

ecta



Developing Data Sharing Arrangements Between Part C and EHDI To Improve Early Identification and Services

EHDI 2020 Meeting

Instructional Session

March 8, 2020

Welcome

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Tell us about yourself

- Who is in the room? Raise your hand
 - EHDI
 - Family based organizations
 - Part C
 - Other state staff
 - Projects
 - Associations
- Who has not raised their hand?
- Who has been in the role 3 years or more?
- Who has been in the role less than 3 years?
- Who is currently sharing data between EHDI and Part C?

Intended Outcomes

Participants will:

- Increase their understanding of the privacy requirements (e.g. under IDEA, FERPA and HIPAA) and important technical aspects needed to address data sharing.
- Gain knowledge of data sharing arrangements including challenges and strategies from selected states and will share and receive resources on data sharing
- Network with other participants and presenters to draft a plan for developing data sharing arrangements between EHDI and Part C

AGENDA

- Introductions/Icebreaker - successful or most challenging experience in data sharing
- Addressing Data Sharing: Privacy regulations/requirements
- Why Share Data - State presentations: Louisiana and Arizona
- Small Group Work
- Regroup into Large Group - Share ideas from small group discussions
- Share Additional Resources
- Wrap-Up and Plans for Next Steps at Home

Action Plan Worksheet Instructions

Ideas to pursue
in our state

Things I want to
know more about

People/states I
want to contact

First thing that I
will want to do
when I get home

Something I want
to accomplish
over the next few
months

My thoughts

Icebreaker Activity

- ❖ Introduce yourself to those at your table and discuss:
 - ❖ Share one success you've had sharing data. Each participant records one success on a post-it
 - ❖ Share one challenge you've encountered sharing data. Each participant records one success on a post-it
- ❖ Report out in large group - Each table shares top 2 successes and challenges
- ❖ All post-its are posted on pre-titled flip charts

IDEA, FERPA, HIPAA Requirements Related to Data Sharing Arrangements

State Data Sharing Arrangements



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EHDI and Part C Data Linking

Welcome



ARIZONA DEPARTMENT OF HEALTH SERVICES

Health and Wellness for All Arizonans

Fran Altmaier-Newborn Screening Manager

Fran.Altmaier@azdhs.gov



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Early Hearing Detection & Intervention

- Office of Newborn Screening includes screening for 31 conditions
 - One of those conditions is hearing
 - Early Hearing Detection and Intervention Program (EHDI)
-

Early Hearing Detection & Intervention



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- IDEA Part C Program
 - Arizona Early Intervention Program (AzEIP)
 - Part C Coordinator and Data Manager

Where We Started

- Some collaboration
 - Paper Forms
 - Manual tracking of data
 - Awareness of the need to formalize sharing of information
-

“Before”

CONSENT TO SHARE EARLY INTERVENTION REFERRAL AND INITIAL IFSP DATE

I, _____, give my informed consent for the Arizona Early Intervention Program, including AzEIP team-based service provider, Division of Developmental Disabilities (DDD) Service Coordinator, and/or Arizona School for the Deaf and Blind (ASDB) team member, 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

Email to: hearing@azdhs.gov or Fax to: (602) 364-1495

Sharing AzEIP Referral Date: _____

Sharing Initial Individualized Family Service Plan (IFSP) Date: _____

For the purpose of: 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 are deaf or hard of hearing 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 different levels of hearing, 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 as part of this report.

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.

“After”

J-119 DSA (7-17)

ARIZONA DEPARTMENT OF ECONOMIC SECURITY
Information Risk Management
3443 North Central, Mail Drop 1426, Phoenix, Arizona 85012
Phone: (602) 771-2676 | Fax: (602) 364-0481

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DATA SHARING REQUEST/AGREEMENT

BETWEEN

REQUESTING ENTITY:

DES Division/Administration/Program/Office Name or External Organization Name:

Arizona Department of Health Services /Office of Newborn Screening (ADHS)

AND

DATA MANAGER: ARIZONA DEPARTMENT OF ECONOMIC SECURITY

Division/Administration/Program/Office Name:

Division of Developmental Disabilities/Arizona Early Intervention Program (AzEIP)

DSA Effective Date: 07/01/2019 DSA Agreement No.: 15625

Contract Start Date: 03/01/2018 Contract No.: HS871012

Contract Max End Date: 02/28/2021 UID: _____
(if applicable)

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 Non-Discrimination 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. To request this document in alternative format or for further information about this policy, contact (602) 771-2676; TTY/TDD Services: 7-1-1. • Free language assistance for DES services is available upon request. • Disponible en español en línea o en la oficina local.

Data Sharing

- Manual process currently
 - Automation is launching in April 2020
 - Bi-weekly transmission
 - Child level data being linked with a shared identifier
-

How did we make the change?

