Improving Data, Improving Outcomes Virtual Convening

October 19 - 22

2020

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DaSy The Center for IDEA Early Childhood Data Systems

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DaSy The Center for IDEA Early Childhood Data Systems

The Power of Data Linking: Increasing Your Capacity to Use Data

IDIO Virtual Convening

October 19-22, 2020

SRI Education™
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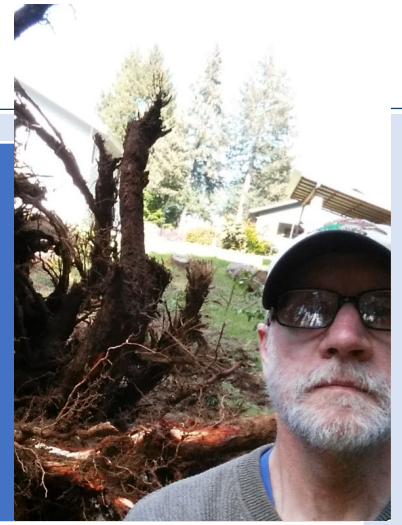
Session Objectives

- Increase participant knowledge about the benefits of data linking
- Increase participant knowledge about the partners for data linking
- Increase participant understanding of the steps of data linking

DaSy Session Presenters

Denise Mauzy

- TA Provider
- Specializes in early childhood data systems, linking and governance
- Dog lover and cycling enthusiast



Bruce Bull

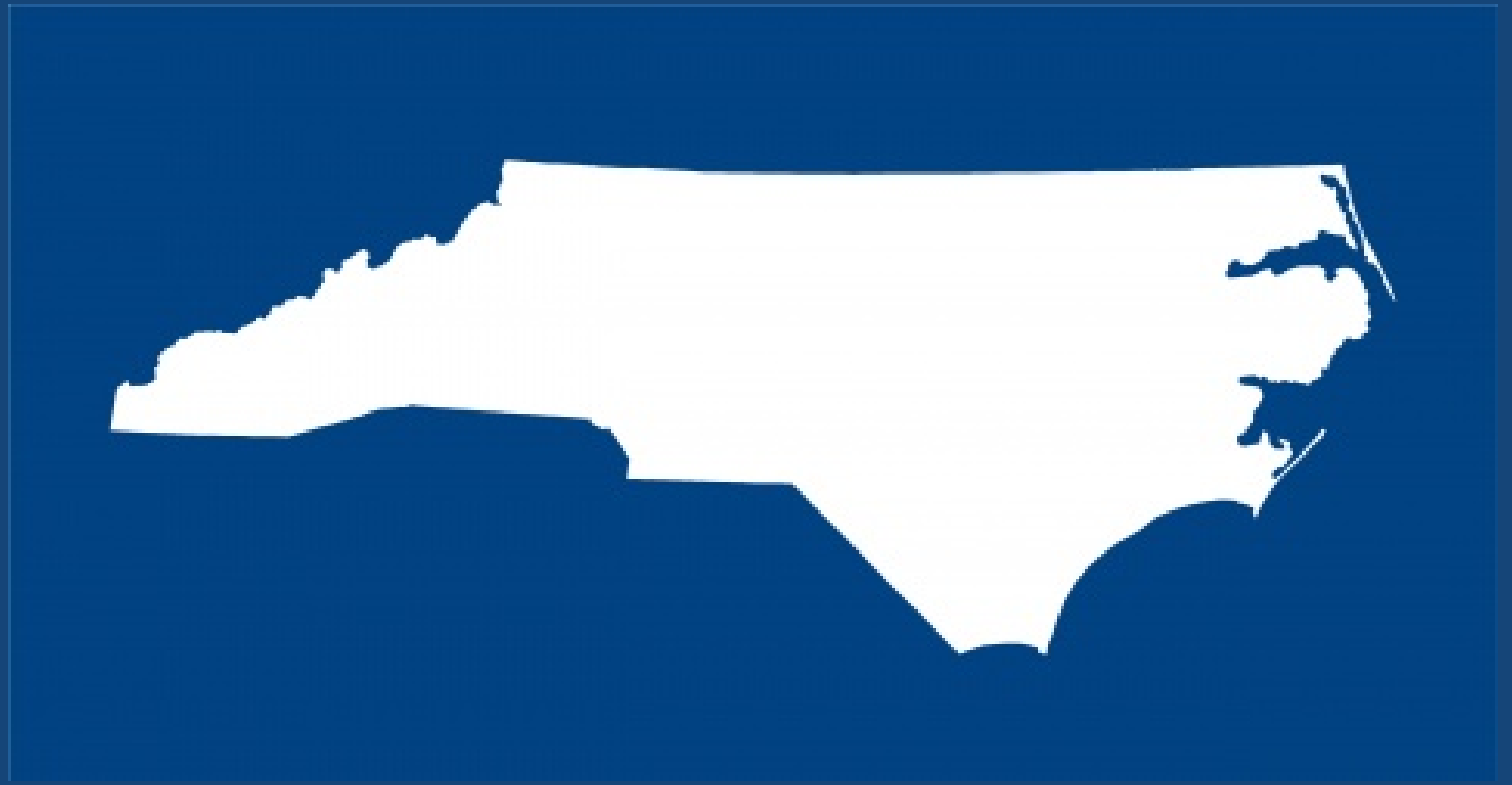
- TA Provider
- Former Part B and C data manager
- Forest management student

Gary Harmon, PhD

- TA Provider
- Former Part C data manager
- Loves data (Epidemiologist)
- 3 kids (7, 10, 15)

Sarah Argue

- TA Provider
- Specializes in longitudinal data systems, data governance, and data quality
- Has two dogs named Fred



Amy Hawn Nelson, PhD

- Research Faculty and Director of Training and Technical Assistance AISP
- Community engaged researcher who has presented and written extensively on data integration and intersectional topics related to educational equity
- Lives in Charlotte with her husband, two feisty daughters, and a naughty labradoodle.

ahnelson@upenn.edu

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THE ANNIE E. CASEY FOUNDATION

MacArthur Foundation

Penn Social Policy & Practice

To the polls...

