

September 22, 2021



# Communities Share Cross-Sector Data to Improve Child and Adolescent Health

Ben Donlon, Metro United Way; Kathleen Kelly, Lifting Up LLC; Kerri Lowrey, Network for Public Health Law; Clare Tanner, Michigan Public Health Institute

Network for Public Health Law Conference 2021

# Welcome and Agenda



- Data Across Sectors for Health – Clare
- Metro United Way – Ben
- Lifting up LLC – Kathleen
- Network for Public Health Law – Kerri
- Facilitated Discussion – Clare
- Next Steps and Closing - Clare

# Data Across Sectors for Health



DASH is a national program office led by the Illinois Public Health Institute, in partnership with the Michigan Public Health Institute, with support from the Robert Wood Johnson Foundation.



# DASH Focus and Strategies



**Shared data and  
information**



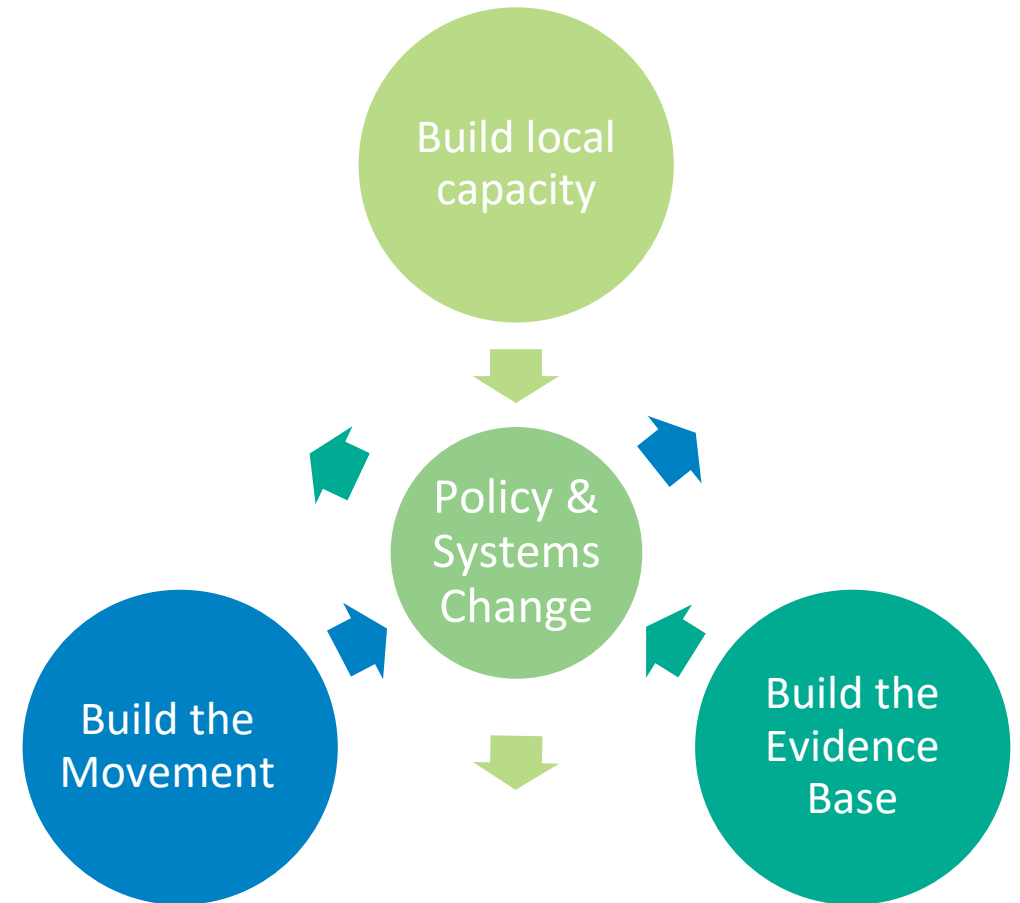
**Collaboration**



**Multi-Sector**



**Focused on improving the  
health of communities**



# Funding Programs



**10 DASH Original Grantees**  
18-24 months, \$200K



**60 DASH Community Impact Contracts**  
~6 months, \$25K



**75 Mentees**  
10 months, \$5K  
6-7 Mentors, \$25K



**6 LAPP Awards**  
1 year, \$100K  
State-community partnerships

**The Peer-to-Peer Network**

# DASH Framework

## Community Health, Well-being, and Equity

### Shared Data Use Cases

#### Whole-person Systems of Care

- Intake and determine eligibility
- Screen and assess patients
- Create/present shared care plan
- Send/push referrals, reports, notifications
- Query/look up client history
- Support decision-making

#### Total Population/Community-wide Health and Well-being

- Assess community needs and resources
- Hot spot (geographic pinpointing)
- Understand/address root causes
- Conduct surveillance
- Research, evaluate, and monitor

### Community Data Sharing Capacity

#### Shared Data

- Workflow redesign and training
- Technical function
- Consent and privacy
- Data governance
- Pathway to yes

#### Community Alignment

- Shared vision and language
- Collaboration and governance
- Existing data systems
- Trust
- Resources and assets
- Community engagement

### Policy and Market Environment

- Standards development/adoption
- Privacy and data use laws
- Technology innovation

- State and national investment in health and human services information technology
- Payment and funding models
- Market competition





# Two Broad Aims for Data Sharing



Whole Person Systems of Care



Place-based System, Policy, and Environmental Change

# DASH focuses on Data



Service (EHRs, case management) data



Surveillance data



Administrative data



Outcomes data



Geographic data



Community-generated data



Personal demographic data



Census and civic data





**Communities are diverse, and so are their data and data types.**





## Data travel.



**Data come together to benefit community.**



**Data are most useful when community voices are centered.**







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**COMMUNITY**



**STRENGTHENING  
CONNECTIVITY &  
ACCELERATING  
RENEWAL**





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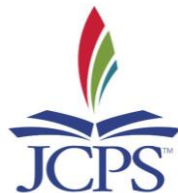
# OUR EARLY INVESTORS