- Willingness to partner
 - Funding is always helpful
 - Technical Assistance
 - Strong, Dedicated Team
-

Benefits of Technical Assistance

- Education on FERPA requirements
 - Identification of critical questions
 - Review of documents, policy, best practice
 - Directed towards available tools
-

Benefits of Technical Assistance

- Facilitated review by the Privacy Technical Assistance Center (PTAC)
 - Regular phone calls and check-ins
 - Accountability
 - Cheerleading
-

How Well is the Agreement Working?

- Filling the gaps with complete data
 - Identifying children missing from early intervention
 - Identified technical assistance needs for our local early intervention programs
-

Next Steps

- Increase transparency with families by updating privacy policy and Procedural Safeguards
 - Use as a template for other data linking projects with Part B and Child Safety
 - Exploring additional critical questions around the data that is linked
-



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Thank you!



ARIZONA DEPARTMENT OF HEALTH SERVICES

Health and Wellness for All Arizonans

Data Sharing In Louisiana

Susannah Boudreaux – Program Manager

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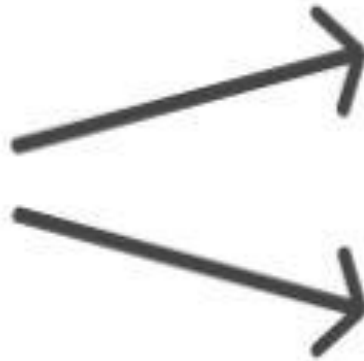
Terri Ibieta – EHDl Coordinator

Terri.Ibieta@la.gov



Louisiana EHDI and Part C - EarlySteps

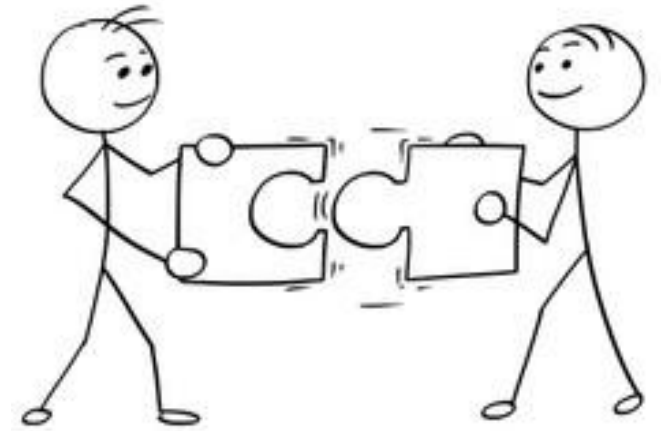
- Single lead agency- Louisiana Department of Health
- Two separate data systems for Part C and EHDI



Louisiana Early Hearing
Detection and Intervention
Program

Process of Developing Our Agreement

- Collaborative working relationship
- Face to face meetings and follow-up calls
- Reviewed other templates & agreements
- Draft, review, revise, review Approve!



Benefits to Both Programs

EHDI

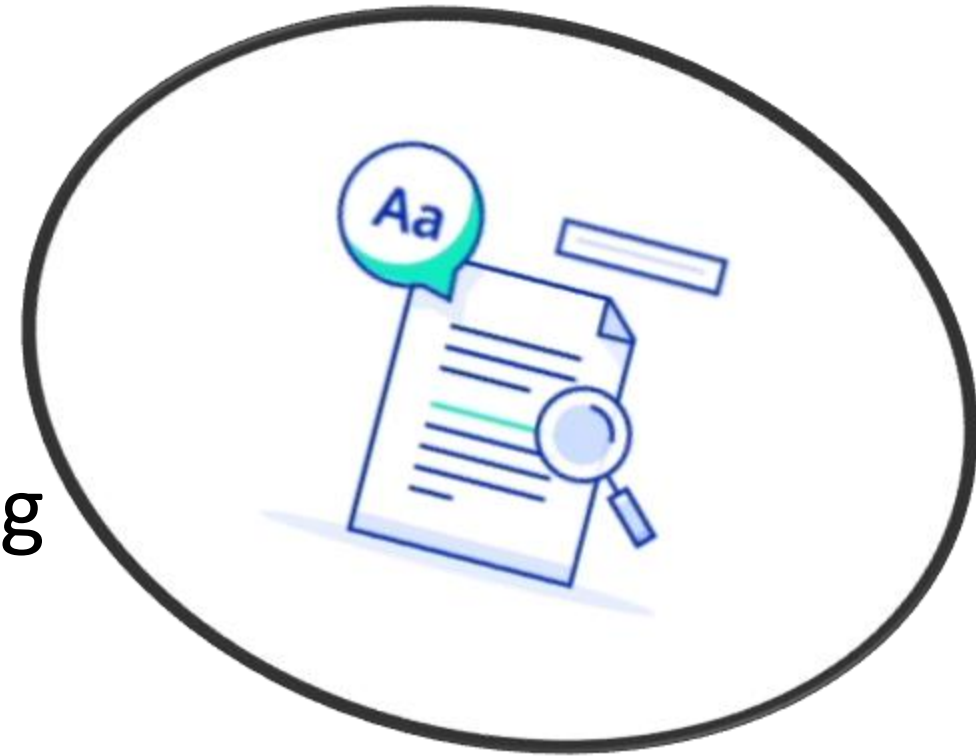
- Complete Data
 - children with PCHL
 - children who are LTF or In-Process of Diagnosis
- Achieve 1-3-6 milestone
- Meet all EHDI-IS Functional Standards
- Analyze data to identify gaps and needs

