

ecta



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

EHDI 2020 Meeting

Instructional Session

March 8, 2020

ecta



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 flip charts

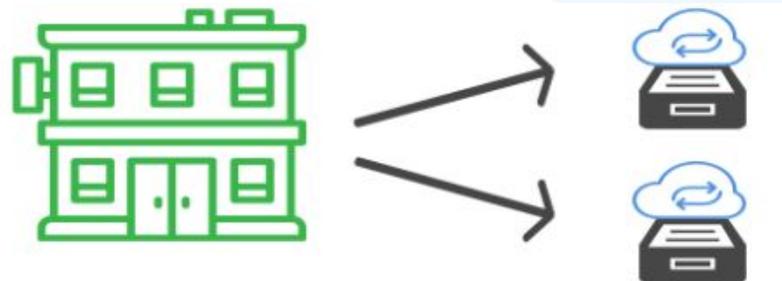
IDEA, FERPA, HIPAA Requirements Related to Data Sharing Arrangements

Participants will increase their understanding of the privacy requirements (e.g. under IDEA, FERPA and HIPAA)

Consider Two Scenarios

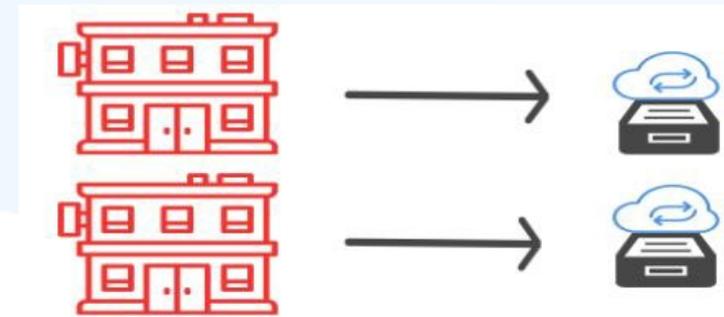
Scenario A

- * Single lead agency, Health Department, two separate data systems for Part C and EHDI



Scenario B

- * Two different lead agencies, Health for EHDI and Non-Health for Part C, each has its own data system



When Do Requirements Apply Under Part C?

Confidentiality procedures apply to the PII of a child/family that:

- ❖ Is contained in early intervention records collected, used, or maintained under Part C by the **lead agency or an EIS provider**; and
- ❖ Applies **from the point in time when the child is referred for early intervention** services under Part C until the later of when the participating agency is no longer required to maintain or no longer maintains that information under applicable Federal and State laws.

***Can always release data with parental consent
and properly de-identified data (no PII)***

IDEA Part C Participating Agency

- ❖ PII data **can only be shared** outside of participating agencies **with parental consent**
- ❖ Any individual, agency, entity, or institution that collects, maintains, or uses personally identifiable information to implement the requirements in Part C.
- ❖ Includes LA, EIPs, and any individual/entity that provides any part C services.
- ❖ **Does not include primary referral sources** or public agencies or private entities that act solely as funding sources for Part C services.

All participating agencies (including the lead agency and EIS providers) must comply with the Part C confidentiality procedures

Disclosure of PII Under FERPA Without Consent

- **FERPA** permits disclosure of PII without parental consent under several exceptions including:
- To authorized representatives of federal, state, and local educational authorities conducting an audit, evaluation, or enforcement of education programs;
- To school officials with legitimate educational interests (defined in annual notification);
 - Staff or employees who need access to perform duties
 - School official exception
 - “Legitimate educational interest”
 - External entities
 - Studies exception
 - **Audit or evaluation exception**
 - Uninterrupted Scholars Act
 - Other (e.g., court order, health or safety emergency)

What Is Required in a Data Sharing Agreement?

It can be called many different names: MOU, MOA, Contract, Written Agreement, etc.

The written agreement must:

- ❖ Designate individual or entity as an authorized representative;
- ❖ Specify:
 - ❖ The PII from education records to be disclosed;
 - ❖ The purpose for which the PII is disclosed for an audit or evaluation of Federal or State supported education programs, or to comply with Federal requirements; and
 - ❖ A description of the activity with sufficient specificity to be clear the work falls within the exception, including a description of how the PII will be used;

What Is Needed in a Data Sharing Agreement (cont)?

- ❖ Require the authorized representative to destroy PII when the information is no longer needed for the purpose specified;
- ❖ Specify the time period in which the information must be destroyed; and
- ❖ Establish policies and procedures, to protect PII from further disclosure (except back to the disclosing entity) and unauthorized use, including limiting use of PII to only authorized representatives with legitimate interests in the audit or evaluation.