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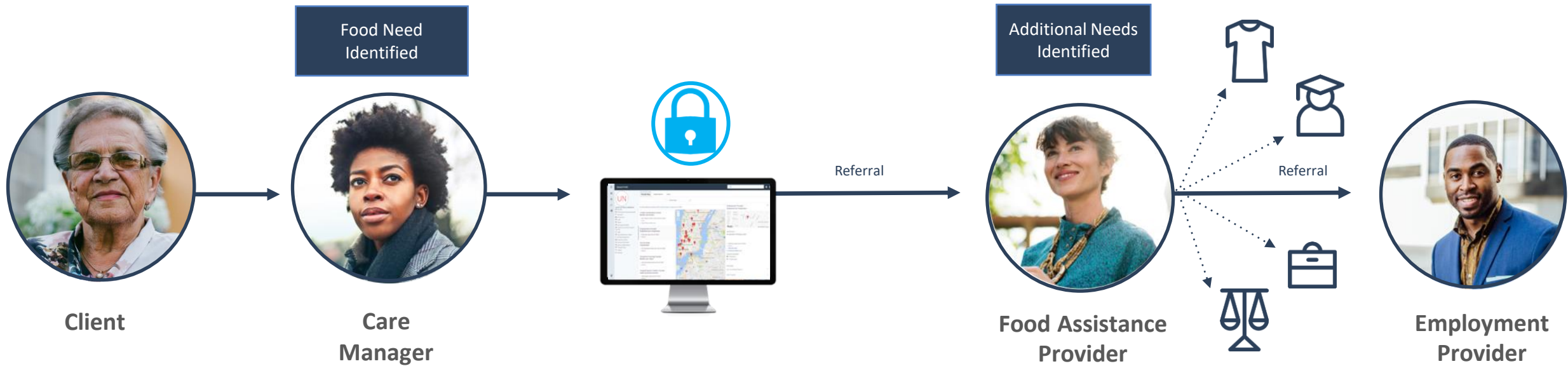


**Jewish Heritage  
Fund for Excellence**



# Network Model: Any-Door Approach

Understanding Referral Workflows





What is



United Community connects community partners (such as social service organizations, government agencies, and health care providers) to deliver integrated whole person care through a shared technology platform to:

- Make electronic referrals
- Securely share client information
- Track outcomes together
- Inform community-wide outcomes

# Privacy & Security


consent.uniteustraining.com

INFORMED CONSENT FOR PARTICIPATION & INFORMATION SHARING

Welcome to the community of service providers powered by Unite US who will help you get the resources you need!

In order to begin, we will need some information from you and your consent to share that information across our network of service providers. Your personal information will be kept in strict confidence and will be used solely for the purpose of helping you obtain the services you have voluntarily requested from us. Our service providers are required to comply with federal, state and local privacy and data protection

Please sign in the box below:



Clear Signature

**ACCEPT**

DECLINE



CLIENT



HOUSING

Informed consent is requested by the system ONCE before the first referral is made. Clients consent to have their information shared in order to receive services from network partners.



TRANSPORTATION



MENTAL HEALTH



PHYSICAL HEALTH



Compliant with Security & Data Storage Standards and Breach & Enforcement Rules.

Protected information (e.g. outcomes for Mental Health or Substance Use cases) is restricted from view based on users' viewing permissions.

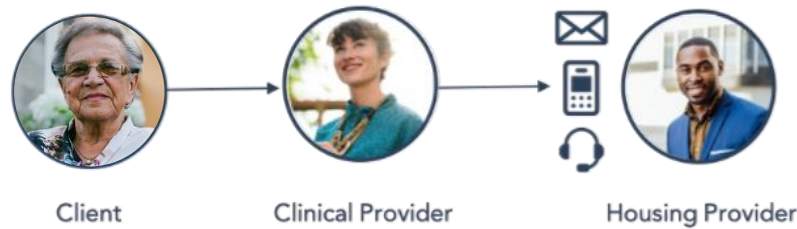
Compliant with Health Insurance Portability and Accountability Act (HIPAA) & Personally Identifiable Information (PII) standards.

# Why Participate?

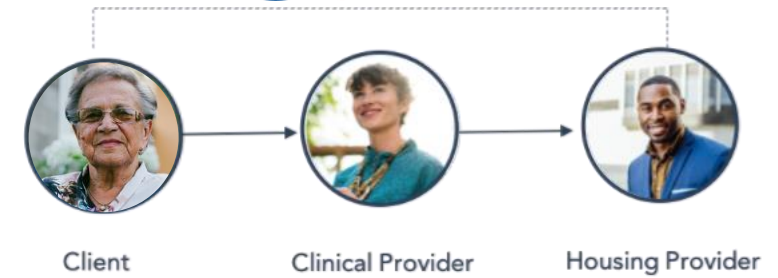
Improve efficiency & client experience



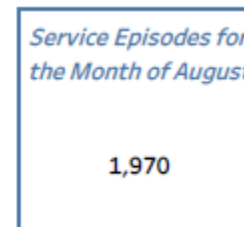
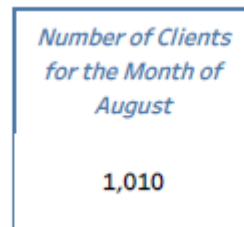
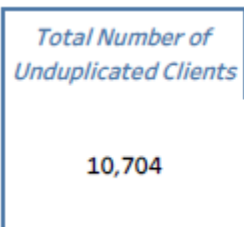
## Traditional Referral



