

# Bridging the Agency-Academic Divide to Integrate Data and Serve “The Whole Child”

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Association for Public Policy  
Analysis & Management (APPAM)

November 2019

# Agenda

- **Introductions**
- **Presentations from Wisconsin**
  - University Perspective
  - Agency Perspective
- **Presentations from Iowa**
  - University Perspective
  - Agency Perspective
- **AISP: A National Perspective**
- **Questions & Discussion**

# Actionable Intelligence for Social Policy (AISP)

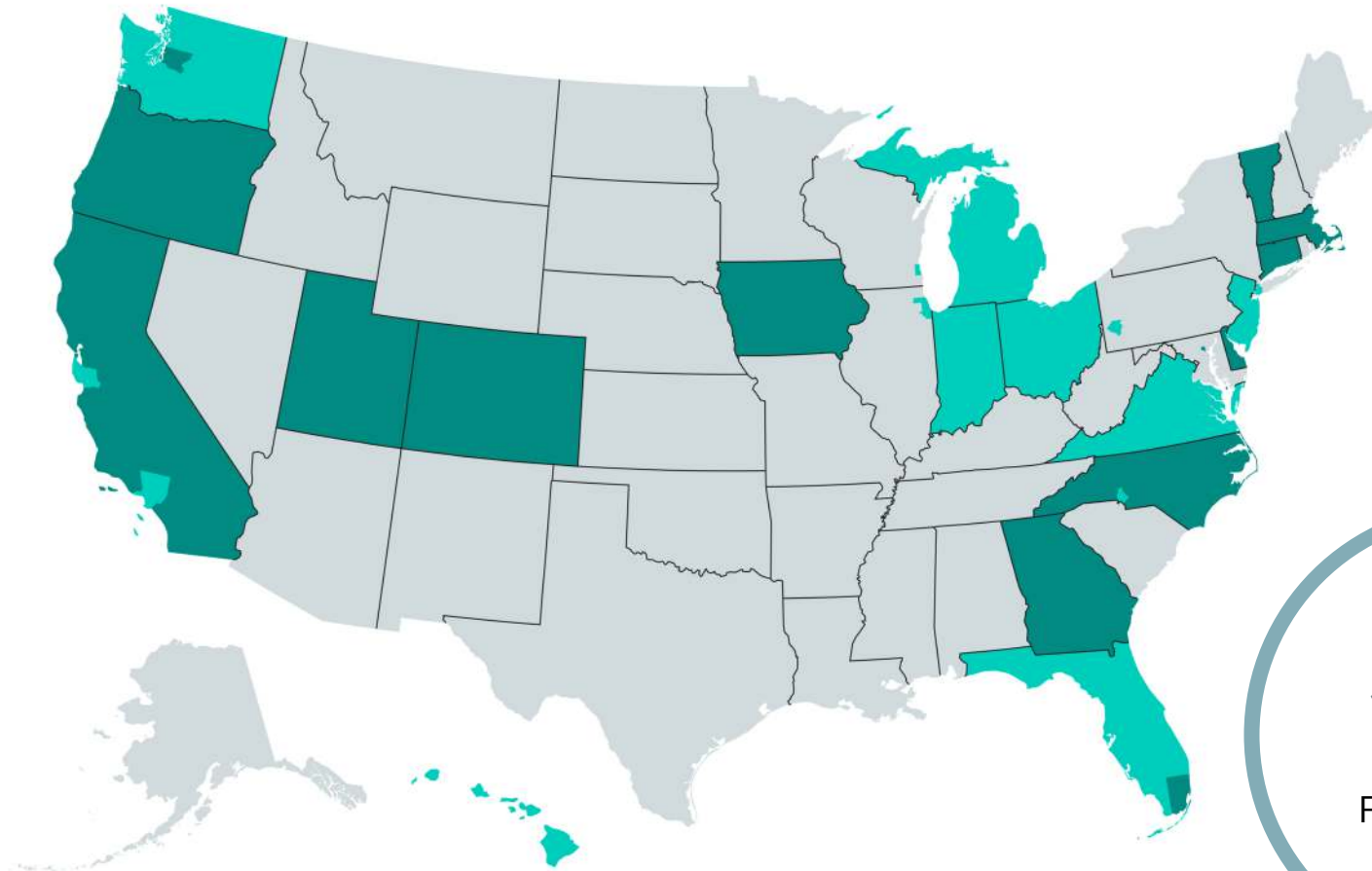
We are:	We are not:
Data sharing enthusiasts	✗ A data holder or intermediary
Connectors, community builders, thought partners	✗ A vendor or vendor recommender
Focused on ethical data use for program evaluation, resource allocation, policy change	✗ Focused on purely academic research

# We work to promote partnership efforts that:

- Link administrative data across at least three domains/agencies
  - ✗ *Not just across several programs within an agency*
- Serve as a public utility
  - ✗ *Not research for research's sake*
- Have a clear organizational home and defined governance structure
  - ✗ *Not one-off projects*



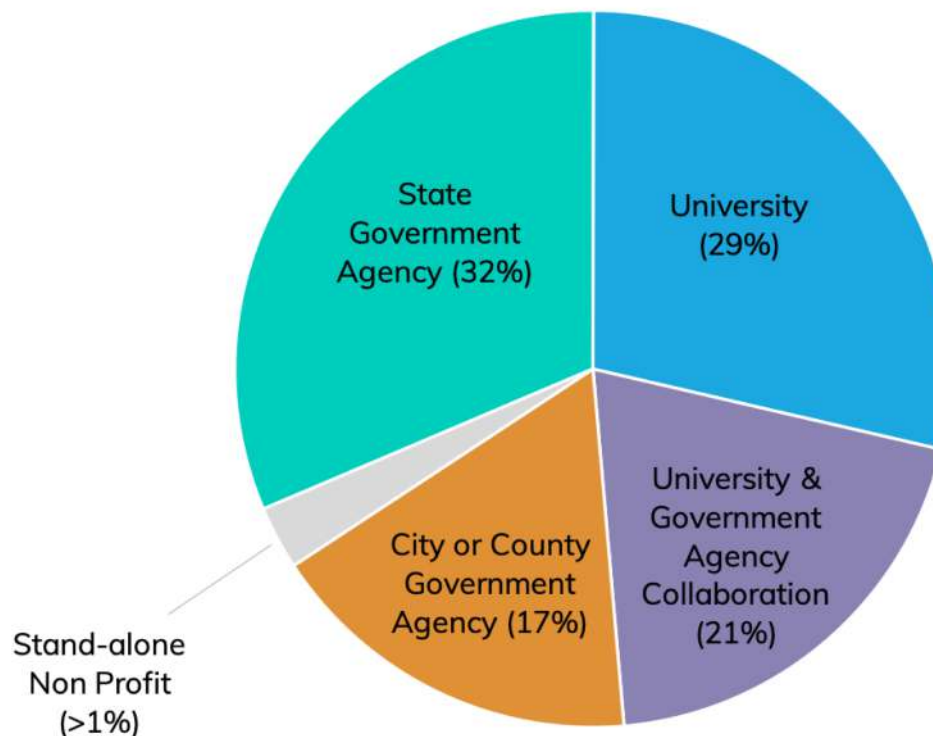
# AISP Network Sites + Learning Community Sites



**53%**  
OF THE US  
POPULATION

# 2018 Survey Findings

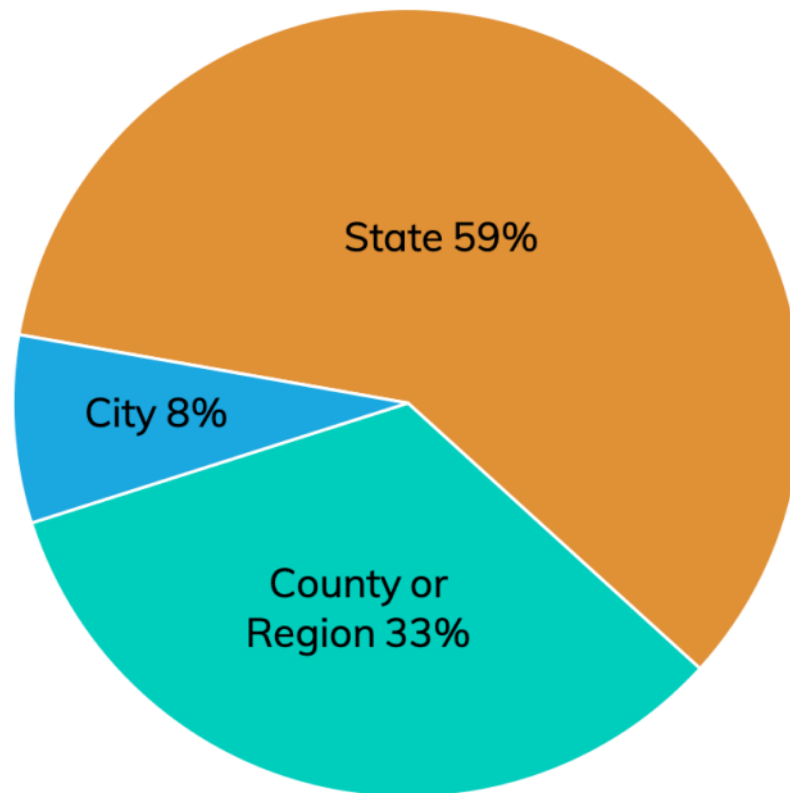
Lead Organization For Data Sharing Effort