Who is here

Sharing

Providing individual or aggregate data (e.g. sending transition notification data from Part C to Part B 619)

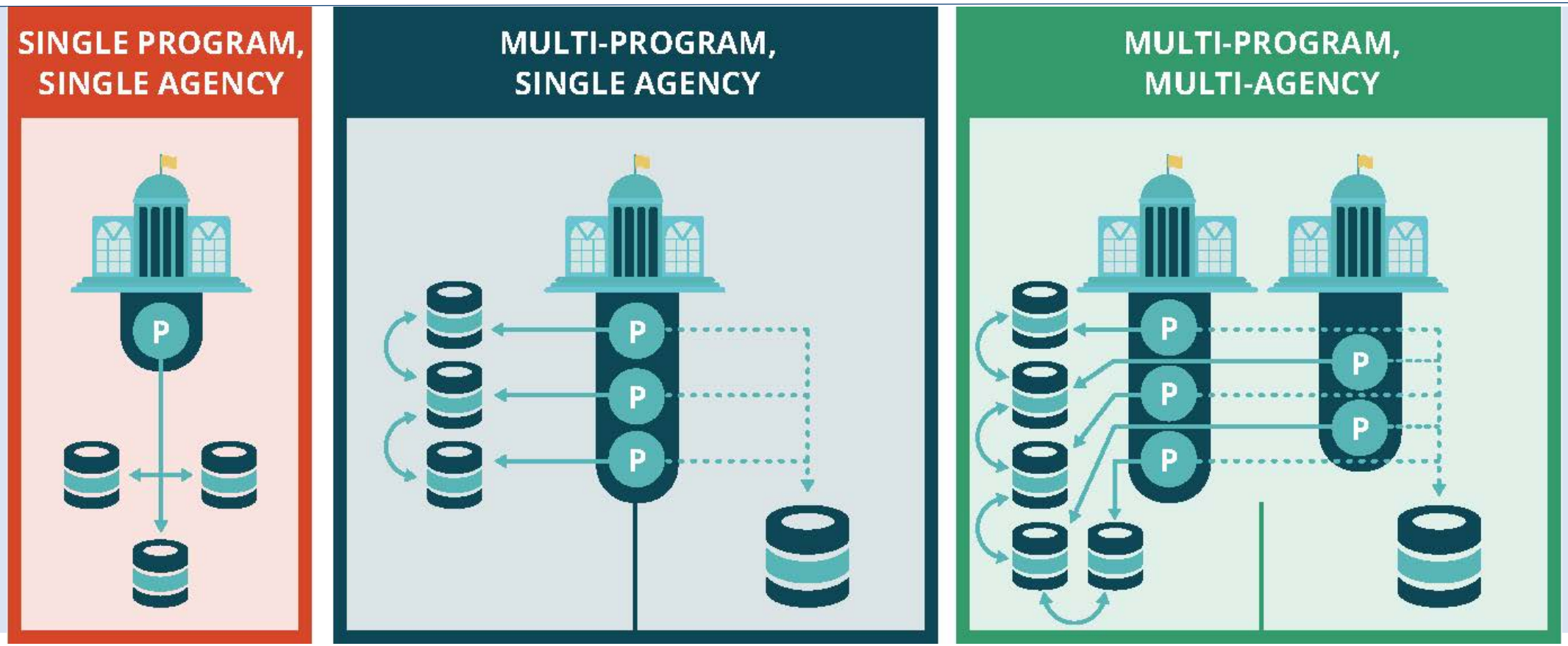
Linking

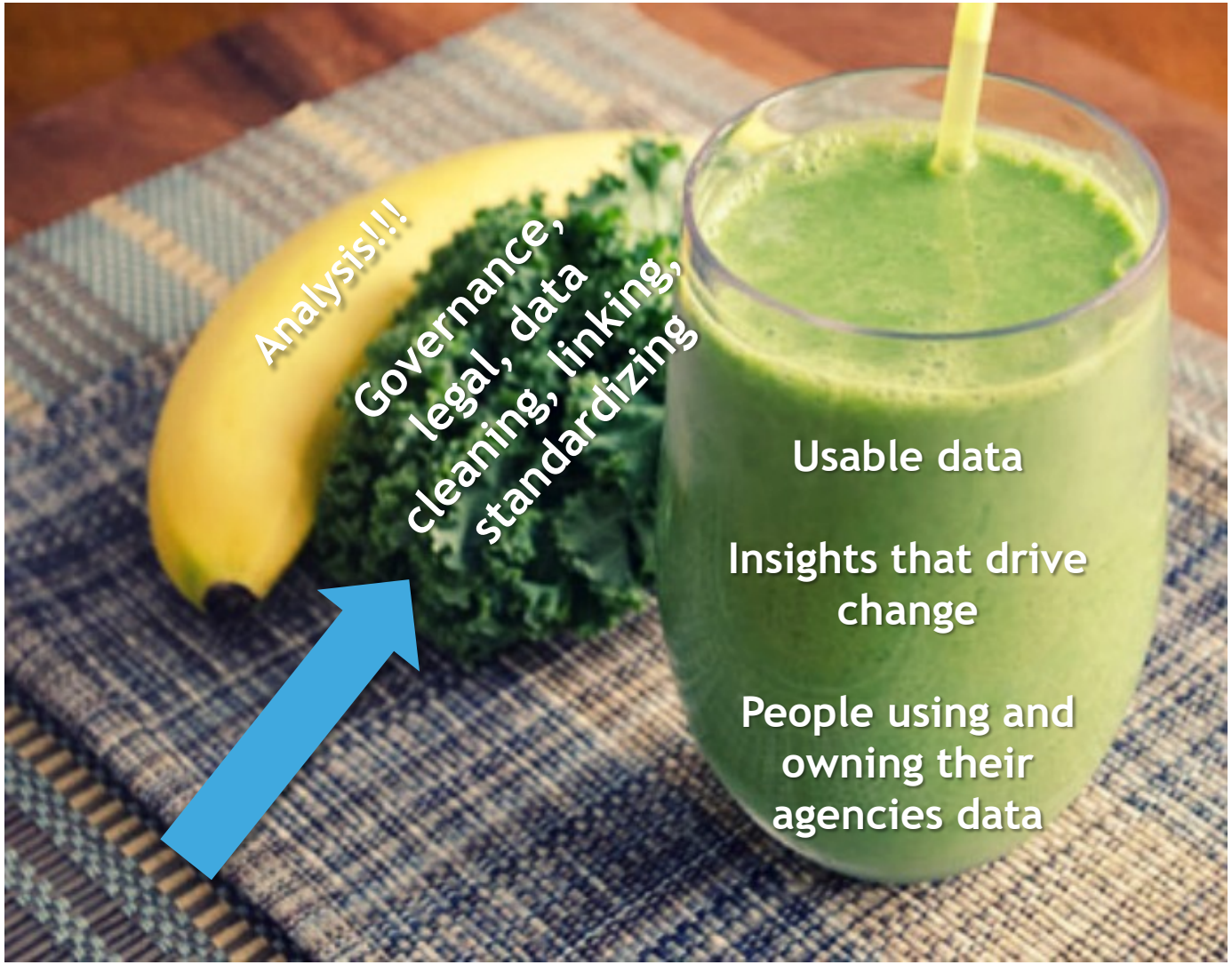
Combining data from two systems (e.g. matching records in Part C to Part B 619)