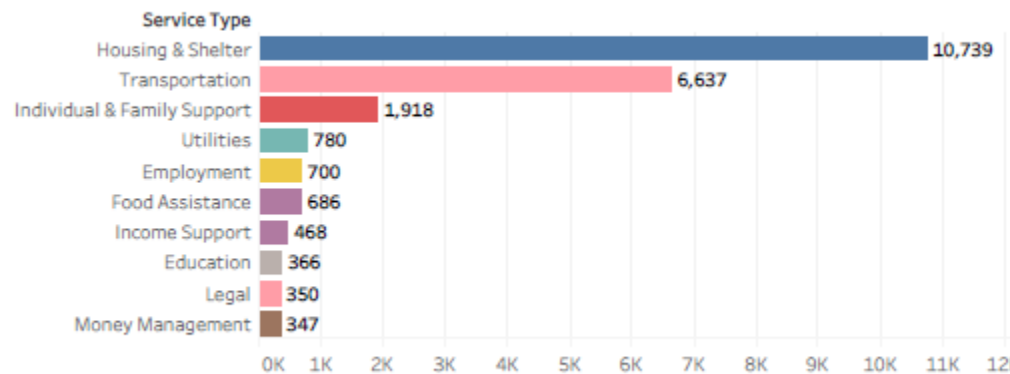
- ✗ Service providers cannot always exchange PII or PHI securely.
- ✗ There is limited prescreening for eligibility, capacity, or geography. The onus is usually on the client to reach the organization to which he/she was referred.
- ✗ Service providers have limited insight or feedback loops.
- ✗ Client data is siloed, and transactional data is not tracked.



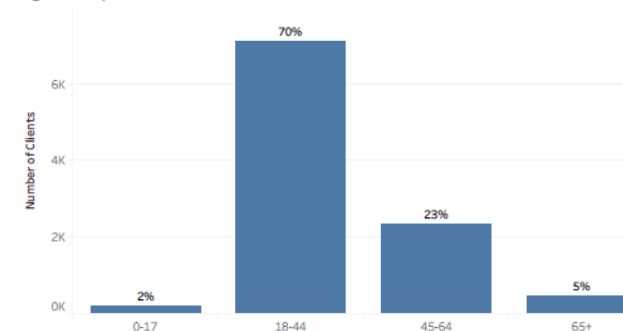
- ✓ All information is stored and transferred on our HIPAA-compliant platform.
- ✓ Clients are matched with the provider(s) they qualify for.
- ✓ Client information is captured once and shared on his/her behalf. Service providers have insight into the entire client journey.
- ✓ Longitudinal data is tracked to allow for informed decision-making by community care teams.



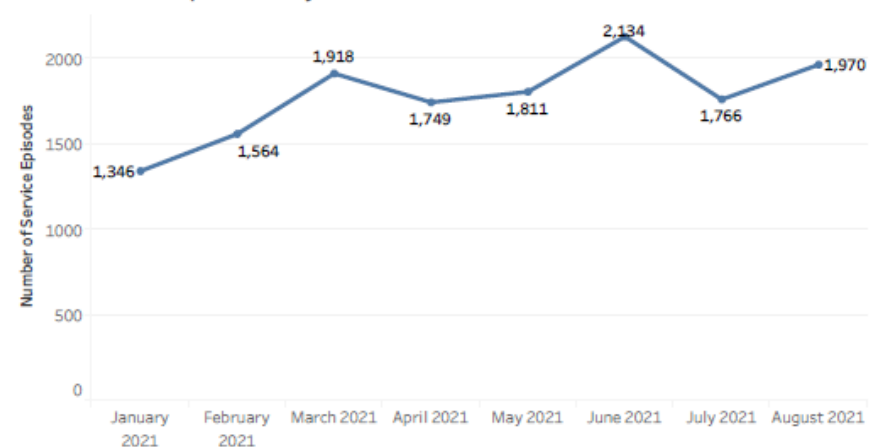
### Top 10 Needs



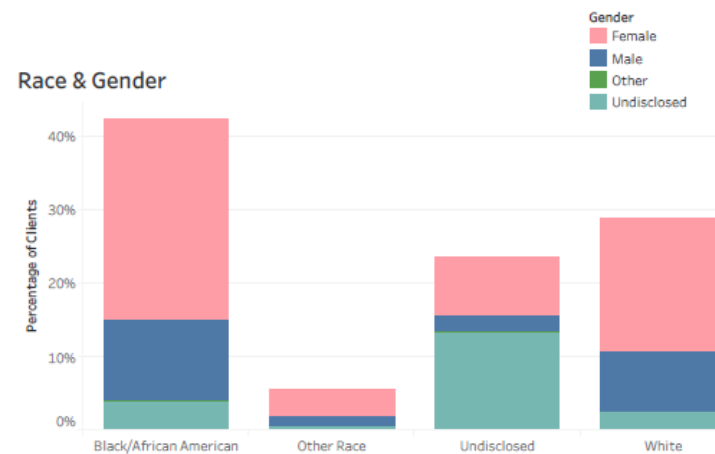
### Age Groups



### Total Service Episodes by Month



### Race & Gender







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Visit [metrounitedway.org/uc](https://metrounitedway.org/uc) to learn more



Email [ben.donlon@metrounitedway.org](mailto:ben.donlon@metrounitedway.org) to find out more!

2021

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**Sep. 21-23, 2021  
PHLC2021.org  
#PHLC2021**

