, Sondi Aponte, Gidget Carle

Ensuring infants and toddlers with hearing loss are enrolled in Early Intervention Services timely

Objectives

- Identify Challenges & Barriers related to EHDI being able to capture Part C enrollment information
- 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 AzEHDI
 - Meet with state legal representatives to identify required language
- 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



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 EHDI database

Lessons Learned

It takes time for Part C to incorporate the form into their every day process

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

Barriers

- Educational rights VS. medical rights
- AzEHDI (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 Language 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 Federal Communications Commission and Section 508 of 2001, the Department provides discrimination in education, program, and services to all children with disabilities in all parts of a program, including delivery, for accessible, age, disability, genetic information, race, sex, and national origin. The Department will make a reasonable effort to ensure that children with disabilities are not denied the benefits of its programs. If you have any questions or concerns, please contact the Department's Office of Equal Opportunity and Accessibility at (602) 364-1495. If you have any questions or concerns, please contact the Department's Office of Equal Opportunity and Accessibility at (602) 364-1495. If you have any questions or concerns, please contact the Department's Office of Equal Opportunity and Accessibility at (602) 364-1495. If you have any questions or concerns, please contact the Department's Office of Equal Opportunity and Accessibility at (602) 364-1495.

Measures of Success

- Found cases that were potentially LTFU in the EHDI database
- Improved collaboration between Part C and EHDI
- Clarified a consistent definition of IFSP date versus enrollment date
- Provides current enrollment information in real time

www.aznewborn.com



This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number H61MC00047 and titled "Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening". This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government