N = 35

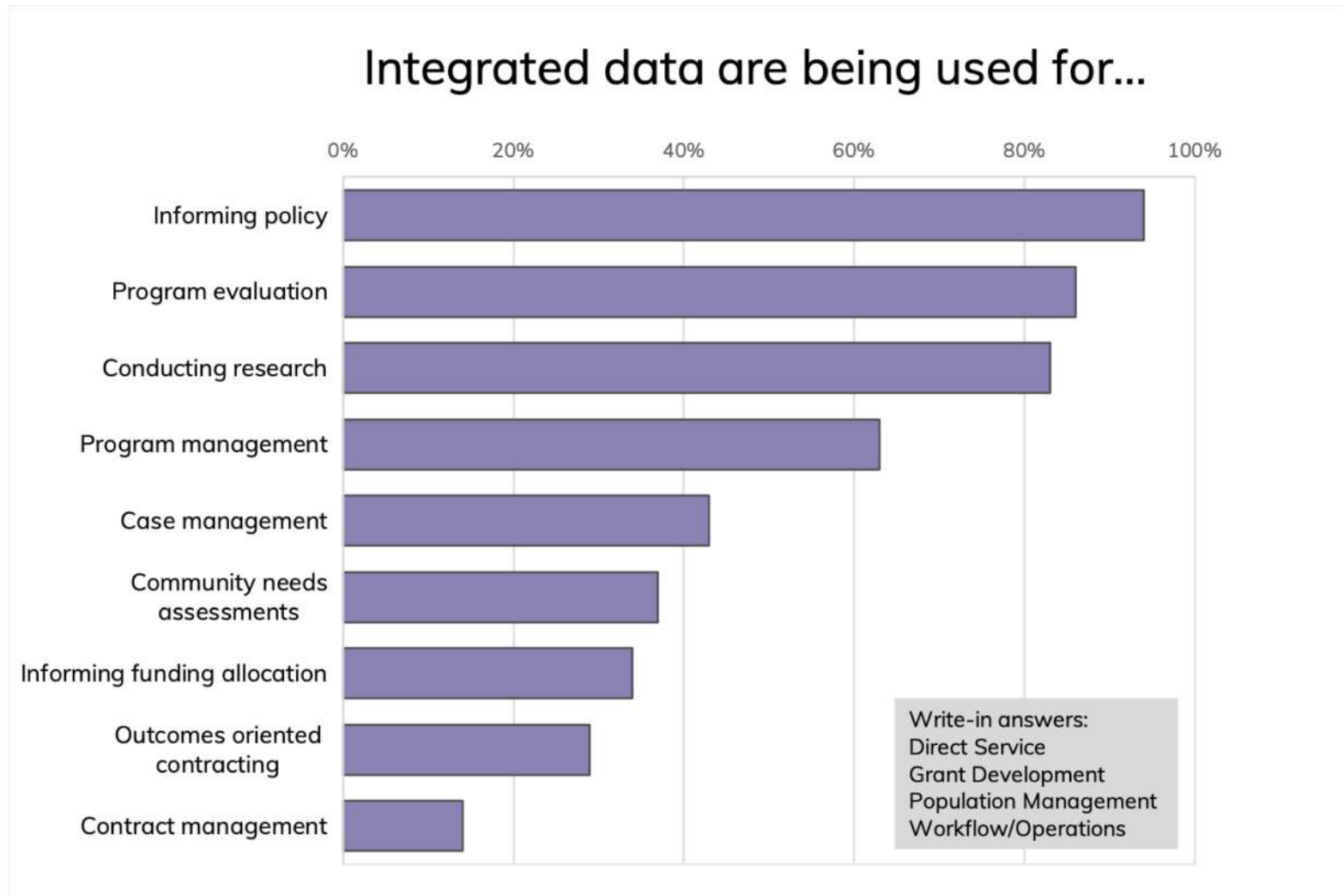
# 2018 Survey Findings

What level of data do you integrate?



N = 39

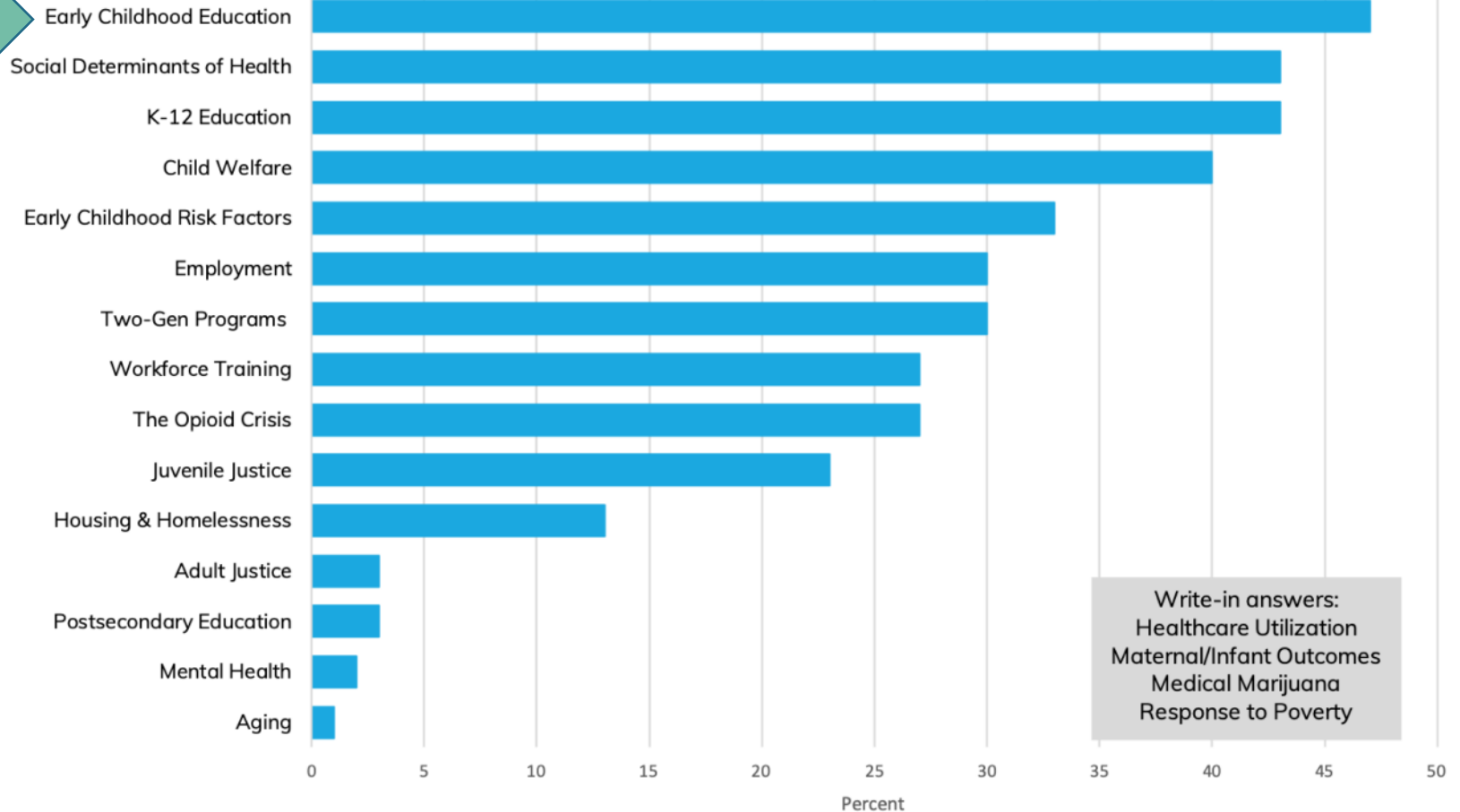
# 2018 Survey Findings





# 2018 Survey Findings

What policy areas are you interested in exploring?