# Case Study: Peoria, IL

Kathleen Kelly

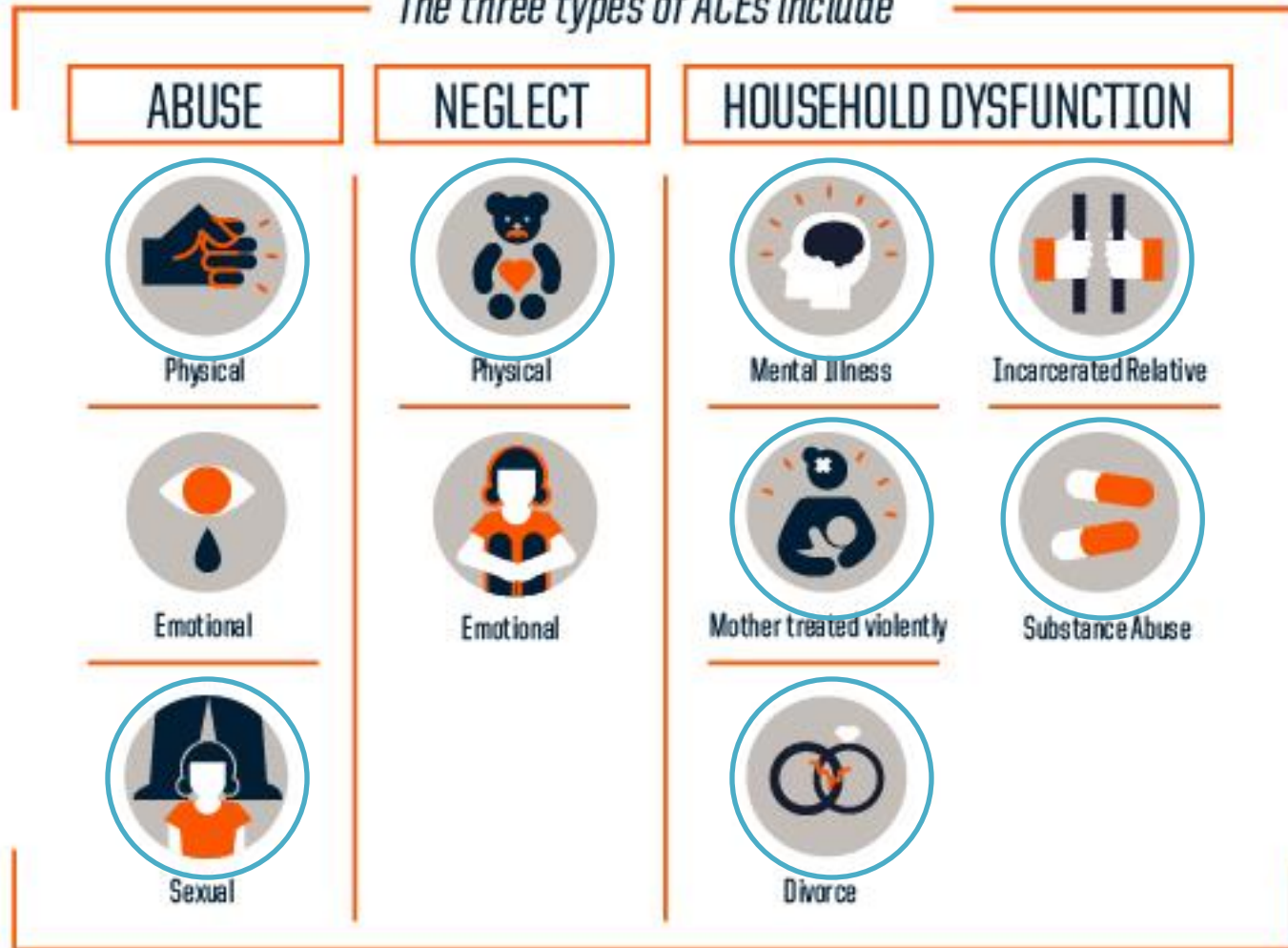
Founder & CEO at Lifting Up, LLC

# Background: Racial Inequality 2016

City of Peoria Demographics: 27% Black

- 98 shooting incidents with 122 victims; 93% of victims were Black
- Black students account for 30% of enrollment, but 60% of suspensions, expulsions, and referrals to law enforcement
- 31% of 10<sup>th</sup> graders stopped their activities due to sadness or hopelessness
- 16.7% of 10<sup>th</sup> graders seriously considered attempting suicide in the past year