Integrating

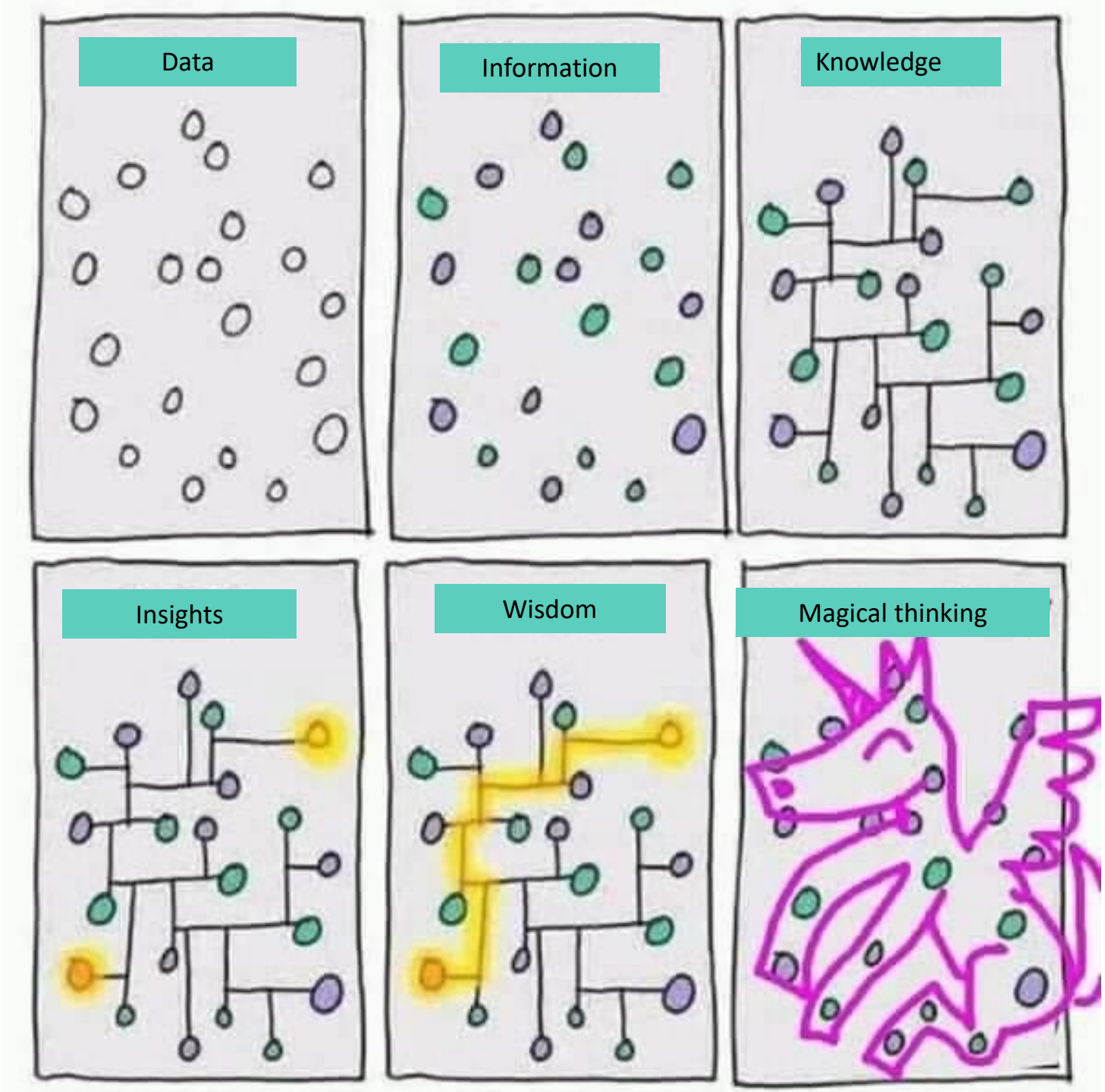
Transforming data from two or more systems into one (e.g. appending Part C child outcomes into Part B 619 data)

Types of Data Linking





Slide adapted and used with permission from RI Data Ecosystem.