# Presenters

- **Wisconsin**

- Hilary Shager, University of Wisconsin-Madison, Institute for Research on Poverty
- Kristina Trastek, Wisconsin Department of Children and Families

- **Iowa**

- Cassandra Dorius, Iowa State University
- Betsy Richey, Iowa Department of Public Health



Institute for  
Research on  
Poverty

UNIVERSITY OF WISCONSIN-MADISON

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# Bridging the Agency-Academic Divide to Integrate Data and Serve “The Whole Child” : The Wisconsin Experience

Association for Public Policy  
Analysis & Management (APPAM)

Hilary Shager  
November 9, 2019

# Institute for Research on Poverty (IRP)

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- Established in 1966 during the War on Poverty
- Functions as independent, multi-disciplinary center within the College of Letters & Science at the UW-Madison

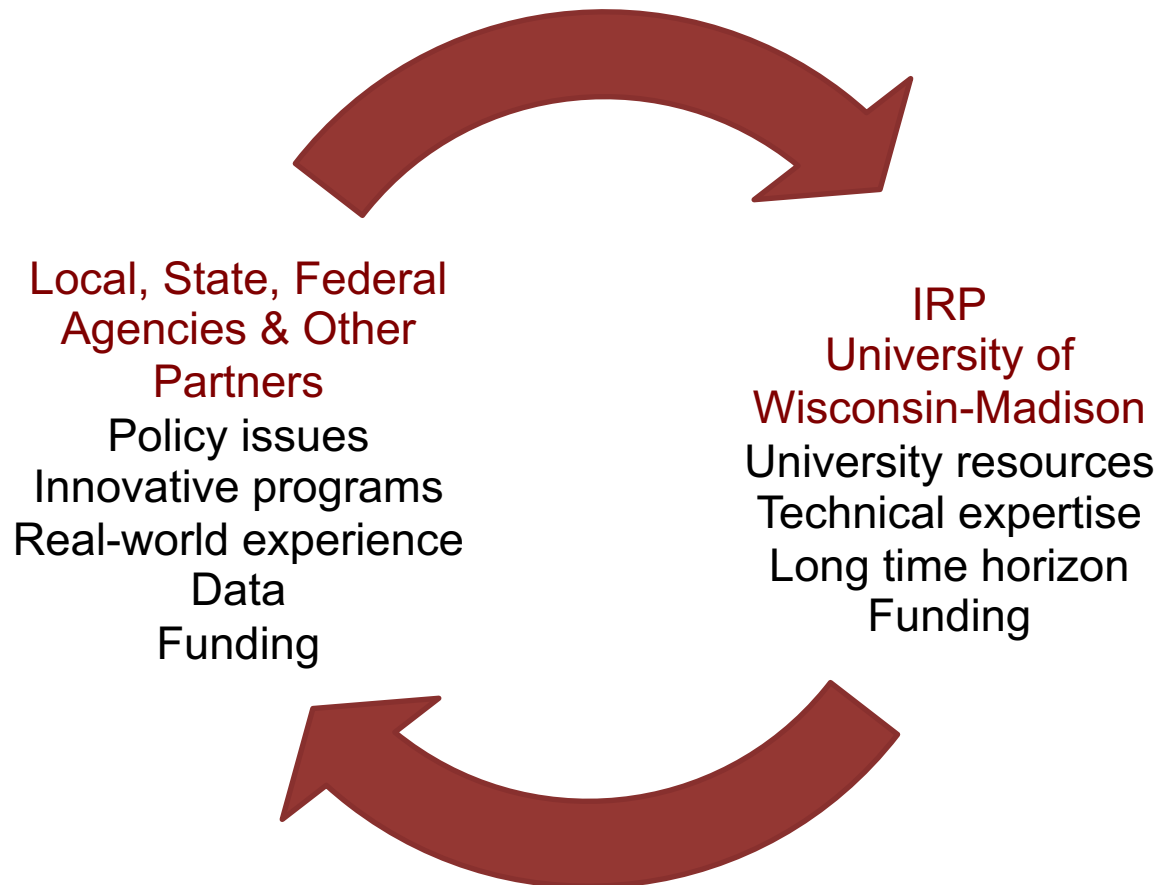
- Core infrastructure funding from UW-Madison and U.S. Dept. of Health & Human Services
- ~\$30 million in grants and contracts from foundations, state and federal agencies



# Realizing “The Wisconsin Idea”

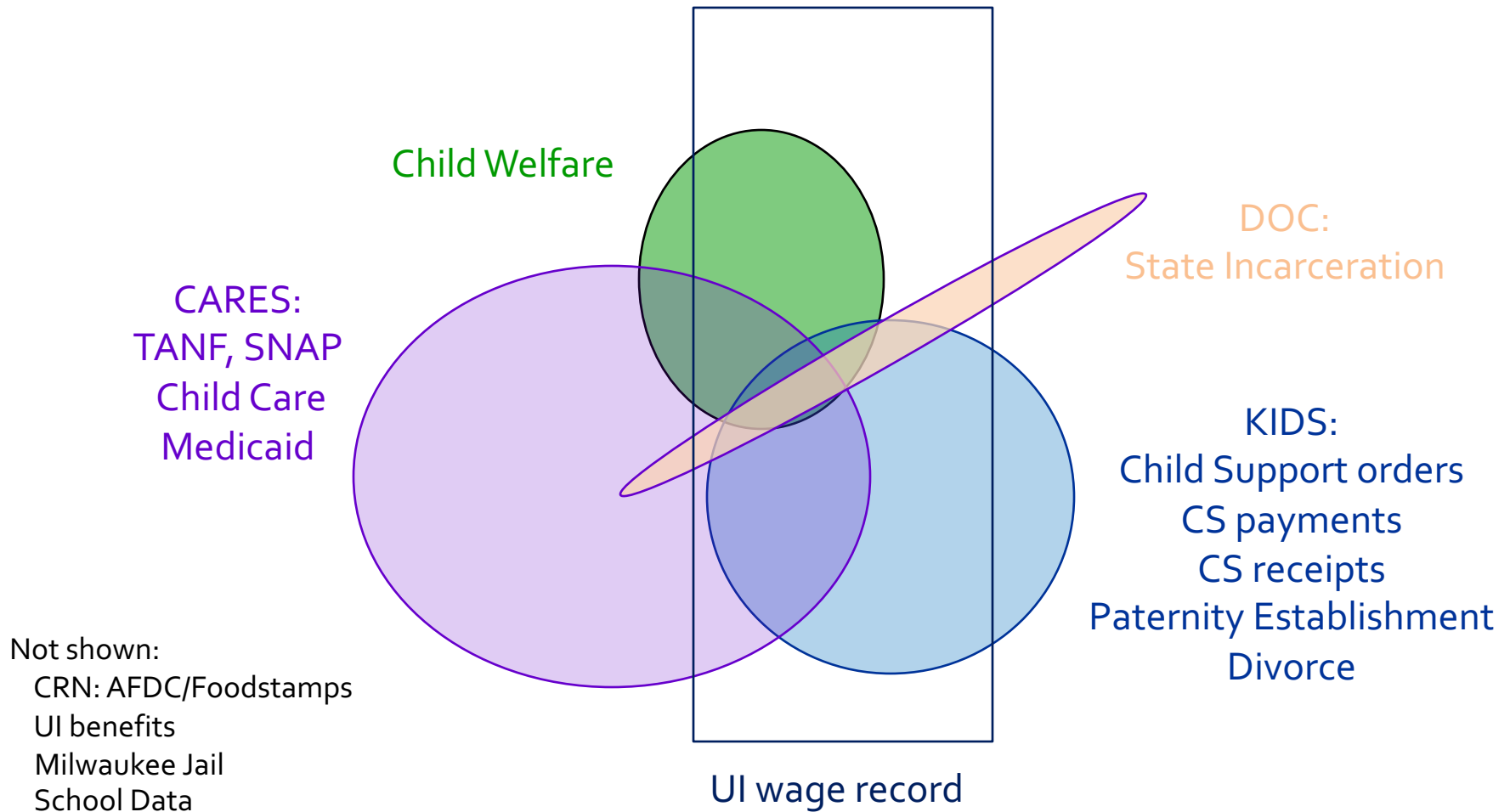
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## Collaboration Supports Policy Development and Academic Research



# The Wisconsin Administrative Data Core

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N = 7 million +

# Current Wisconsin State Administrative Data Resources

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## **CORE – fully linked:**

- SNAP/Food Stamps (CRN, CARES)
- Child Protective Services (WiSACWIS)
- AFDC/TANF (CRN, CARES)
- Medicaid/Badgercare eligibility & claims (CRN, CARES)
- Child Care Subsidy (CARES)
- Child Support (KIDS)
- Unemployment Insurance Benefits (UI)
- Incarceration (Dept. of Corrections)
- Milwaukee Jail