*The three types of ACEs include*



Source: Robert Wood Johnson Foundation



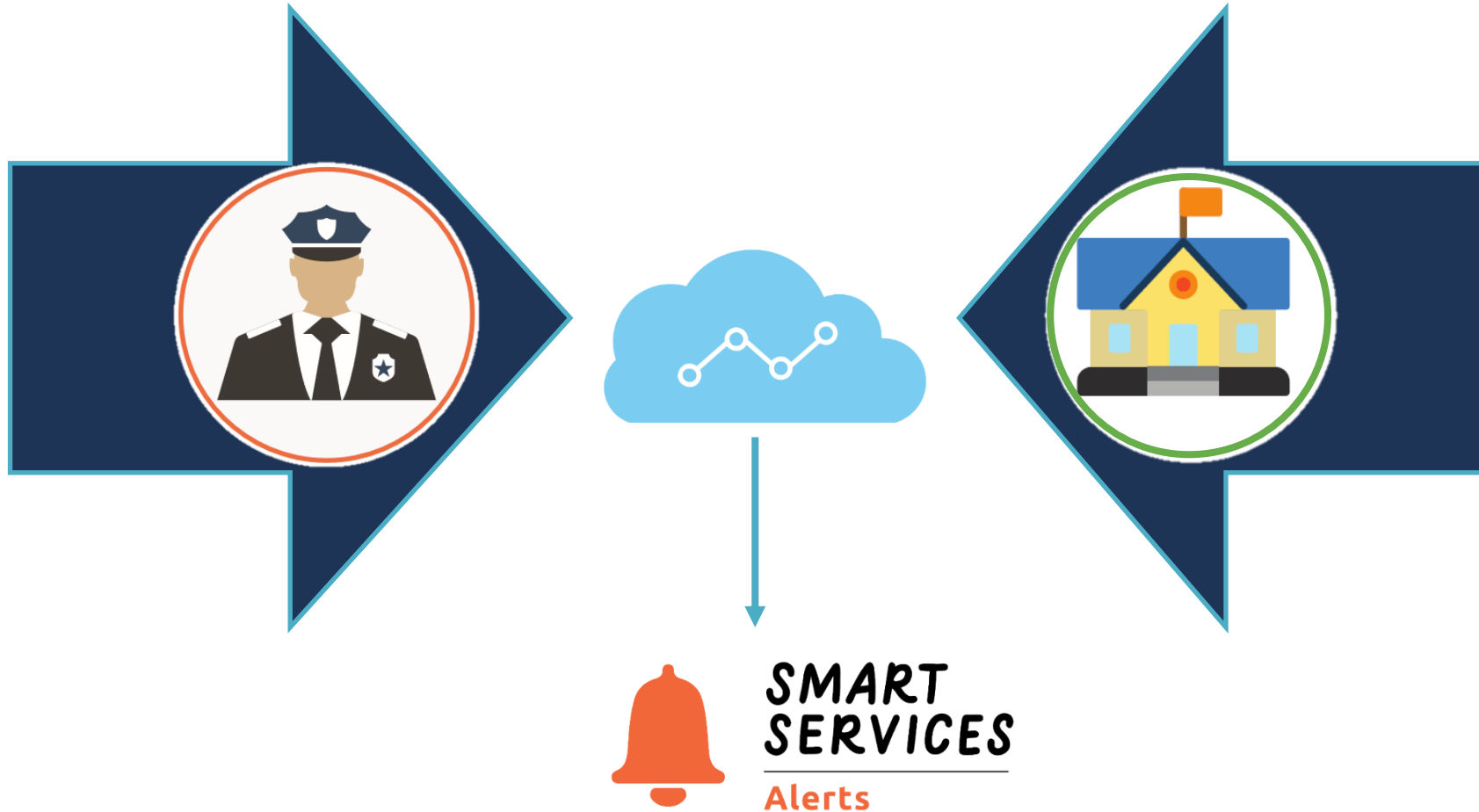
2021

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#PHLC2021

# Making the Research Actionable

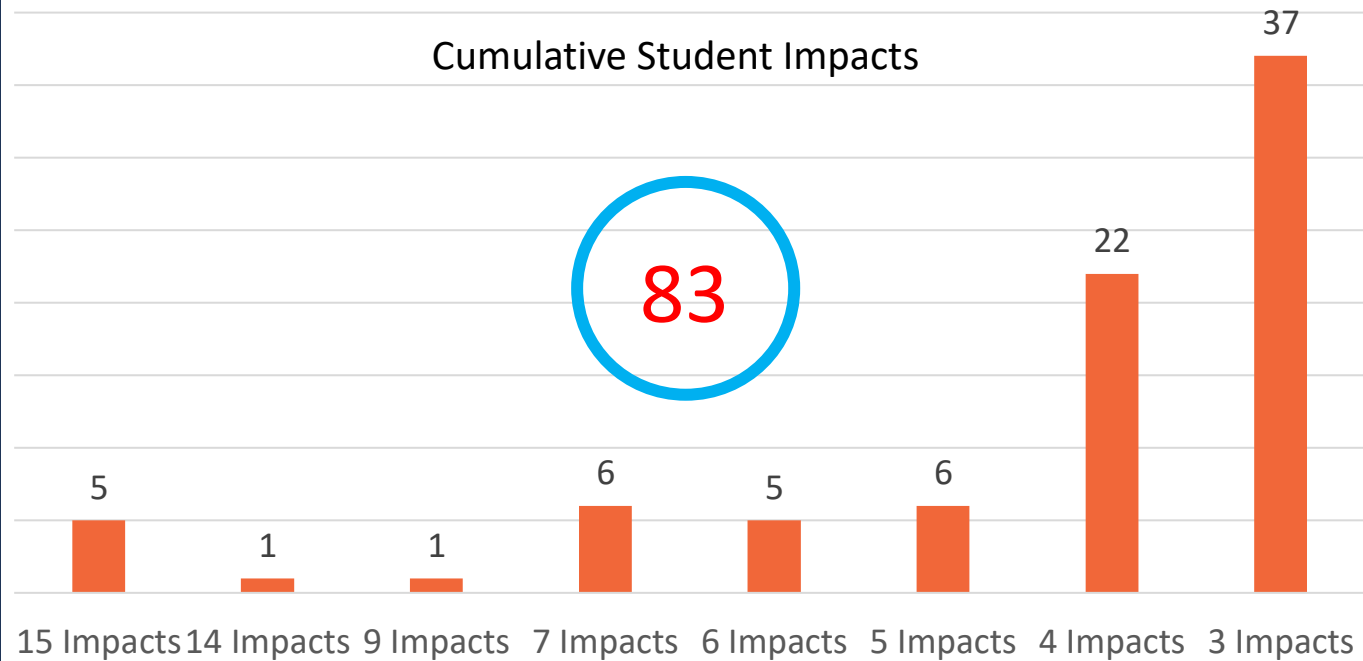




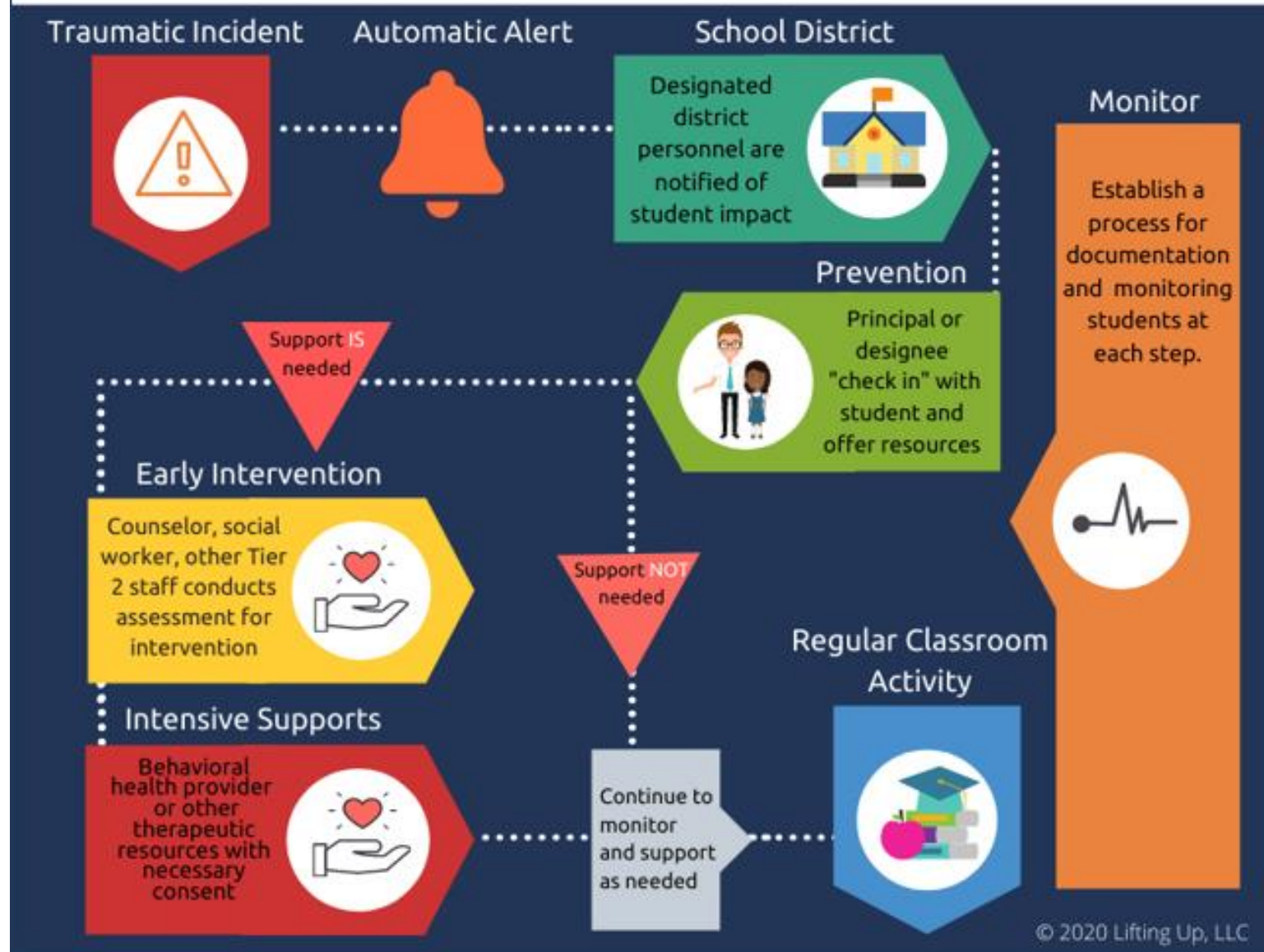
## Results from Pilot



- 10 months, 25 schools
- 1748 notifications sent
- 1247 different students
- 77%  $\leq 8^{\text{th}}$  grade



# Automated Handle With Care



# Getting to Yes

1. Information Sharing  $\neq$  All or Nothing
  - Targeted pieces of data for use
2. Perceived Legal Barriers
  - No HIPAA
  - Layers of Data Governance Agreements
3. Trust
  - Time and patience!



# ***The Legal Environment:* Navigating federal and state law to facilitate care coordination across the community for children and adolescents**

Kerri McGowan Lowrey, J.D., M.P.H.

*Deputy Director, Network for Public Health Law – Eastern Region*

National Public Health Law Conference  
September 22, 2021

## Disclaimer

The Network for Public Health Law is a national initiative of the Robert Wood Johnson Foundation. This presentation was developed by Kerri McGowan Lowrey, Deputy Director, for the Network for Public Health Law Eastern Region, at the University of Maryland Carey School of Law.

*The Network for Public Health Law provides information and technical assistance on issues related to public health law. The legal information and assistance provided in this presentation does not constitute legal advice or legal representation. For legal advice, please consult legal counsel in your state.*



## Objectives

Gain an enhanced understanding of:

- The Health Insurance Portability and Accountability Act (HIPAA)
- The Family Educational Rights Act (FERPA)
- State mental health law

✓ Understand important factors to consider in data sharing arrangements and partnerships across sectors



Source: *Star Tribune*



## HIPAA

- Health Insurance Portability and Accountability Act of 1996 (Associated HHS regs.= “The Privacy Rule”)