Data
Information
Knowledge
Insights
Wisdom
Magical thinking

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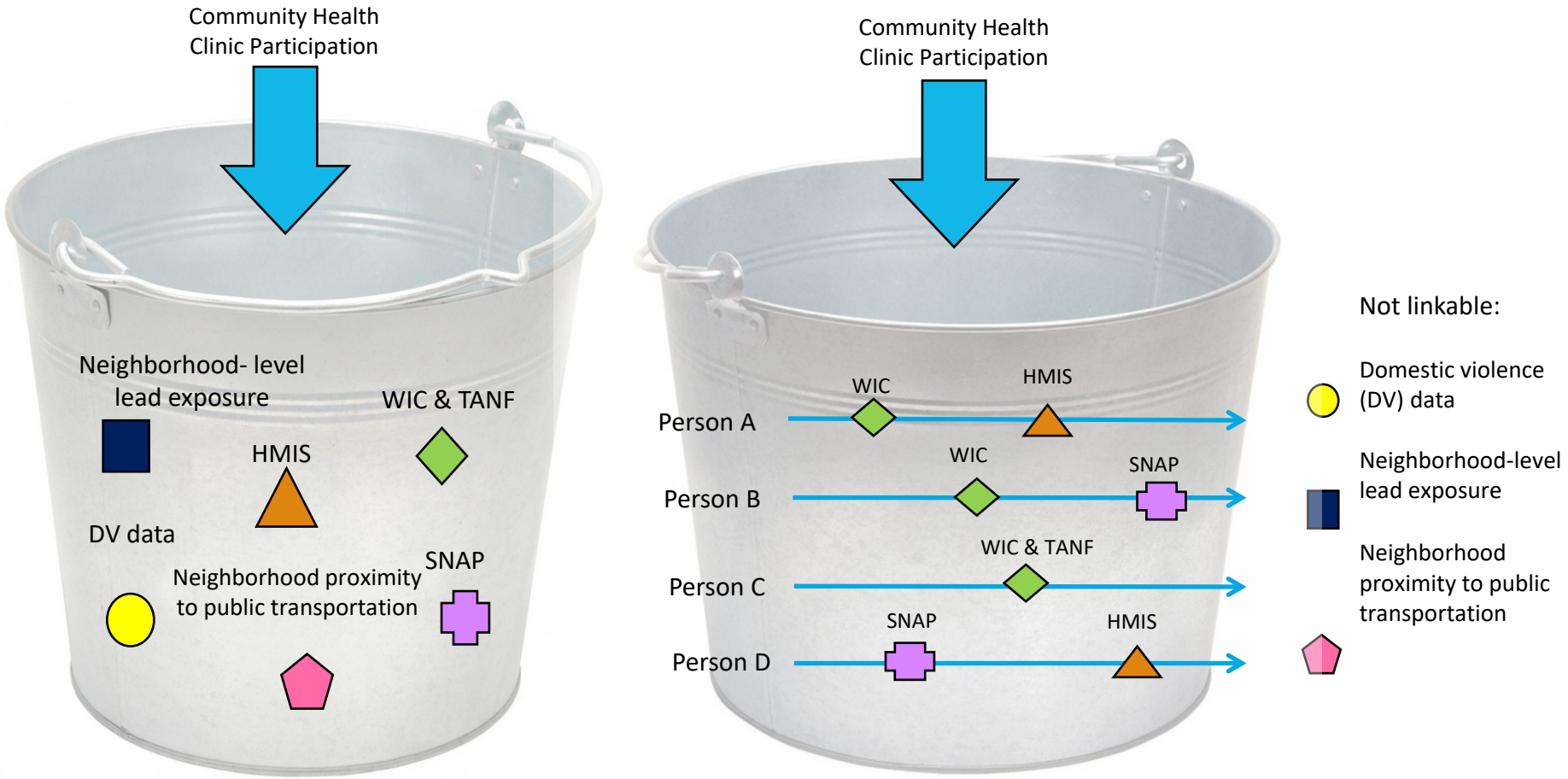
Data sharing vs integration at a community health clinic



Potential Data Linking Partners and Benefits

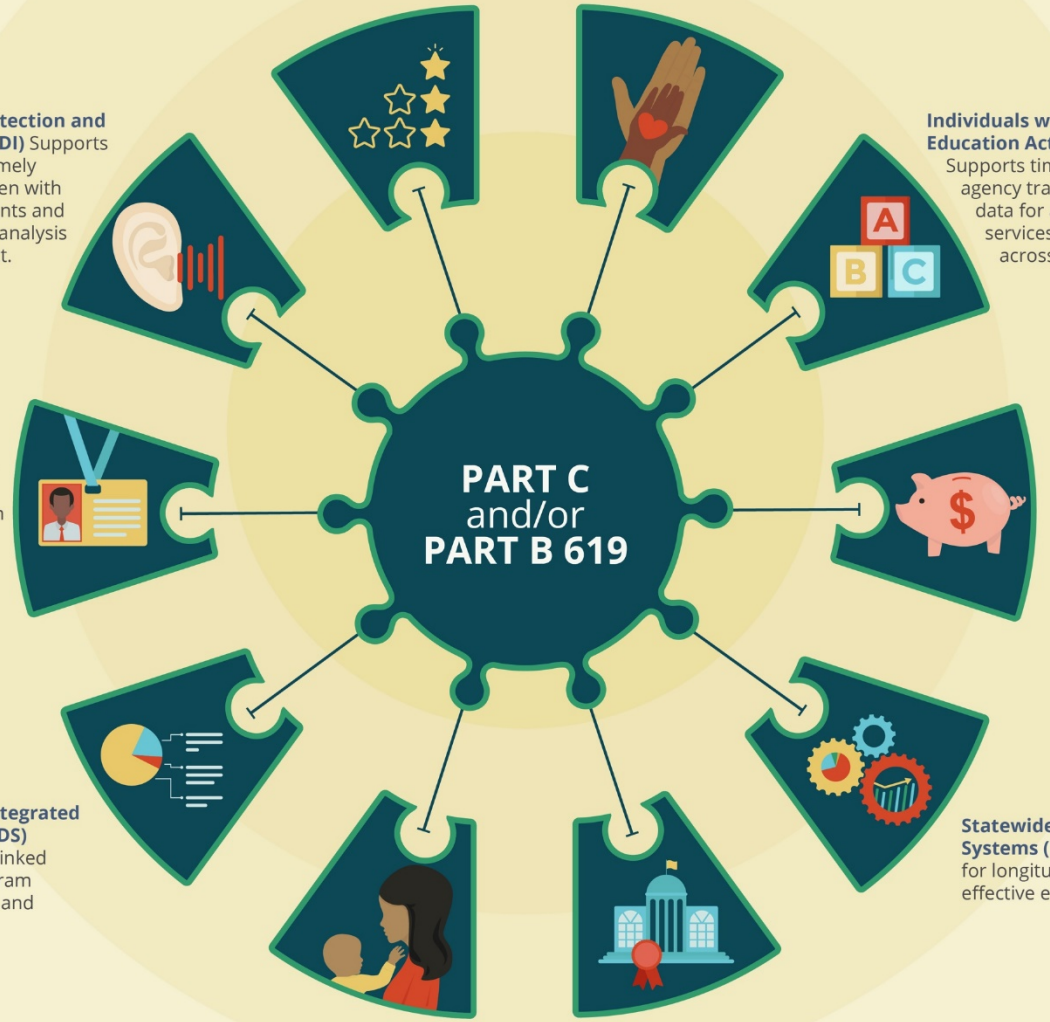
POTENTIAL DATA LINKING PARTNERSHIPS AND THEIR BENEFITS