## **REGULAR MATCH:**

- Wage Records (UI)
- Dept. of Public Instruction (K-12)

## **SPECIALIZED MATCH**

### **(ad hoc/samples):**

- Department of Revenue
- Juvenile Circuit Court Records
- SSI records (CARES)
- Vital Records (births/paternity)
- Circuit Court Records (CCAP; foreclosures)
- Family Court Records (not electronic)
- TANF Applicants (not electronic)
- Parent Surveys
- CSPED

# Identifying Questions of Interest

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- IRP staff and faculty affiliates meet regularly with agency leadership and staff
- Sustained research agreements for specific programs
- Contracts for specific programs and projects
- Identification of joint funding opportunities
- Quarterly “Learning Exchanges”
- Ad-hoc TA provided by IRP staff and faculty
- Ad-hoc consultation provided by state agency leadership and staff
- “Translation by design”—how findings will be shared with and used by agency partners



# How the WI Data Core Requires and Sustains the Partnership

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- **Provides a unique resource for agencies that cannot otherwise link and analyze across systems**
  - Sustains state support of Data Core data access and funding
- **Provides a unique data resource for research that cannot otherwise be completed**
  - Sustains commitment and interest of academic researchers

***Yours, mine, and (increasingly) ours***

# How Institutional Constraints Shape the Partnership

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- **Data may only be used to inform policy and program administration**
  - State agencies are not permitted to provide data access for research not relevant to the agency's mission, so researchers need to accept limitations, and understand and explain utility
- **Research results must be made public, and identified matched data cannot be returned to agencies**
  - IRP faculty and staff are not permitted to submit research for clearance by funders nor to return matched data to agencies, so agencies must value and accept independence

# Educational Outcomes for Children in Out of Home Care (OHC): Questions

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- On average, children in OHC exhibit poorer developmental outcomes than children who have never experienced OHC
- BUT...children who experience OHC are also more likely to experience other risk factors, including poverty, parental substance abuse and mental health problems, etc., that are also likely to influence developmental outcomes
- *Are poorer outcomes the result of OHC or driven by other factors?*

# Educational Outcomes for Children in Out of Home Care (OHC): Results

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- Use linked administrative data to investigate
  - Bivariate evidence that children who experience OHC have poorer achievement (test scores) than those not experiencing OHC
  - Bivariate evidence that OHC have poorer achievement than general population of those receiving SNAP, but economic disadvantage appears to explain more than half of this gap
  - *Multivariate* results confirm that OHC itself is NOT significantly related to school achievement
  - BUT...OHC is significantly related to lower graduation rates
  - These findings have led to ongoing work with DCF and DPI, currently trying to understand this difference and what can be done to alleviate it

# Other Integrated Data Research Focused on Child Outcomes

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- Recent NIH proposal submission examining longitudinal health and wellbeing outcomes for mothers who used opioids during pregnancy and their children
- Socioeconomic Disadvantage and Educational Achievement: Evidence from Integrated Education and Social Service Administrative Data
- Gestational Age, Early Literacy, and Moderation by Maternal Sociodemographic Factors
- Post-Divorce Placement Arrangements and Children's Test Scores
- The School Breakfast Program and Elementary School Students' Attendance and Test Scores
- The Effect of Housing Assistance on Student Achievement: Evidence from Wisconsin
- Young Adult Outcomes Associated with Out-of-Home Placement Experiences
- Patterns of Postsecondary School Enrollment of Low-Income Students: An Analysis of Data from the National Student Clearinghouse

# Next Steps

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- Address challenges and increase utilization
  - Increase technical efficiencies, quality
  - Lower transactional costs
  - Seek out new data to answer relevant questions
- Empanel State Advisory Council
  - Systematize data sharing processes, agreements
  - Develop cross-system research agenda
  - Work with new agencies
- Work with agencies on internal data matching projects
  - State Longitudinal Data System Grant
  - Preschool Development Grant
  - Child Welfare/Medicaid data matching



WISCONSIN DEPARTMENT OF  
CHILDREN AND FAMILIES

# Bridging the Agency-Academic Divide to Integrate Data and Serve “The Whole Child” The Wisconsin Experience

Kristina Trastek  
November 9, 2019

# Wisconsin Department of Children and Families (DCF)

*It is DCF's vision that all Wisconsin children and youth are safe and loved members of thriving families and communities.*

Formed in 2008, DCF is responsible for providing and overseeing the following programs and services:

- Child Welfare
- Community-Based Youth Justice
- Child Support
- Work Programs (W-2)
- Early Care and Education (Child Care)



# Data-Informed Foundation

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*DCF is an organization built upon a foundation which embraces continuous quality improvement, innovation, and the responsible use of finite resources.*

- Formal and Informal CQI Activities/Projects
- Key Performance Indicators (KPIs)
- Integrated Research Priority List
- Contracts with Academic Partners

# Academic Partnerships: Institute for Research on Poverty

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## Technical Assistance Contract

- Quarterly Learning Exchanges
- Targeted Analyses using the Data Core
- Technical Assistance on Research Projects
  - Draws on Data Core
  - IRP Affiliates and Staff Experience

# Learning Exchanges

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- Discussion between DCF and IRP to learn about new research that either uses DCF data or has lessons for DCF programs
- IRP reports findings and engages in a dialogue with key department staff about their implications for policy and practice
- Leverages the lessons from IRP research to influence DCF policy, programs, and practice
- Past Topics:
  - Child Support Non-Custodial Parent Employment Demonstration
  - Father Child Relationships during Re-entry from Prison
  - Kids Aging Out
  - Intergenerational Poverty

# DCF/IRP Formal Projects

## Support DCF Program/Policy Decisions

- Education Outcomes for Children for Children in OHC
- Young Adult Outcomes associated with OHC
- Understanding Declines in Regulated Child Care Supply and Subsidy
- Child Support Demonstration Evaluation

## Of Interest to DCF: Utilizing DCF Data

- Wisconsin Poverty Project
- Children's Court Improvement Project
- School Meal Programs and Educational Outcomes
- Family Support Study
- Economic Well-being and Educational Outcomes

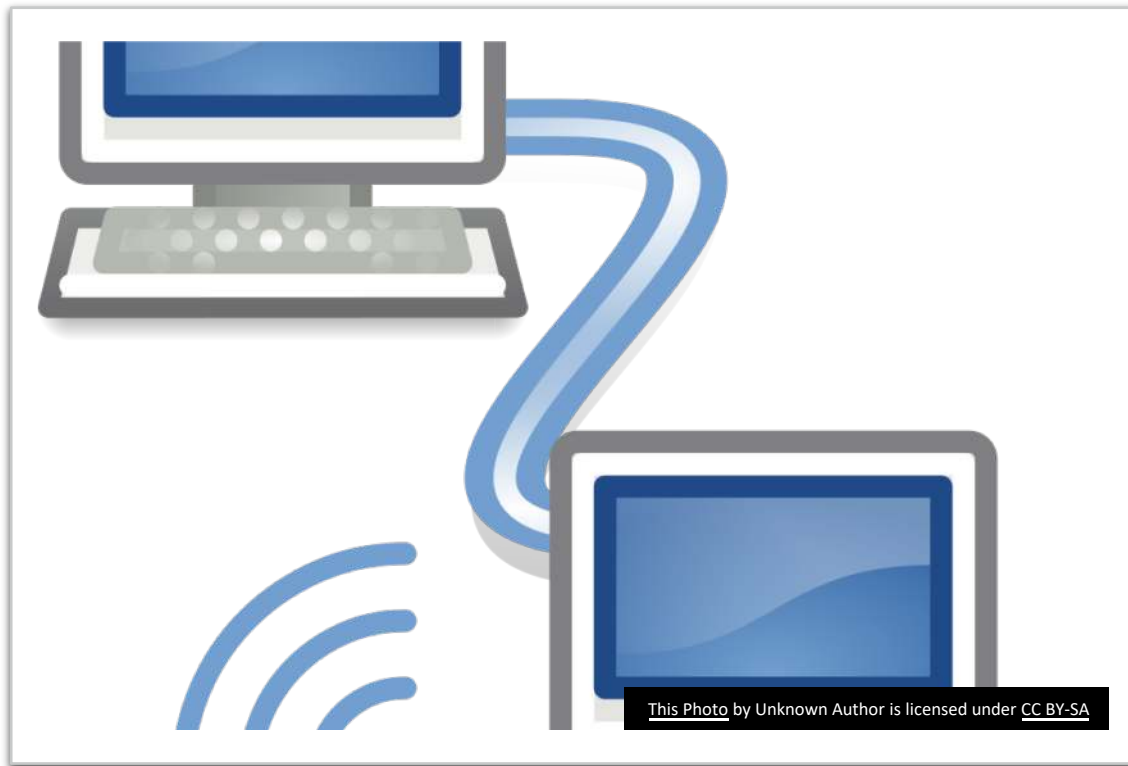
# The Data Core Meets Practice

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As a result of the Educational Outcomes for Children in OHC project, DCF and DPI are working together to:

- Share operational data with child welfare workers, increasing their ability to be educational advocates
- Engage school districts, encouraging them to share data with DCF to assist in case management and policy development
- Develop an overarching data sharing agreement, between the two agencies, streamlining future data exchanges



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Using Multiple Integrated Data  
Systems to Improve Practice

# Wisconsin Early Childhood Integrated Data System (WI ECIDS)

Initially developed to answer policy questions and make improvements to the early childhood programs which share data into the ECIDS

- Funded via Race to the Top Early Learning Challenge Grant
- Post-Grant period, use has been expanded outside of early childhood focused questions and policy

Three WI state agencies share data via the ECIDS:

- Department of Public Instruction (DPI)
- Department of Health Services (DHS)
- Department of Children and Families (DCF)

# WI ECIDS: What does it do?

## Does

## Does Not

✓	Provide a consistent framework for matching and sharing data.	✗	Pool agencies' data together in a centralized data warehouse.
✓	Require adherence to all federal and state privacy laws and regulations.	✗	Abridge agencies and programs ownership of their data or data managers' data security responsibilities.
✓	Enable analysts to use de-identified data to study characteristics and outcomes of groups of participants.	✗	Provide data on individuals needed for day-to-day operations or case management.
✓	Strictly control access to data through agency assigned roles and by requiring data use agreements.	✗	Enable interested individuals to view and use agencies data at will.



# WI ECIDS Available Data

## Department of Children and Families:

- Child Welfare
- Child Care Subsidy
- Wisconsin Works
- Child Support

## Department of Public Instruction:

- Student Demographic Data
- Attendance
- Enrollment
- Suspensions/Expulsions/Incident Type
- English Proficiency
- WSAS Assessments (3<sup>rd</sup> Grade Math & Reading)

## Department of Health Services:

- Birth Records
- Immunizations
- Lead Screening
- Birth to 3
- Maternal and Child Health



# The Data Core and ECIDS



Early Care and  
Education  
Partnership  
Projects



Five County  
Demonstration  
Project



Explore 2-Gen  
Opportunities

# IOWA STATE UNIVERSITY

Department of Human Development and Family Studies

## Iowa's Integrated Data System: A State-University Partnership to Inform Early Childhood Policy & Practice

Cassandra J. Dorius & Heather L. Rouse

November 9, 2019

APPAM Annual Meeting, Denver, CO

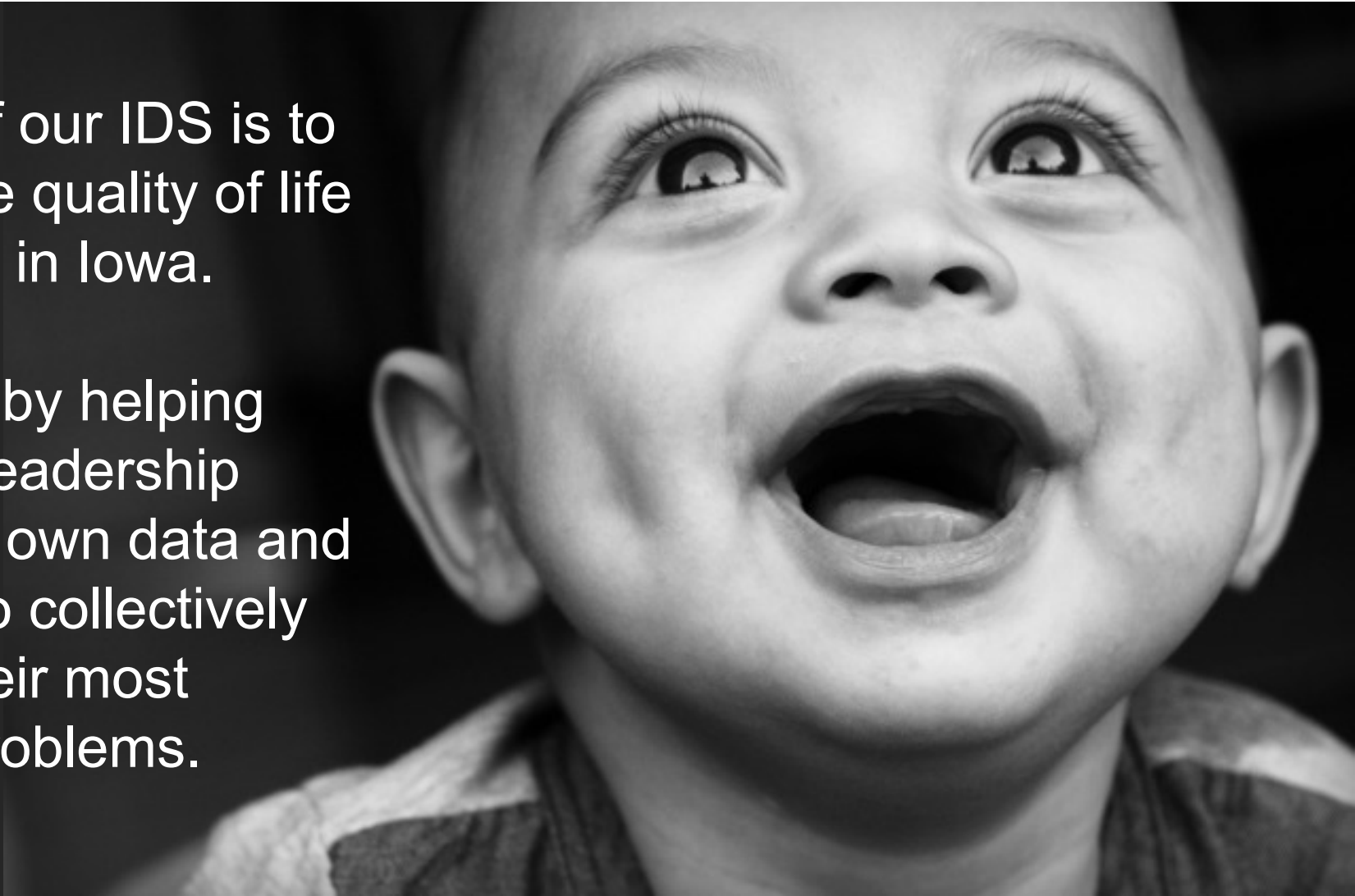
The first 1000 days  
make all the difference in a child's life



There is an increasingly complex context  
for early childhood programming and policy

The goal of our IDS is to improve the quality of life for children in Iowa.

We do this by helping executive leadership utilize their own data and expertise to collectively address their most pressing problems.



IOWA STATE UNIVERSITY



## IOWA'S VISION:

*Every child, beginning at birth, will be healthy & successful.*

“Empower the *creation of collaborations* to support children 0-5 through a primary focus on working together to improve efficiency & effectiveness”  
(Iowa Code 256i.2)

**An Integrated Data System Approach**





**ECl is a  
system of  
systems**



**Iowa Department of  
Management**



[www.earlychildhoodiowa.gov](http://www.earlychildhoodiowa.gov)



## IOWA'S VISION:

*Every child, beginning at birth, will be healthy & successful.*

### **Integrated Data System (IDS) Taskforce: A subcommittee of ECI Results Accountability Workgroup:**

Jeff Anderson (DOM)

Tammi Christ (DHS)

Kelly Davydov (DHR)

Cassandra Dorius (ISU)

Marion Kresse (BooST)

Ryan Page (DHS)

Tom Rendon (DOE)

Betsy Richey (DPH)

Heather Rouse (ISU)

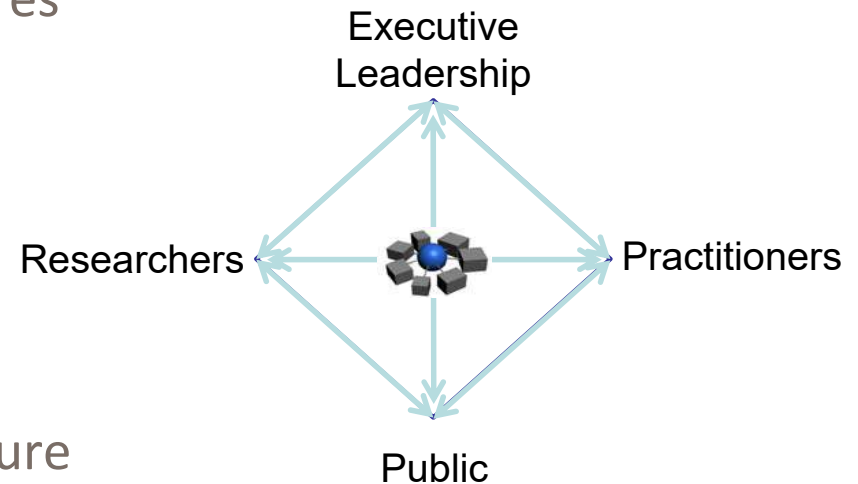
Amanda Winslow (DOE/DOM)