  - ✓ Applies to “covered entities”: health plans, health care providers, health care clearinghouses
- Requires covered entities (and business associates) to have policies and procedures that protect privacy of *protected health information (“PHI”)*; cannot disclose PHI without authorization
  - ✓ Personal identifiers + health information = PHI
  - ✓ Covers all individually PHI held or transmitted by a covered entity or its business associates, in any form or media, whether electronic, paper, or oral.

# HIPAA

- Exceptions: treatment of patient, imminent threat to health & safety, public health, court order, etc.
- Many entities that may have health information are not subject to HIPAA, like:
  - ✓ Employers
  - ✓ Most state and local police or other law enforcement agencies
  - ✓ Many state agencies like child protective services, and
  - ✓ Most schools and school districts.
- Schools *could be* covered entities if they engage in covered transactions (e.g., billing Medicaid for Medicaid-covered services in the school setting)

## FERPA

- ✓ Family Educational Rights and Privacy Act of 1974—enacted to protect students' *personally identifiable information (PII)* from *education records*.
- ✓ Applies to all schools that accept funds from the U.S. DOE (public, private, charter, etc.)
- ✓ Private schools that do not accept federal funds are not subject to FERPA but are usually still subject to state privacy laws.

Knock, Knock!  
-Who's there?  
FERPA!  
-FERPA who?

I can't tell you  
that.

someecards  
user card



## FERPA

- ✓ FERPA applies in most school health situations, because HIPAA expressly states that HIPAA does not apply to the education records covered by FERPA. 45 CFR § 160.103 (2)(i) and (ii)
  - ✓ b/c FERPA came first (HIPAA passed 22 years later in 1996)
- ✓ However, a school that is not subject to FERPA (e.g., private/religious school not receiving funding from the U.S. DOE), which also qualifies as a HIPAA-covered entity, must comply with HIPAA.