Privacy Considerations

Where do the data reside?

What data do you want to share?
how will the data be shared safely?
where will data be stored? who will
have access?

?

What federal, state, and local
laws apply to data sets?

What data sharing agreements
need to be in place?
Requirements?

Three Main Privacy Laws

Family Educational Rights and Privacy Act (FERPA)

- Entities receiving U.S. Department of Education Funds
- Confidentiality of “education records”

Health Insurance Portability and Accountability Act (HIPAA)

- Title II, Privacy Rule
- Use of Protected Health Information by covered entities

Part C Regulations

- IDEA (Individuals with Disabilities Education Act)
- Birth to 3 early intervention population

What is HIPAA?

- ❖ Health Industry Paying All Attorneys
- ❖ Highly Intricate Paperwork in Abundant Amounts
- ❖ High Income Potential for Aggressive Attorneys
- ❖ Huge Increase in Paperwork and Aggravation Act

HIPAA

- ❖ **Covered entity:** A health plan, clearinghouse, or health care provider who conducts financial and administrative transactions electronically (**i.e., bills for provision of services**)
- ❖ **Protected Health Information (PHI):** Individually identifiable health information transmitted or maintained by covered entities
- ❖ **Sharing information**
 - ❖ Signed consent required to use PHI for marketing or research
 - ❖ Signed consent is NOT required:
 - ❖ For health providers to exchange information for treatment, payment, health care operations.
 - ❖ To share information for Public Health purposes
 - ❖ Providers must keep a record of information that is shared

Part C Privacy Regulations

- ❖ Signed consent **IS** needed for Part C to share any personal information with “non-participating entities” (i.e., entities outside the Part C system who contribute substantially to multiple components of the system --- not just to Child Find)
- ❖ Signed consent **IS NOT** needed for anyone to refer a child to Part C (name, contact info, reason for referral)
- ❖ Signed consent **IS NOT** needed for Part C to share info with “participating entities”
- ❖ Part C is more restrictive than either HIPAA or FERPA

State laws, regulations, and practices:

- Can provide **MORE** privacy protections, but not less (i.e., state laws seldom, if ever, enable sharing of education and health related information that is not already allowed under HIPAA, FERPA and/or Part C)
- Can encourage (or discourage) reporting

Impact of Federal Privacy Regulations on:

- ❖ Hearing Screening
- ❖ Diagnostic Evaluations
- ❖ Early Intervention
- ❖ Linkages with Medical Home and other health care providers
- ❖ Family Support programs

Federal Privacy Regulations Related to: Hearing Screening

❖ HIPAA

- ❖ Written consent **NOT** needed for hospitals and/or health care providers to share hearing screening information with EHDI programs, other health care providers and/or Part C, because screening information:
 - ❖ Is needed for public health activities (e.g., surveillance, program improvement, etc)
 - ❖ Is needed for facilitating ongoing health care
- ❖ Documentation required whenever information is shared

❖ FERPA

- ❖ Does not apply until children are enrolled in programs that receive federal education funding.

❖ Part C Privacy Regulations

- ❖ Does not apply until children are referred to Part C
- ❖ Once children are referred to Part C, any information possessed by the Part C cannot be shared with **non-participating** entities without written consent

Federal Privacy Regulations Related to: **Diagnostic Evaluations**

❖ HIPAA

- ❖ **Written consent NOT needed for health care providers to share Dx info with EHDI programs, other health care providers, and/or Part C, because such information:**
 - ❖ Is needed for public health activities
 - ❖ Is needed for facilitating ongoing health care

❖ FERPA

- ❖ **Written consent required for education agencies to share individual Dx info with non-participating entities (except for “honor roll” exception).**

❖ Part C Privacy Regulations

- ❖ **Written consent required to share individual Dx info with non-participating entities**

Federal Privacy Regulations Related to: Medical Home and Other Health Care Providers

❖ HIPAA

- ❖ **Written consent NOT needed for sharing of info among health care providers (e.g., medical home, geneticist, audiologist, physical therapist, etc) EHDI programs, and/or Part C when such information:**
 - ❖ Is needed for public health activities
 - ❖ Is needed for facilitating ongoing health care
- ❖ **Documentation of shared information is required**