# Simultaneous Development Approach:

## 1. Develop IDS governance structure that ensures ETHICAL USE

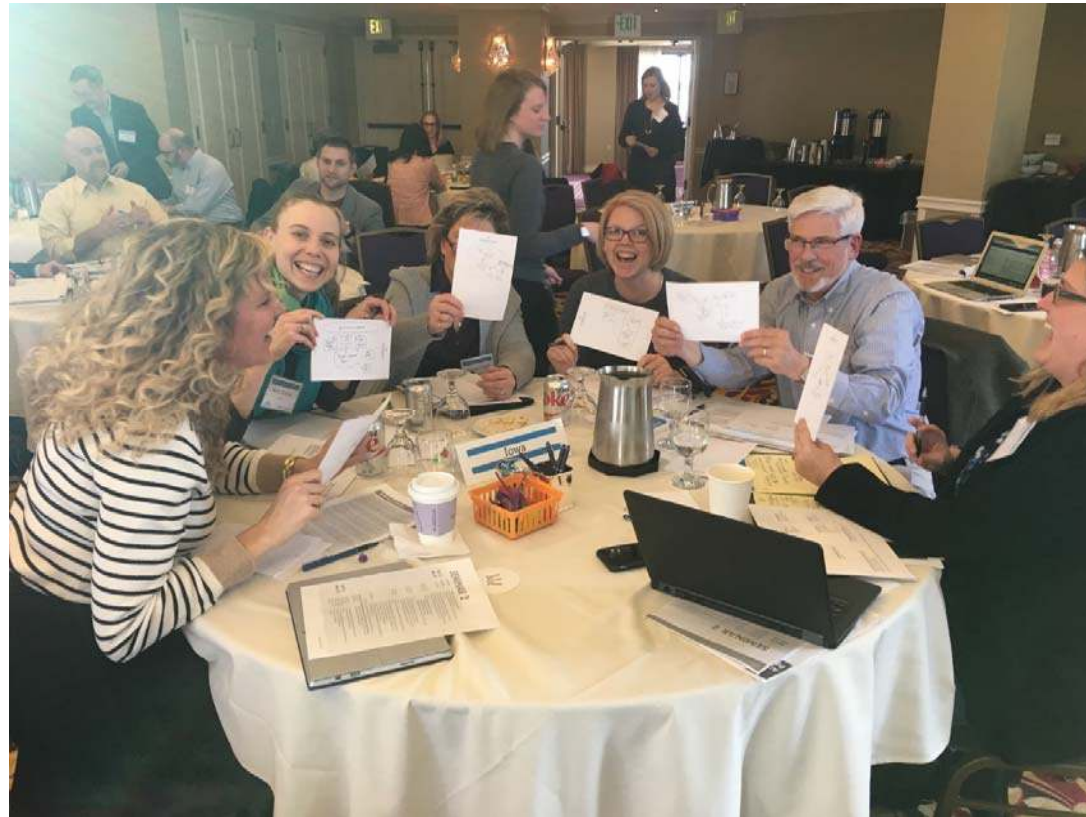
- State maintains control
- High standards for PRIVACY protection & rigorous science
- Strong communication and participation THROUGHOUT the inquiry process to ensure analytics are USED to meet our ECI mission



## 2. Initiate demonstration(s) of IDS Capacity

## IDS Taskforce subgroup at the AISP Seminar: 2018

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# State-University Partnership Model

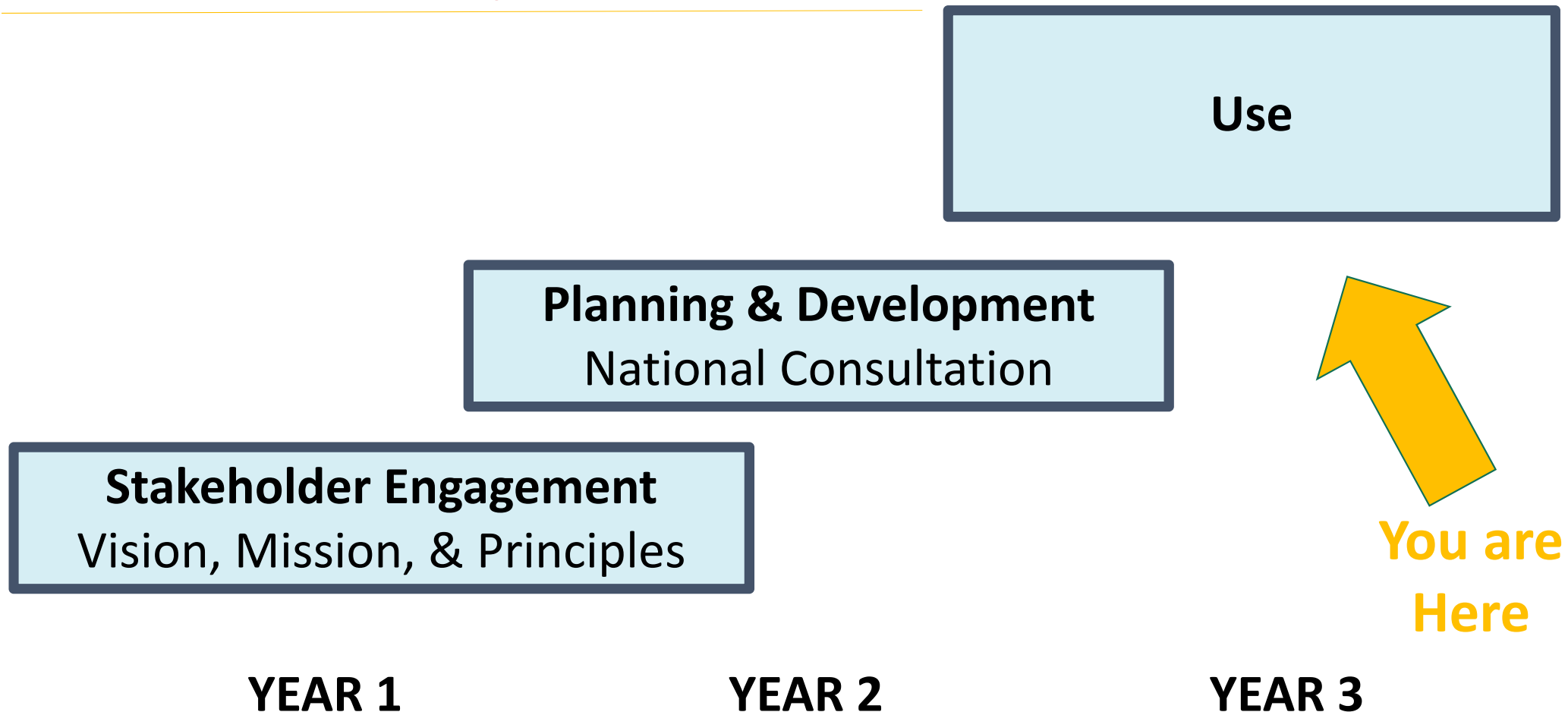
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- State maintains control of the “use” of data
- University staffs the infrastructure with a flexible capacity to expand or contract depending on IDS project demands
- Capitalizes on ISU’s land-grant mission and expertise in data management, analytics, security
- Neutral “3<sup>rd</sup> Party” approach for data integration that meets federal and state legal requirements
- Political & economic sustainability



# Iowa's IDS Development Timeline

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# Iowa's Preschool Development Grant (PDG)

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IDS “Demonstration”



# Meet the PDG Core Team



**Shanell Wagler**

Early Childhood  
Iowa  
Administrator



**Ryan Page**

Child Care  
Regulatory  
Program  
Manager



**Mary Breyfogle**

Early Childhood  
Consultant



**Rick Roghair**

Professional  
Development  
Manager



**Heather Rouse**

Assistant  
Professor,  
Human  
Development &  
Family Studies



**Kelly Davydov**

PDG  
Coordinator &  
2-Gen

**Amanda  
Winslow**

Early Childhood  
Iowa Systems  
Coordinator



**Tom Rendon**

Head Start State  
Collaboration  
Office  
Coordinator

**Cass Dorius**

Assistant  
Professor,  
Human  
Development &  
Family Studies





## ECI's Comprehensive Needs Assessment

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- Who are Children 0-5 in Iowa?
- Underserved and Vulnerable Populations
- Access to Care
- Quality of Early Care
- Workforce & Professional Development