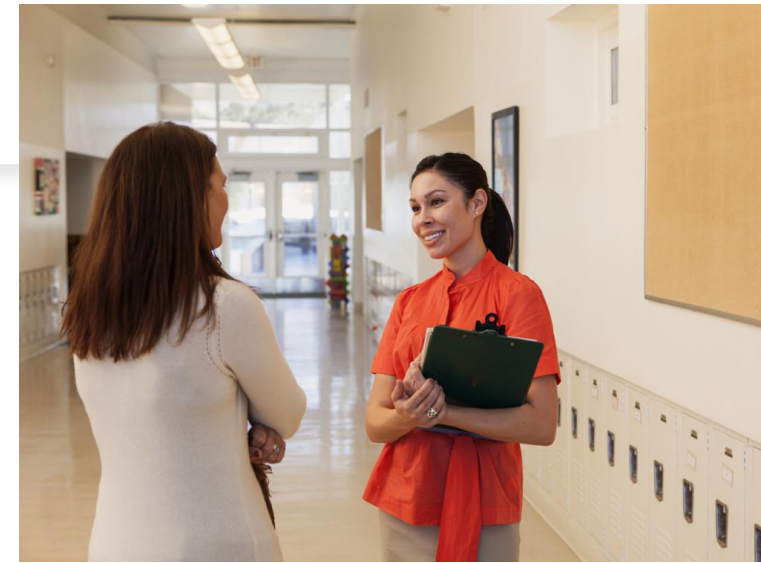
## FERPA

- What is an *educational record*?
  - ✓ Records directly related to a student maintained by the school or an entity acting on behalf of the school (e.g., a contractor)
  - ✓ Student health records (e.g., immunization records, physical exam, health screening results)
  - ✓ Nurses' notes in official student file
  - ✓ Records related to special education or health plans
- What is *PII*?
  - ✓ Any information that, alone or in combination with other information, could be used to identify a specific student
  - ✓ *Names* of student, parent, or other family members
  - ✓ Personal identifiers (date of birth, address, SSN, student id, etc.)

## FERPA

Exceptions (*when may PII be shared without consent?*)

- ✓ School officials with a “legitimate educational interest”
- ✓ Other schools to which student is transferring
- ✓ Court order or valid subpoena
- ✓ Educational studies or federal or state audit
- ✓ To appropriate officials in health and safety emergencies
- ✓ Directory information (with public notice and opt out opportunity)
- ✓ Parties with whom the school has outsourced institutional services functions.



## When HIPAA and FERPA Intersect

Health care providers may share health information with the school nurse under HIPAA for “treatment purposes” without authorization of patient or patient’s parent. There is no such FERPA exemption.

- ✓ So, a physician may discuss the student’s treatment record with the student’s school nurse, and the school nurse may call the physician to *discuss* or *clarify* the physician’s recommendations and student’s Tx plan.
- ✓ But once that information is entered into the student’s school record, FERPA applies in determining permissible disclosures.
- ✓ Best practice: A signed consent form that allows schools to share health information with other health care providers.





# Data Sharing



## Data Sharing and FERPA: How it can be done...



- PII may always be shared with parental consent
  - ✓ Only as much information as necessary and as described in the release (to whom, for what purpose)
  - ✓ Adhere to FERPA requirements re: third parties (no redisclosure without additional parental consent)
  - ✓ Data sharing agreements among parties with access is important to ensure all parties adhere to requirements on use, maintenance, and disclosure of the PII
  - ✓ Standards of ethics and professionalism

## Example: Consent Form for Improved Care Coordination with Information Sharing with Key (“Need-to-Know”) Individuals

- Child’s Health Care Provider(s)
- Child’s Health Insurance Plan
- Michigan Department of Health and Human Services and Detroit Health Department
- School-based health service providers
- School Based Health Centers (SBHC)
- Dental Service Providers
- Vision Service Providers
- Immunization Service Providers
- Behavioral Health Service Providers

**Detroit Public Schools Community District 2018-2019 -DRAFT**  
**Consent To Release Health Information Form**

<b>Student Information:</b>			
Student Last Name	First	Middle	Date of birth
Parent/Guardian First and Last Name		Home or cell number	

**Consent for Release of Information**

By signing this Consent To Release Information form, I consent to the following:

- I authorize my child’s school to disclose the following student information to the individuals/groups listed below: child’s family and emergency contact information, attendance and disciplinary records, immunization history, results of health screenings such as hearing and vision, psychological evaluations, special education records, section 504 accommodation plan and any information related to medical conditions, such as asthma, diabetes or seizures.
  - My child’s Health Care Provider(s)
  - My child’s Health Insurance Plan
  - Michigan Department of Health and Human Services and Detroit Health Department (immunization records only)
  - School-based health service providers – see below
- I understand that sharing this information will allow DPSCD to work with each of these individuals/groups to coordinate care, provide outreach services if necessary, and keep my child healthy and safe at school.
- I understand that I am entitled to receive a copy of any disclosed records. (If you wish to receive a copy please provide an email or street address to which where the records should be sent.)
- I understand that these individuals may further use records provided by DPSCD for contacting me and/or verifying information for student health related purposes.
- I understand that my authorization to allow sharing the above information is voluntary and that it expires when my child leaves the school district, or graduates. **I understand that I may revoke this authorization at any time by submitting a note or letter in writing to the school administration office.**

School-based health service providers may include any of the following:

- School Based Health Centers (SBHC): ability to diagnose and treat many common conditions such as sore throats, headaches, and ear infections, and also manage chronic health conditions. The SBHC may also provide behavioral health services.
- Dental Services: may include oral health education, screenings, fluoride varnish application, preventative care and cleaning, restorative/corrective care.
- Vision Services: may include screening, examination, treatment and/or corrections such as eyeglasses.
- Immunization Services
- Behavioral Health Services

In order for your child to receive these services, from these providers, you will need to complete a separate enrollment form with each of the providers.

Parent/Guardian Name:	Relationship to Child:	Date:
Parent/Guardian Signature:		

DPSCD does not discriminate on the basis of race, color, national origin, sex (including sexual orientation or transgender identity), disability, age, religion, height, weight, citizenship, marital or family status, military status, ancestry, genetic information, or any other legally protected category, in its educational programs and activities, including employment and admissions opportunities. Questions? Concerns? Please contact:  
Title IX Coordinator and ADA/ Section 504 Coordinator





## Data Sharing and FERPA: How it can be done...

- **Non-PII** may always be shared *without* parental consent
  - ✓ Non-personally identifiable information (*e.g.*, aggregate or de-identified)
  - ✓ Ensure that unique identifiers aren't inadvertently disclosed
    - *Example:* 50% of Asian/Pacific Islander students at Southwest H.S. were seen by school nurse for an STI, and there are only 2 students who fit that description...
  - ✓ While consent is not required, schools might want to inform parents of intention to share data to preserve transparency/build trust

# Analyzing any data sharing issue: The important questions to ask

1. What is the *purpose* for the data sharing?
  - ✓ Be specific. Permissible and prohibited use and disclosures often depend on the purpose of the data sharing.
2. Who are the *parties* involved?
  - ✓ Open and trusting relationships are key
3. What specific *types* and *sources* of data will be shared?
  - ✓ Which elements will be shared? Identifiable?
4. Which federal and state *laws* apply?
  - ✓ Aspects: collection, use, sharing, protection
5. What kind of *agreement* do you need?