❖ FERPA

- ❖ **Written consent required for education agencies to share info w/ health care providers (many health care providers complain about sending info to a “black hole”)**

❖ Part C Privacy Regulations

- ❖ **Part C cannot share info with health care providers without written consent**
- ❖ **Hard to imagine a situation where a health care provider would be considered a “participating entity.”**
- ❖ **Entities that have legally received Part C information must abide by privacy regulations when sharing that information with others.**

www.infanthearing.org/privacy

update

SEARCH WEB SITE

NAVIGATION

- Who We Are
 - Our Background
 - EHDI National Resource Center
 - Research Projects
 - Contact Us
- EHDI Components
 - Newborn Hearing Screening
 - Diagnostic Audiology
 - Early Intervention
 - Early Childhood
 - Family Support
 - Medical Home
 - EHDI Legislation
 - Data Management
 - Program Evaluation
 - Financing & Reimbursements
- EHDI Resources
 - Resource Center Home
 - Issues & Evidence
 - Addressing Privacy Regulations
 - JCIH 2007 »
 - EHDI/UNHS FAQ
 - Slideshow Presentations
 - Ed. & Training Videos
 - Fact Sheet [PDF]
 - Upcoming Events
 - Links
 - Even More...

Home » Resources » Addressing Privacy Regulations

ADDRESSING PRIVACY REGULATIONS

NCHAM conducted an investigation into the impact of privacy regulations on the exchange of information among EHDI, Part C, health providers, and families. This information includes.

White Paper on Privacy Regulations: How EHDI, Part C, and Health Providers can Ensure that Children and Families Get Needed Services

[Survey of EHDI Program Practices Related to Federal Privacy Regulations](#)

[Survey of Part C Program Program Practices Related to Data Sharing with EHDI](#)

[State examples of Tools to Facilitate Information Exchange](#)

[PowerPoint: Federal Privacy Regulations and Information Sharing Among Programs](#)

NCHAM has gathered examples of the following information exchange tools from several states.

- Legislation
- Memoranda of Agreement
- Coordinated Referral Forms
- Data Sharing and Reporting
- IFSP's

Privacy Regulations

State Examples

Recommended Strategies

- 1. Well informed families who are given own copies of consents and medical/educational records to share as needed**
- 2. Coordinated consent forms (and training) so that a single signature gives permission to share info with broad array of providers.**
 - ✓ Ideally, consent would be obtained when newborn hearing screening is failed
- 3. Memoranda of Agreement (MOA's) among EHDI, Part C, Family Support Programs and others**
- 4. Designation of “participating entities ” as part of Part C system.**
 - ✓ Inclusion in Part C State plan
 - ✓ Memoranda of Agreement and inclusion in Part C State Plan
 - ✓ Clear responsibility for significant role **MULTIPLE** components of Part C system (not just a “child find” provider)

Recommended Strategies *(continued)*

- 5. State laws that require reporting do not remove Federal privacy protections but may encourage better reporting**
- 6. Obtain written permission from parents as part of IFSP/IEP document to share information with relevant agencies**
- 7. Integrate computer-based public health information systems (e.g., immunization, blood-spot screening, hearing screening) and include info about services provided to children with special health care needs**

State Data Sharing Arrangements



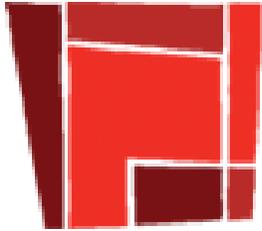
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EHDI and Part C Data Linking

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



DEPARTMENT OF ECONOMIC SECURITY

Your Partner For A Stronger Arizona

- 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”

GCI-1109A FORFF (06-18)

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

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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.

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. To request this document in alternative format or for further information about this policy, contact your local office; 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.

“After”

J-119 DSA (7-17)

ARIZONA DEPARTMENT OF ECONOMIC SECURITY
Information Risk Management
3443 North Central, Mail Drop 1428, 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

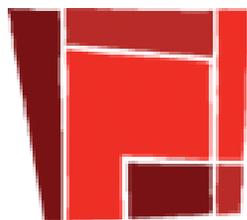
- Increase transparency with families by updating privacy policy and Procedural Safeguards
 - Use as a template for other data linking projects with Part B and Child Safety
 - Exploring additional critical questions around the data that is linked
-



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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