## ECI's Comprehensive Needs Assessment

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1. Synthesize existing statewide assessments & strategic plans
2. Integrated Data System (IDS) approach
3. Child care survey- all licensed providers
4. Family survey
5. Family focus groups
6. Provider focus groups
7. Community listening sessions



# Iowa's Integrated Data System Approach

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## **Engage & Build:**

Identify data and priority questions, develop legal agreements, implement security procedures, and integrate relevant data



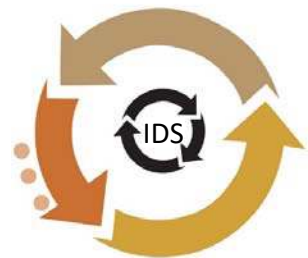
## **Needs Assessment:**

Analyze child and family characteristics, service participation, and kindergarten outcomes



## **Strategic Planning:**

Report findings to stakeholders, solicit their input, and use results to inform Strategic Plan



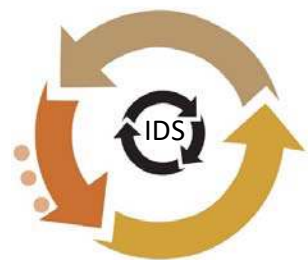
## Identify Priority Variables

### **IDPH Birth Records:**

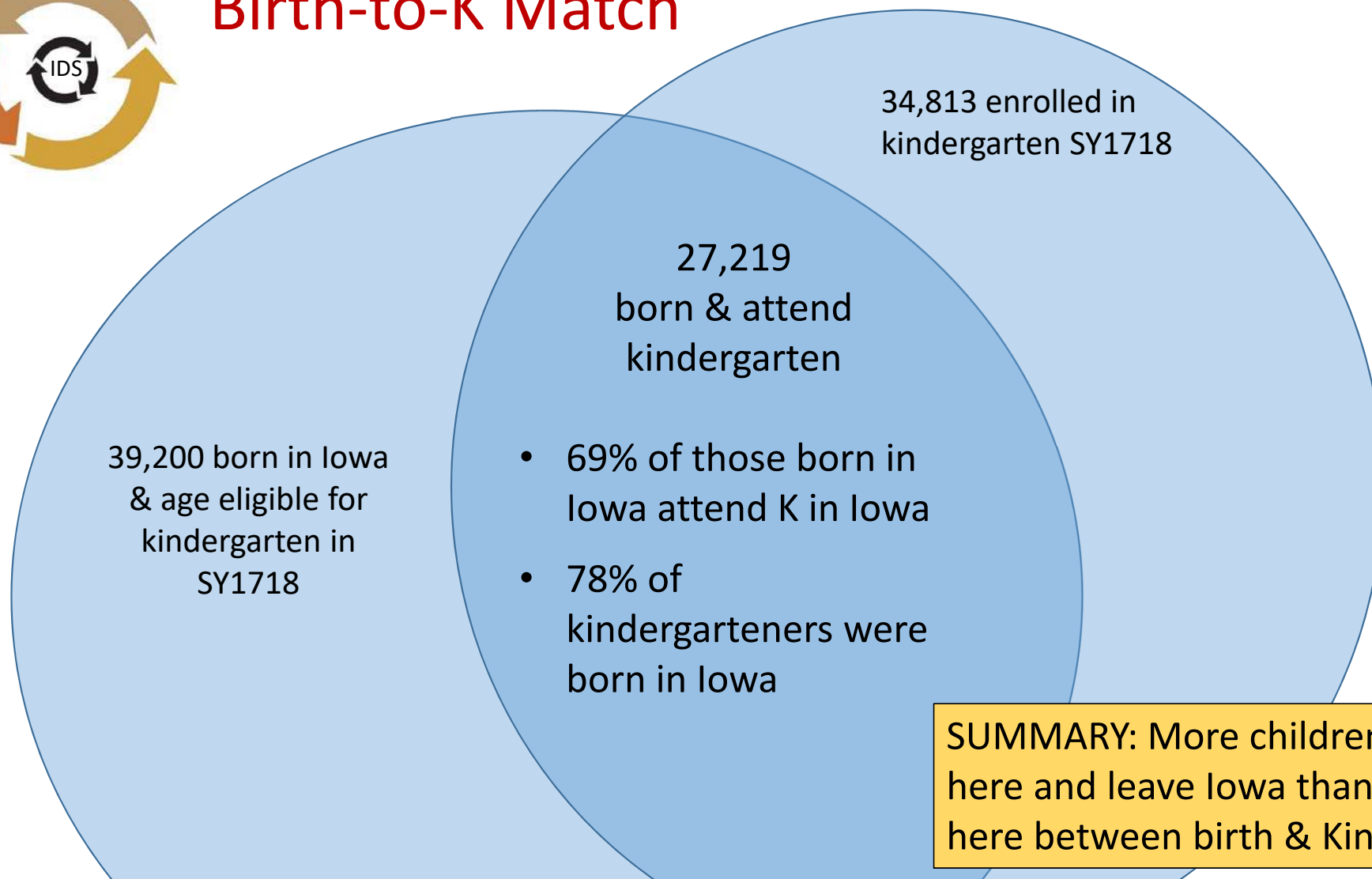
Child demographics (gender, race, birth order)  
Low birthweight  
Preterm birth  
Inadequate prenatal care  
Low maternal education (<12y)  
Birth to teen mother  
Birth to single mother  
Poverty

### **Department of Education:**

Child demographics (age, gender, race/eth)  
Free/reduced price lunch status  
ELL status  
Kindergarten enrollment (location & dates)  
Kindergarten attendance rate  
Kindergarten literacy assessment



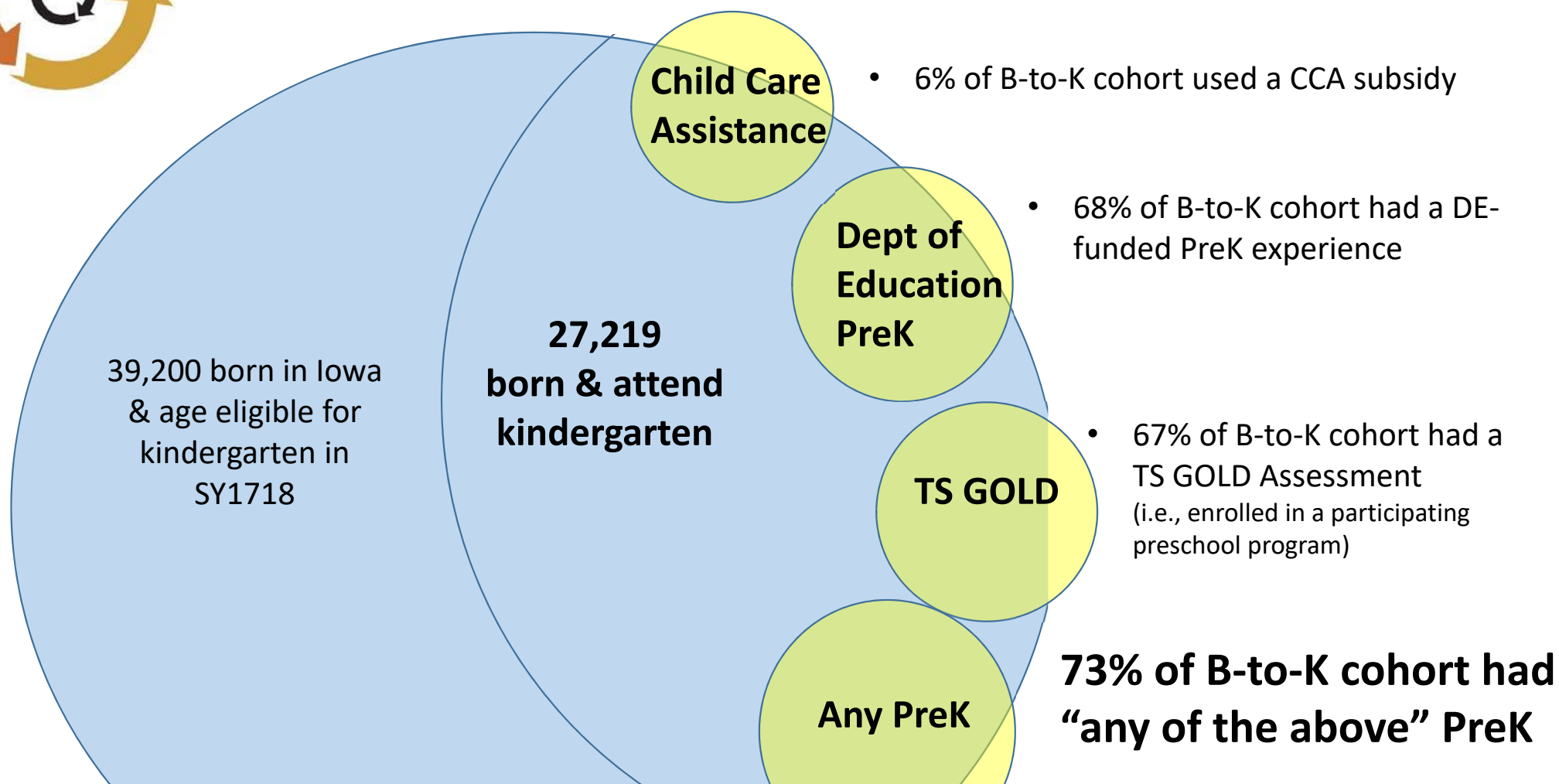
## Birth-to-K Match



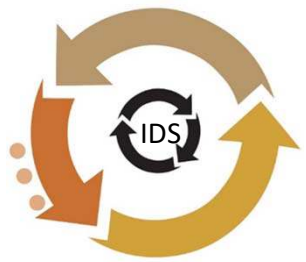
SUMMARY: More children are born here and leave Iowa than who move here between birth & Kindergarten