One bite at  
a time

## Identify Applicable State Laws

- What are the prerequisites or limitations?
  - ✓ 41 states have passed student privacy laws
  - ✓ Most states have laws re: substance use information
  - ✓ *All* states have laws governing privacy of mental health records (three main types, Jost 2006)
    1. Mental health records, generally
    2. Mental hospitals, institutions, and mental health programs
    3. Records of specific mental health practitioners (psychologists, social workers, therapists/counselors)
- These state laws may constitute a barrier to the broad “treatment exception” contemplated by HIPAA

## Data sharing agreement (DSA)/ Data use agreement (DUA)

- ✓ Legally enforceable agreements that operationalize the (electronic) sharing of data among different parties, including organizations and individuals, while protecting data rights including privacy and confidentiality rights.

## Memorandum of understanding (MOU)

- ✓ A legally *non-binding* agreement between two or more parties that outlines terms, scope and details of a mutual understanding, noting each party's requirements, roles, and responsibilities.
- ✓ It often avoids a lengthy contract review process and is therefore easier to execute.



## DUA/DSA vs. MOU: Which should I use?

- ✓ Legal and practical difference between the two.
- ✓ DUA/DSA is a **legal contract**, so it exposes organization to risk of breach.
- ✓ MOU expresses a convergence of will and understanding between parties, indicating an intended common line of action.
  - MOU is most often used in cases where parties do not intend to imply a legal commitment to each other but do wish to engage in an agreement of principle.



## Data Sharing: Best Practices

- ✓ **Data sharing agreements** or memoranda of understanding are important for ensuring that all parties with access to the data are bound by the requirements of HIPAA, FERPA, and other applicable laws, as well as principles of ethics, good stewardship, and professionalism.
- ✓ Use of PHI/PII should be **limited** to purposes specified in DSA
- ✓ **Transparency**—Put data sharing agreements on public websites with data elements, how data are shared, and the purpose for sharing.

## Case Study: Coordinating services with Medicaid and health departments in D.C.

- ✓ In 2014, DCPS entered into innovative data sharing agreement...
- ✓ **Who are the parties involved?** D.C. Public Schools (DCPS), the D.C. Department of Health (DOH), and the D.C. Department of Health Care Finance (DHCF)
- ✓ **Purpose.** To integrate education data (absenteeism, school health services) with existing systems to improve service delivery, eliminate duplication, and harness power of surveillance to identify gaps.
- ✓ **What specific types of data are involved?** Student enrollment list, health services data (including date of last well child visit and dental visit), attendance records, student immunization records, Medicaid enrollment status

## Case Study: Coordinating services with Medicaid and health departments in D.C.

- Which laws apply?
  - ✓ Municipal dpts. that handle health care information would be HIPAA-covered entities (HIPAA allows data sharing for public health purposes).
  - ✓ Student records are subject to FERPA, which does not contain a general public health exemption.
  - ✓ BUT, because the DOH and the DHCF are performing a service or function on behalf of DCPS and are under the “direct control” of the school district regarding the use and maintenance of education records (by mutual agreement), these departments qualify as “school officials” with a legitimate educational interest in the data.



## Case Study: Coordinating services with Medicaid and health departments in D.C.

- What kind of agreement do they need?
  - ✓ D.C. executed an MOA, which outlines the purpose of the data sharing arrangement; the types of data to be shared; responsibilities of the parties; terms of data use, maintenance, and disclosure; and a time limit for the arrangement (5 years).





## Contact

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[klowrey@law.umaryland.edu](mailto:klowrey@law.umaryland.edu)

# DASH is a lead partner *All In: Data for Community Health*



Current Partners:



BUILD  
Health  
Challenge



Data Across  
Sectors for  
Health



Network for  
Public Health  
Law



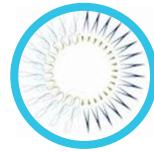
New Jersey  
Health  
Initiatives



Public Health  
National  
Center for  
Innovations



Population  
Health  
Innovation  
Lab



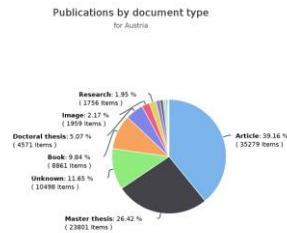
Pew Charitable  
Trusts  
Health Impact  
Project

# Network Engagement



# All In Activities and Communications

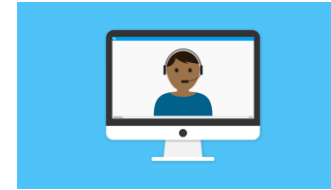
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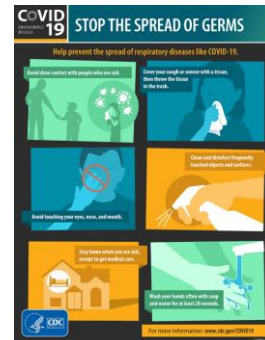
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## Blogs / Spotlights



## Newsletters



## Online Community



## Meetings



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- Check the DASH website for future funding announcements
- All In Activities (#AllInData4Health)
  - Join [Affinity Groups](#): Contact [miriam.castro@iphionline.org](mailto:miriam.castro@iphionline.org) to join
  - Create a profile on the [All In Online Community](#)
  - [Subscribe](#) to the All In Monthly Newsletter
- Attend the All In National Meeting: Nov 8-10, 2021, [Register here](#)





# Closing

Please remember to fill out the conference survey located in the description of this session.