Quality Rating and Improvement System (QRIS) Supports understanding of program quality and professional development needs of staff in programs in which children are participating.

Child Abuse Prevention and Treatment Act (CAPTA) Supports analysis of data across programs, increases efficiencies in referral processes, and enhances agency collaboration.

Early Hearing Detection and Intervention (EHDI) Supports coordination of timely services for children with hearing impairments and provides data for analysis of program impact.

Individuals with Disabilities Education Act (IDEA) Agencies Supports timely agency to agency transitions and provides data for analysis of children's services and child outcomes across programs.



Personnel Supports activities related to licensing/certification and professional development.

Finance Supports access and efficient reimbursement of Medicaid and private insurance.

Early Childhood Integrated Data Systems (ECIDS) Provides access to linked data for cross-program analysis of services and program impacts.

Statewide Longitudinal Data Systems (SLDS) Provides data for longitudinally investigating effective educational practices.

Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Supports effective collaboration and coordination.

Other Agencies

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To the polls…

Who are you already linking with?

Examples of Critical Questions Requiring Linked Data

1.C.2.b. What percentage of children or families in EI/ECSE are receiving other public services (e.g., The Special Supplemental Nutrition Program for Women, Infants, and Children [WIC]; foster care; children with special health care needs [CSHCN]; child protective services [CPS]; supplemental security income [SSI])?

1.D.3.b. What are the characteristics of children who exit EI/ECSE at age expectations and without an IEP but who subsequently receive an IEP later in K-12? How do they differ from EI/ECSE recipients who do not receive special education services later in K-12?

See other examples at https://dasycenter.org/resources/critical-questions/

5 Steps to Data Linking

5 STEPS TO DATA LINKING

DaSy TA is available at every step of the process

STEP 1: Assess Partner Readiness

Activities

a. Consider the value of data linking
b. Jointly discuss and consider data linking opportunity
c. Review and draft data use case
d. Develop talking points for internal use

STEP 2: Formalize Partnership

Activities

a. Finalize data use case
b. Determine questions to be answered by data linking
c. Develop joint data partnership management plan
d. Develop joint data partnership data sharing agreement
e. Secure agency leadership approval for data linking

STEP 3: Complete Technical Work

Activities

a. Determine necessary preparations for data linking
b. Determine and secure agency resources required for data linking
c. Create data linking process and data models
d. Map and align data elements
e. Create resource repository
f. Identify and resolve redundant data elements
g. Compile final list of data elements and share between partners

STEP 4: Link the Data

Activities

a. Conduct data linking and perform data quality checks
b. Identify processes that may improve data quality
c. Partners sign off on linked data and overall process

Review Steps

STEP 5: Sustain Data Linking

Activities

a. Prepare documentation to sustain data linking
b. Update Data Partnership Management Plan
c. Use linked data to address needs outlined in the use case

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LiveChat

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Our Focus: Jointly Discuss and Consider the Data Linking Opportunity

OPEN DATA	RESTRICTED DATA	UNAVAILABLE DATA
Data that can be shared openly, either at the aggregate or individual level, based on state and federal law. These data often exist in open data portals.	Data that can be shared, but only under specific circumstances with appropriate safeguards in place.	Data that cannot or should not be shared, either because of state or federal law, lack of digital format (paper copies only), or data quality or other concerns.

Data Classification Matrix

Data can be shared with agreement and approval through governance	**Open data; can be shared without an agreement**
Not shareable	**Technology and/or data structure limits ability to share data**

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Legal Approaches and Signatories for Data Sharing and Integration Uses

Purpose	Indicators and Reporting	Analytics, Research, and Evaluation	Operations and Service Delivery
Legal Approach	Typically, data are already publicly available or can be accessed in an aggregated format with a simple Data Use Agreement.	Data access will generally require multiple agreements, including a Memorandum of Understanding and Data Use License/Agreement to clearly outline permissible access and use.	Data access may require client consent and non-disclosure agreements. Data agreements will also need to outline clear parameters for role-based, credentialed access.
Signatories	Data owner/s and data users	Data owner/s, data integration staff (if separate from data owner/s), data users/ licensee	Individual receiving service/s (through informed consent), data owner/s, data integration staff (if separate from data owner/s), data users/licensee if applicable