Susannah.Boudreaux@la.gov

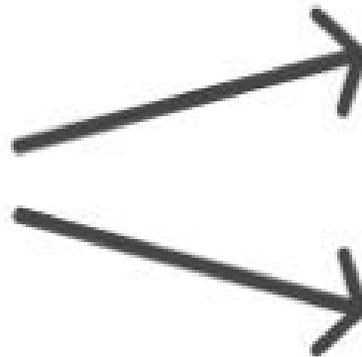
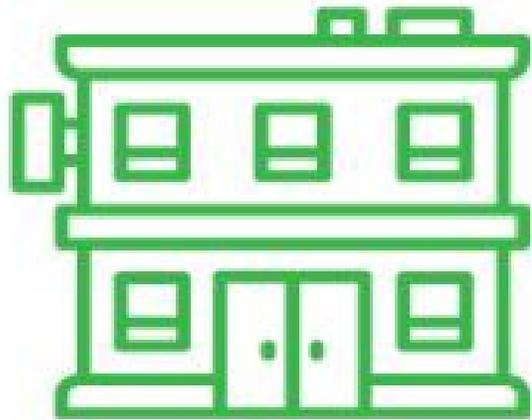
Terri Ibieta – EHDl Coordinator

Terri.Ibieta@la.gov



Louisiana EHDI and Part C - EarlySteps

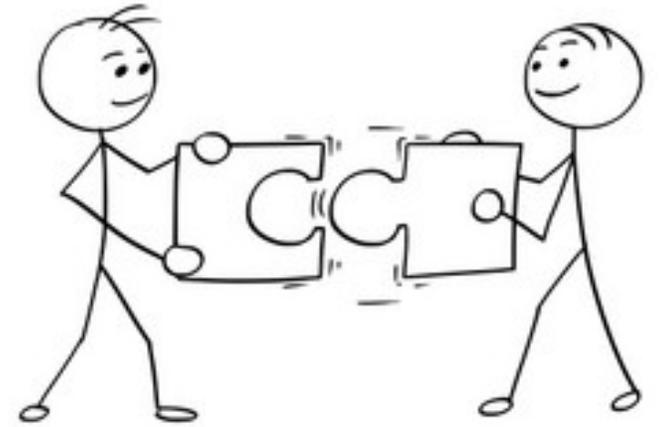
- Single lead agency- Louisiana Department of Health
- Two separate data systems for Part C and EHDI



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

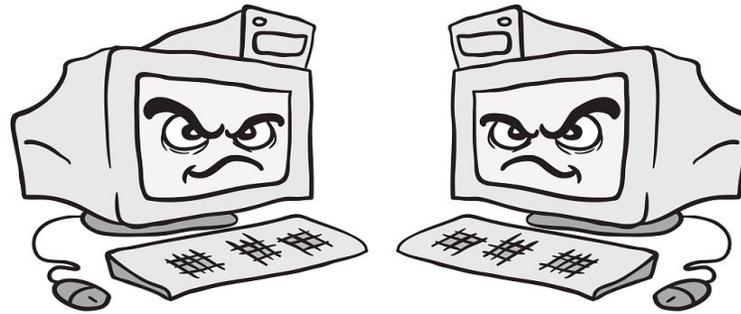
- Purpose/Justification
- Period of Agreement
- Method/Frequency of Data Sharing
- Data Variables



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 sit with others
- Select a notetaker to record main themes of discussion
- Use the work sheet questions for your discussion

Continue to add to your action plan for next week and 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 shared EHDI info with Part C?
 - ❖ Has anyone shared 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/>
- Joint Guidance on the Application of the *Family Educational Rights and Privacy Act (FERPA)* And the *Health Insurance Portability and Accountability Act of 1996 (HIPAA)* To Student Health Records December 2019 https://studentprivacy.ed.gov/sites/default/files/resource_document/file/2019%20HIPAA%20FERPA%20Joint%20Guidance%20508.pdf
- Health Insurance Portability and Accountability Act (HIPAA) Frequently Asked Questions, May 2016, DaSy Center https://dasycenter.sri.com/downloads/DaSy_papers/PCY309_HIPAAFAQ_FINAL_20160502.pdf
- 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 “Ah-Ha”
- Reminders about availability of TA from NCHAM, DaSy and ECTA
- Acknowledgments

Enhancing communication among health care and educational programs while conforming with federal privacy laws and regulations

(according to Leonardo da Vinci)



“Life is pretty simple: You do some stuff. Most fails. Some works. You do more of what works. If it works big, others quickly copy it. Then you do something else. The trick is the doing something else.”