Part C

- Timely referrals for all D/HH children
- Training and support for Part C staff and Coordinators
- Shared data leads to informed decision making

What's in our Data Sharing Agreement

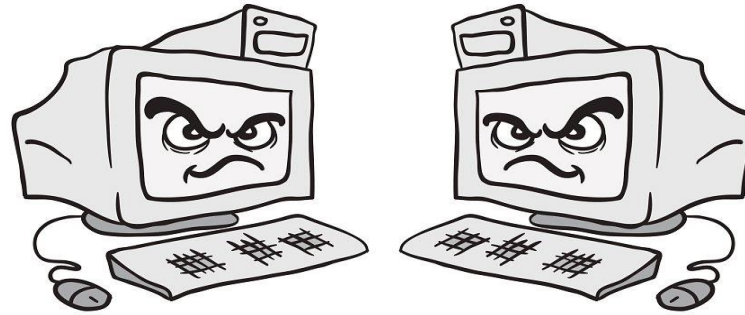
- Purpose/Justification
- Period of Agreement
- Method/Frequency of Data Sharing
- Data Variables



Challenges and Lessons Learned

Challenges:

- Separate data systems that do not communicate
- Not automated
- Timeliness



Lessons Learned:

- It all begins with the relationship 😊
- Explore and Pilot ideas together

Where we are now....

- Programs have mutual respect.
- Working toward a common goal of supporting families
- Mutually sharing data and positive feedback
- Collaborate with Part C Regional Coordinators, presenting at Part C meetings to facilitate communication and support
- Offering educational opportunities when available to Part C staff.

Next Steps

- Reevaluate the current data sharing agreement- expires in Dec 2020
- Add in outcomes for Battelle Developmental Inventory
- Looking to establish a data sharing agreement with Non Part C
- Discussions with DOE to exploring options for data sharing with Part B in an effort to collect long-range developmental outcomes

Small Group Work

Small Group Work Directions

- If you are not sitting with your state partner, move to the same table
 - Keep group to about 6 people
 - Single state participants will be paired
- Select a notetaker to record main themes of discussion
- Use the work sheet questions for your discussion
- Create an action plan for next week and for the next several months

Small Group Discussion

- How do you currently share data to support program improvements and improve child outcomes in EHDI and Part C programs?
 - What have you been able to share?
 - Has anyone been able to share EHDI info with Part C?
 - Has anyone been able to share child outcomes?
- What benefits have you gained?
- If you are not yet sharing data, what steps have you already taken to begin working?
- What would you recommend to others to begin this sharing work?

Resources

- Data Sharing Agreement Checklist for IDEA Part C & Part B 619 Agencies and Programs
https://dasycenter.sri.com/downloads/DaSy_papers/DaSy_Data_Sharing_Agreement_Checklist_Acc.pdf
- DaSy Resources: Special Collections on Privacy/Confidentiality and Linking Data
<http://dasycenter.org/other-resources/>
- Understanding the Confidentiality Requirements Applicable to IDEA Early Childhood Programs Frequently Asked Questions (FAQs)
<https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/idea-confidentiality-requirements-faq.pdf>
- 2014 side-by-side guide of the IDEA and FERPA Confidentiality Provisions
https://studentprivacy.ed.gov/sites/default/files/resource_document/file/IDEA%20FERPA%20Confidentiality%20Provisions%20Comparison%20Chart%2006.06.14.pdf
- Critical Questions About Early Intervention and Early Childhood Special Education
<https://dasycenter.org/resources/critical-questions/>
- US Department of Education: Protecting Student Privacy <https://studentprivacy.ed.gov/>

Wrap-Up and Next Steps

- Take a few minutes and add items to your action planning sheet
- Large group report out on first steps to take and the biggest “aha”
- Reminders about availability of TA from NCHAM, DaSy and ECTA
- Acknowledgments