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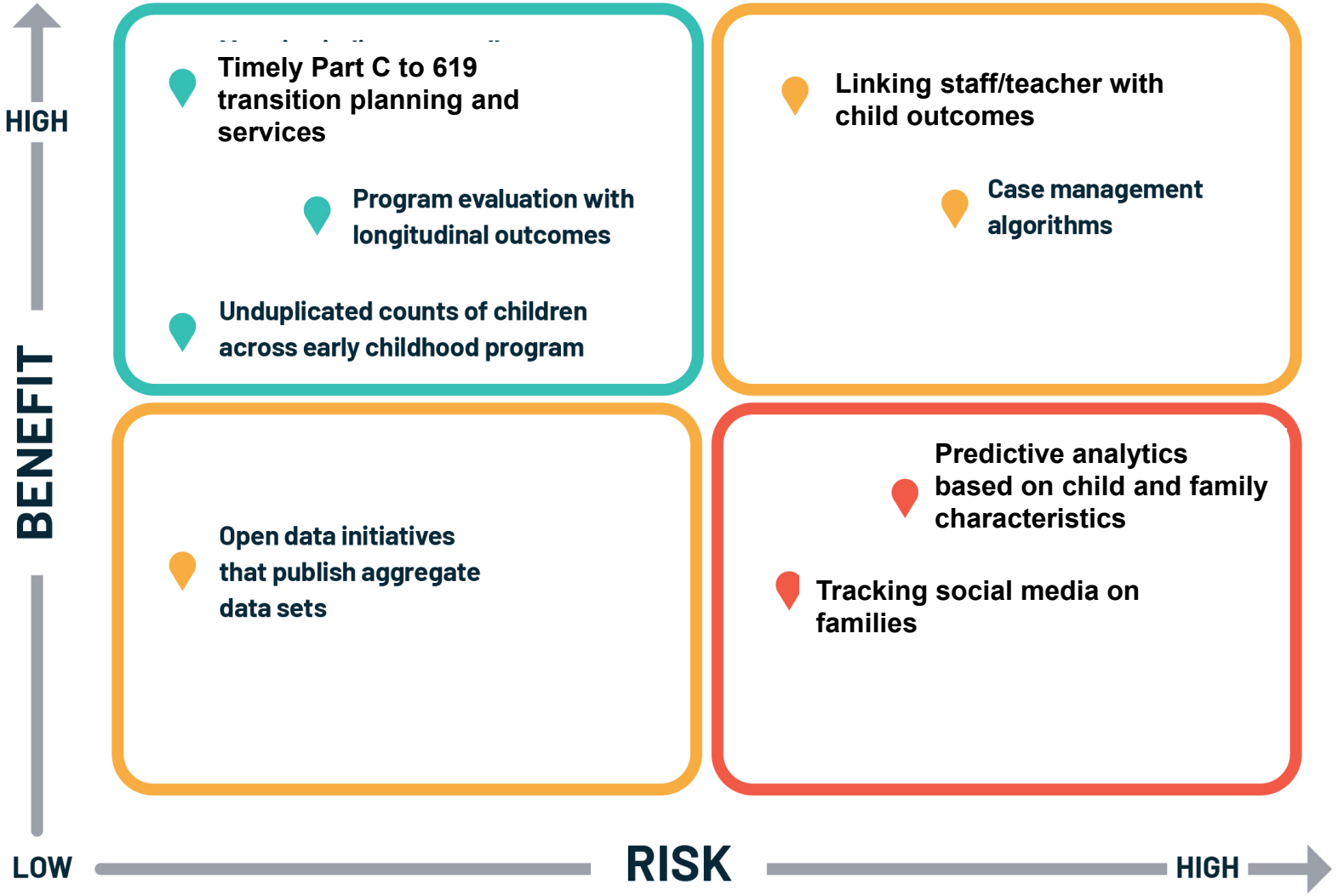
Benefit/Risk Matrix



The Role of Data Owners, Data Stewards, and Data Custodians

	Role in data sharing process	Role within agency
Data Owner	Accountable for the quality and security of the data and holds decision-making authority regarding access and use	Typically agency leadership that has signatory authority
Data Steward	Responsible for the governance of data, including metadata. Support established processes and policies for access and use	Typically the subject matter experts and data analysts that work with data
Data Custodian	Responsible for the technology used to store and transport data	Typically an IT person or team

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To the polls…

What is your role?

Core question	Key considerations	Who decides?	Resources on this topic
Is this data sharing legal?	Are there federal or state statutes that prevent or constrain this data access or use?	This is typically determined by agency-involved legal counsel.	Legal Issues for IDS Use: Finding a Way Forward (2017)
Is this data sharing ethical?	Do the benefits outweigh the risks, particularly for vulnerable populations?	This is typically determined during the review process for data requests that should include data owners.	Data Ethics Workbook (2018)
Is this data sharing a good idea?	What action can be taken as a result of this analysis? What can reasonably be changed or improved based upon the findings?	This is typically determined by a data governance group, including data owners who will respond to insights that emerge from the analysis.	

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Exploring a Potential Partnership Together

1. What level of understanding does each potential partner have on the purpose(s) and potential benefits of the data partnership?
2. In general, how likely is each potential partner's leadership to be supportive of moving forward with a data linking partnership ?
3. To what extent do both potential partners agree to a common timeline?
4. To what extent do both potential partners agree that they can technically link the data?
5. To what extent do both potential partners agree that they have the non-technical resources (e.g., legal, staff expertise, staff availability) to link the data ?

Exploring Joint Timeline

3. To what extent do both partners agree to a common timeline (months, possibly years)?

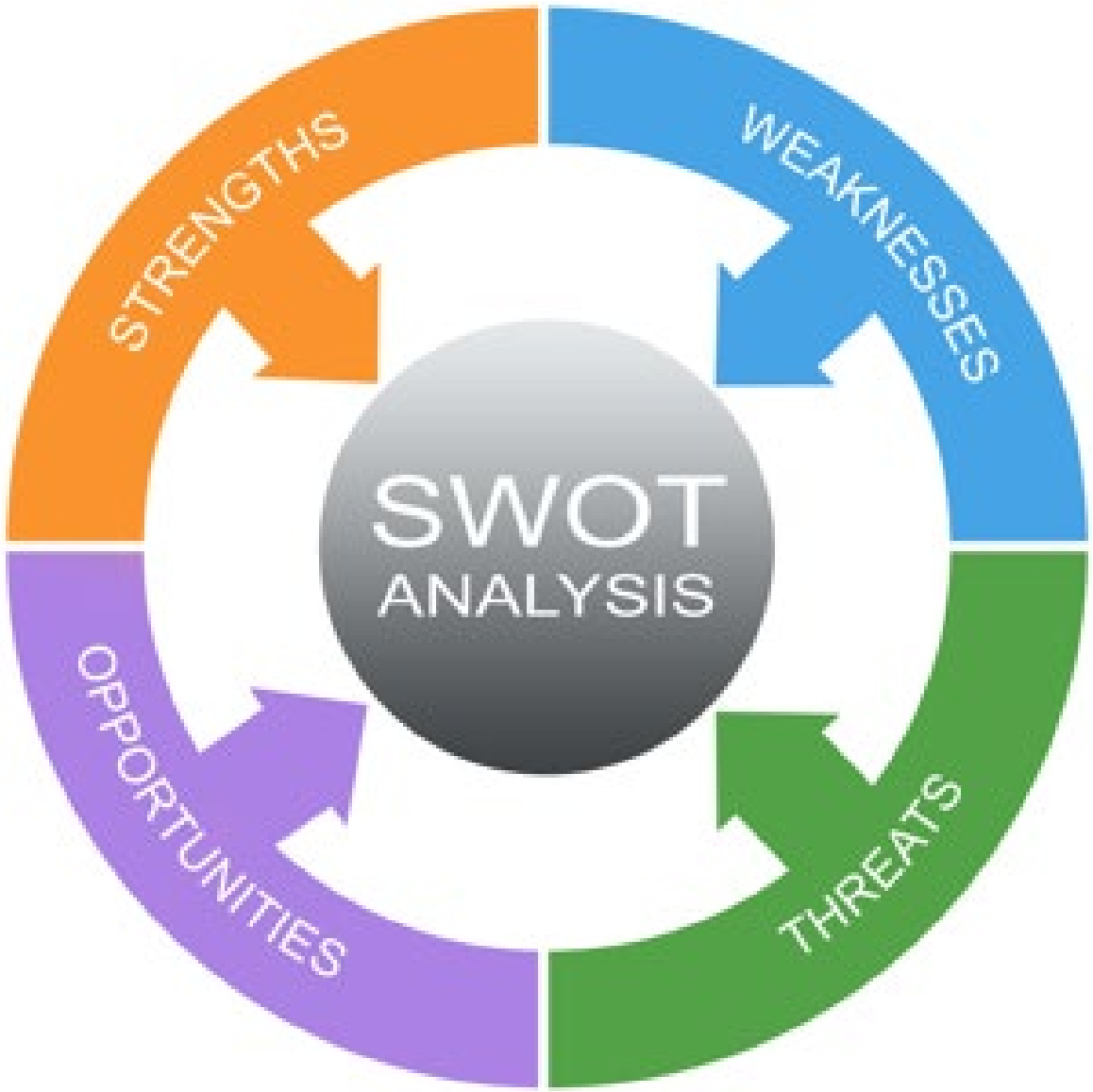
Consider

- Timeline for data linking in relation to other priorities and ongoing work.

(Not Agree) (Agree)

Comments:

Assessing Strengths, Weakness, Opportunities, and Threats for Potential Data Linking Partnership



Step 2: Formalize Partnership

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Activities

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Data Governance Toolkit: Governance of Data Partnerships

Overview
Introduction
Purpose, structure, process
Data breach response
Data quality
Data security & access
Data system changes
Public reporting
Electronic communications
Data requests
Data retention & destruction
Governance of data partnerships
Data governance resources

Data Partnerships [PDF]

Overview	Data Partnerships	Data Sharing Agreement	Data Partnership Management Plan

A **data partnership** is an arrangement between two or more parties that agree to collaborate for the purpose of advancing their mutual data interests (e.g., Part C and Early Hearing Detection and Intervention or Part B 619 and State Longitudinal Data System). Such collaboration often involves matching, linking, and/or integrating record-level data. (A data partnership is not needed when publicly available aggregate data from one agency are being shared and used by another.)

Given the importance and sensitivity of the Individuals with Disabilities Education Act (IDEA) data, it is critical to establish data governance policies when Part C and/or Part B 619 are in any data partnership. This Governance of Data Partnerships section of the DaSy Governance Toolkit does not address "how to" data activities and processes. Instead, it focuses on the joint governance: the legal requirements and the management of the data partnership.

This Governance of Data Partnerships section of the Toolkit is for

What if my agency or program does not have adequate data governance policies and/or a structure?

Agencies in a data partnership are responsible for their own data governance policies. If your agency does not have adequate program-level data governance, DaSy encourages you to use the Data

North Carolina's Roadmap to Data Linking

DPI, DHHS

Who Are We?

- Office of Early Learning/ EC Division (DPI)
  - **Dawn Meskil** – Preschool Exceptional Children 619 Co-Coordinator
  - **Kelley Blas** – Part B IDEA Technical Analyst
- Early Intervention Branch (DHHS)
  - **Sharon Loza** - Branch Head & Part C Coordinator
  - **Barbara Simpson** – Evaluator, Data Manager (Acting)

Step 1: Assess Readiness

- Ensure Buy-In, Commitment, and Education
  - Reconcile Part C to Part B transition notification data
  - Regular communication and meetings
  - Longitudinal data tracking and program improvements
  - Strengthen services for children participating in Special Education

Step 2: Formalize Partnerships

- Data Sharing Agreements/MOUs
  - Explored existing interagency agreements
  - Developed and received approval for a new MOU
- NC Part C to B Linking Group Charter identified:
  - Short- and Long-Term Goals
  - Roles and Responsibilities
  - Meeting Structure
  - Critical Questions
  - Shared Data Elements

Critical Questions for Linking

- How many children who exit Part C in a given time period and who are potentially eligible for Part B 619 transition and are enrolled in Part B 619?
  - How many do not transition into Part B (Pre-School)?
  - How many children who enter Part B 619 in a given time period were ever enrolled in Part C?

Step 3: Complete Technical Work & Step 4: Link the Data

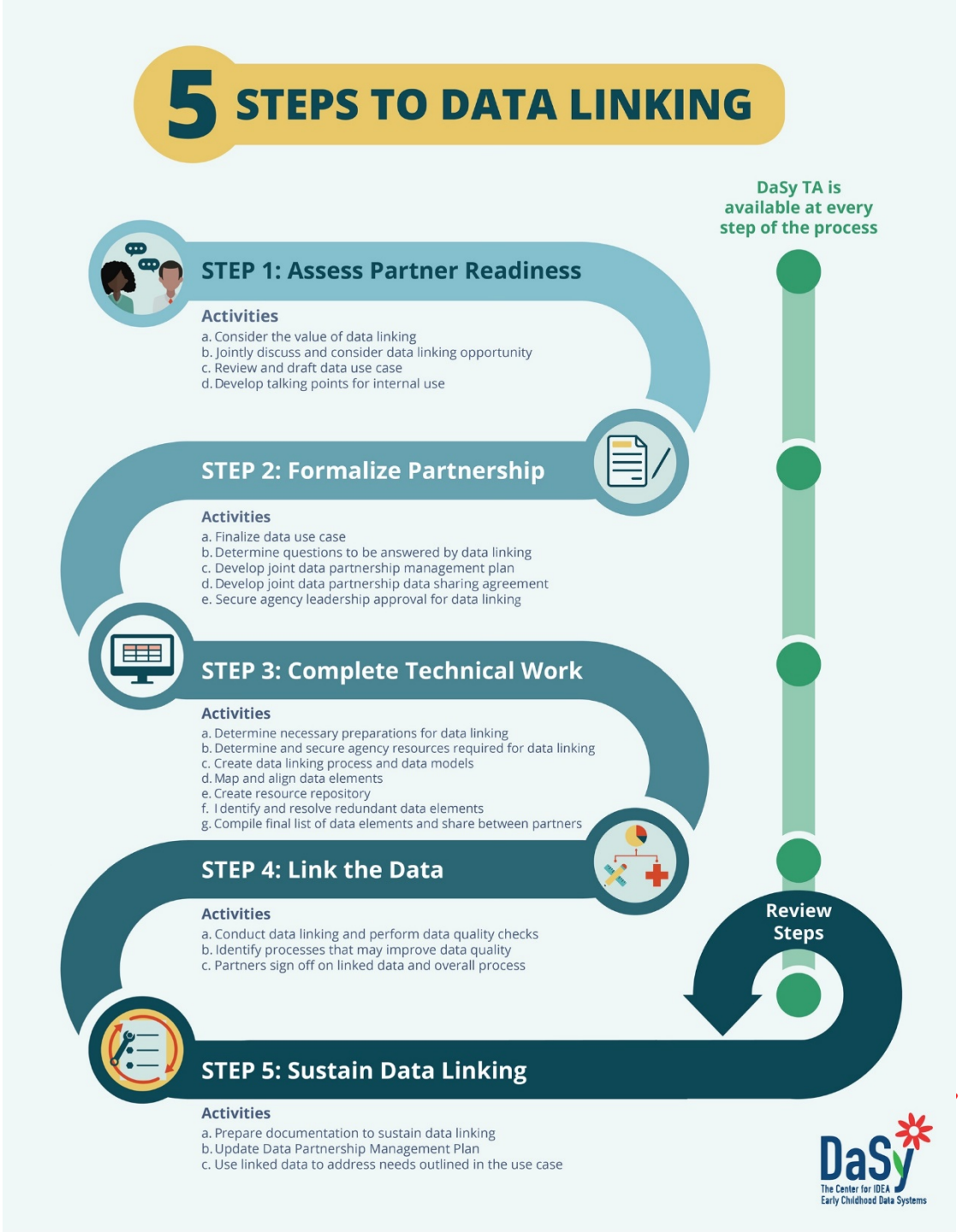
- Data Elements
  - Reviewed elements to answer the critical questions
  - Determined data elements programs contribute
  - Reviewed FERPA nonconsensual PII disclosure exceptions
- Record Matching
  - No universal C/619 unique ID
  - Solution: ECIDS eScholar ID
    - eScholar ID are available in the DHHS Data Warehouse for children enrolled in Part C
    - ECIDS Executive Committee approved Part C access to eScholar IDs

Future Steps: Data Use

- Prepare analysis plans
- Prepare and analyze data to answer critical questions
- Use data for program improvement (e.g. transition plans)
- Generate reports/data visualizations for stakeholders

LiveChat

Technical Assistance to Support Your Data Linking Efforts



Resources

DaSy

- Critical Questions: https://dasycenter.org/resources/critical-questions/
- Data Governance and Management Toolkit: https://dasycenter.org/data-governance-management-toolkit/
- Data Partners Management Plan: https://dasycenter.org/data-governance-management-toolkit/governance-of-data-partnerships/data-partnership-management-plan/
- Data Linking Toolkit and associated tools coming soon!

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- A Toolkit for Centering Racial Equity Throughout Data Integration: https://bit.ly/CenterRacialEquity
- Introduction to Data Sharing and Integration: https://bit.ly/DataIntegrationIntro

To the polls…

How likely are you to move forward with data linking?

Reminder

- Please remember to complete the session evaluation!
  - You will get a notice from the event platform (CrowdCompass) with a link to the evaluation.
  - You can also scroll to the bottom of the session page on CrowdCompass for a link to the evaluation.

Thank you

Visit us at http://dasycenter.org/

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DaSy The Center for IDEA Early Childhood Data Systems

IDEAs that Work
U.S. Office of Special Education Programs

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