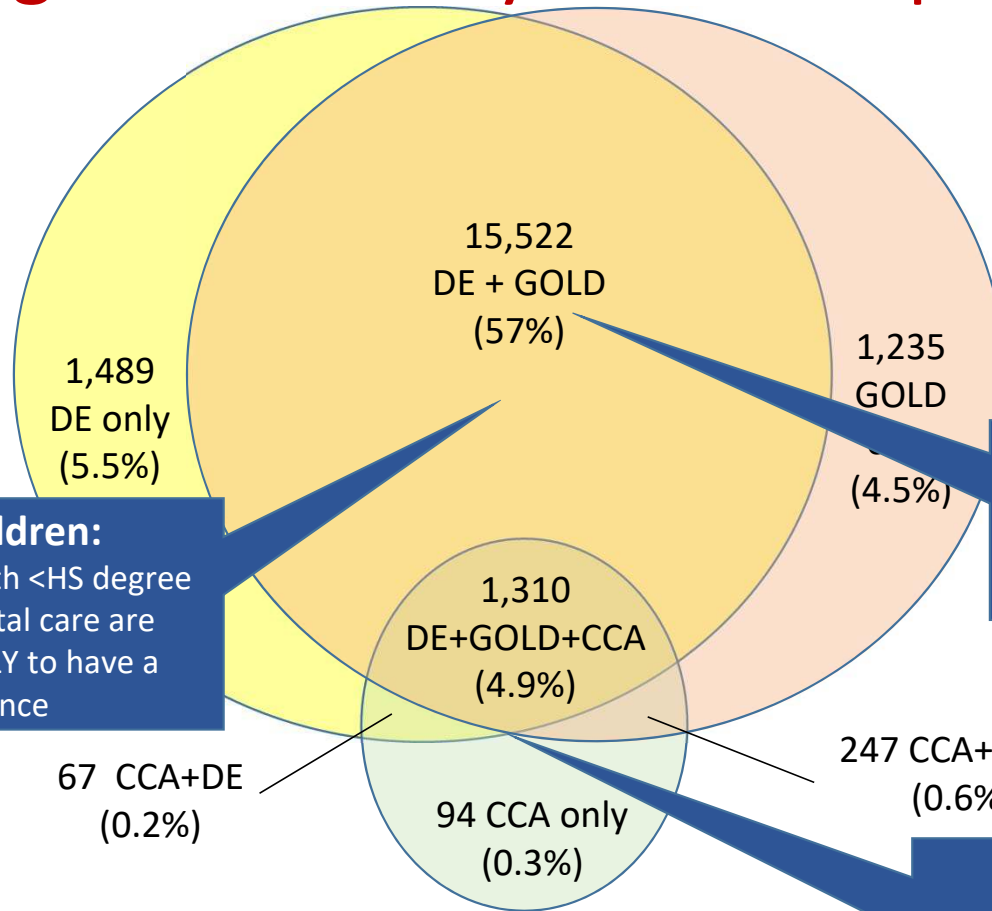
# Birth-to-K Match: Preschool Enrollment



# Integrated Data System: Sample Results



**DE PreK Data**  
(18,388; 68%)



**Preschool  
Assessment  
Data**  
(18,314; 67%)

**Unduplicated Counts:**  
73% of Children had AT LEAST 1 experience  
across systems  
(27% had NONE)

**Underserved Children:**  
Children born to mother with <HS degree  
& with inadequate prenatal care are  
SIGNIFICANTLY LESS LIKELY to have a  
preschool experience

**Child Care Assistance Data**  
(1,718; 6%)

**Vulnerable Children:**  
Children born to teen mothers are  
SIGNIFICANTLY MORE LIKELY to receive a child  
care subsidy and SIGNIFICANTLY LESS LIKELY  
have a DE-funded or Private PreK experience

# Identified Gaps in Data and Research

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Continued Analysis of Data Collected

Expand IDS Capacity

## DATASETS

- Head Start
- Home Visiting
- IDEA Parts B and C
- Health and Nutrition

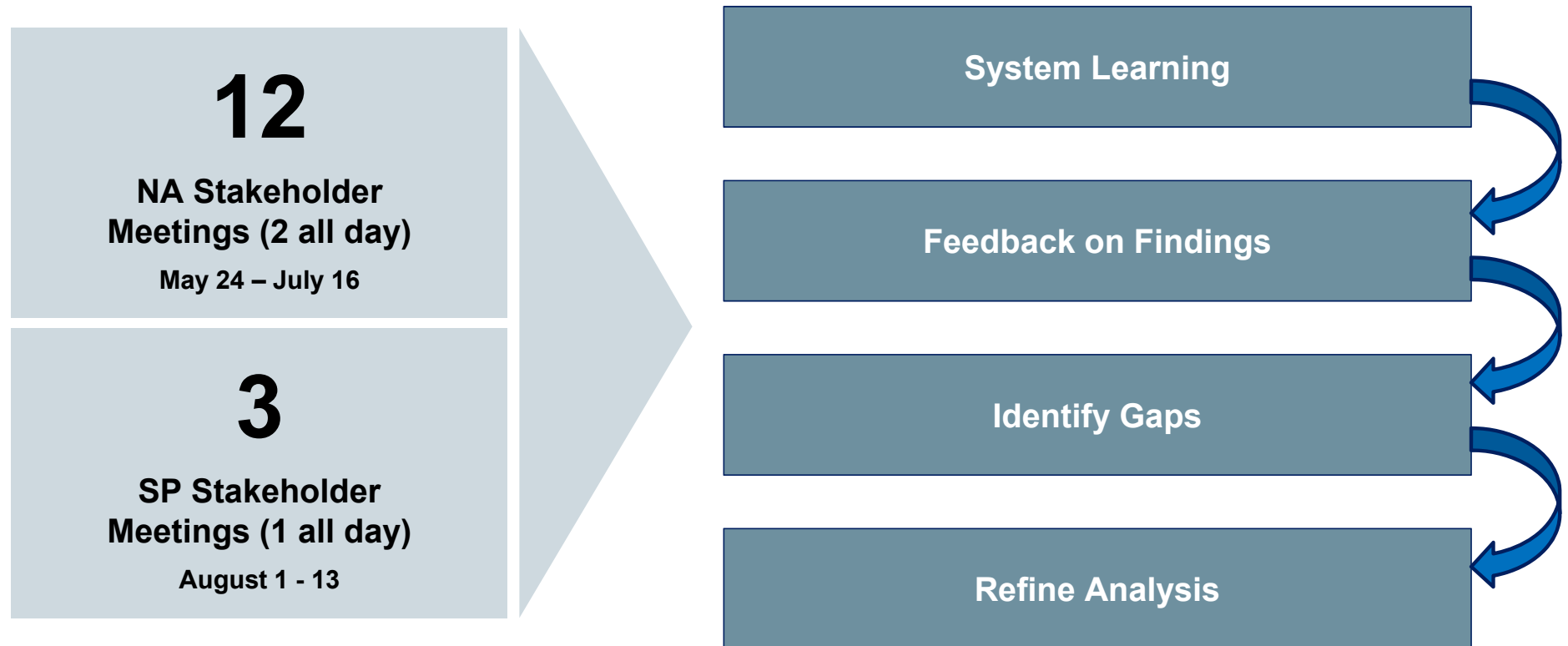
## INFRASTRUCTURE

- Technology
- Legal Agreements
- Communications
- Sustainability

Stakeholder Training & Communications in  
“Use” of Data

# Stakeholder Engagement to Process Results for 'USE'

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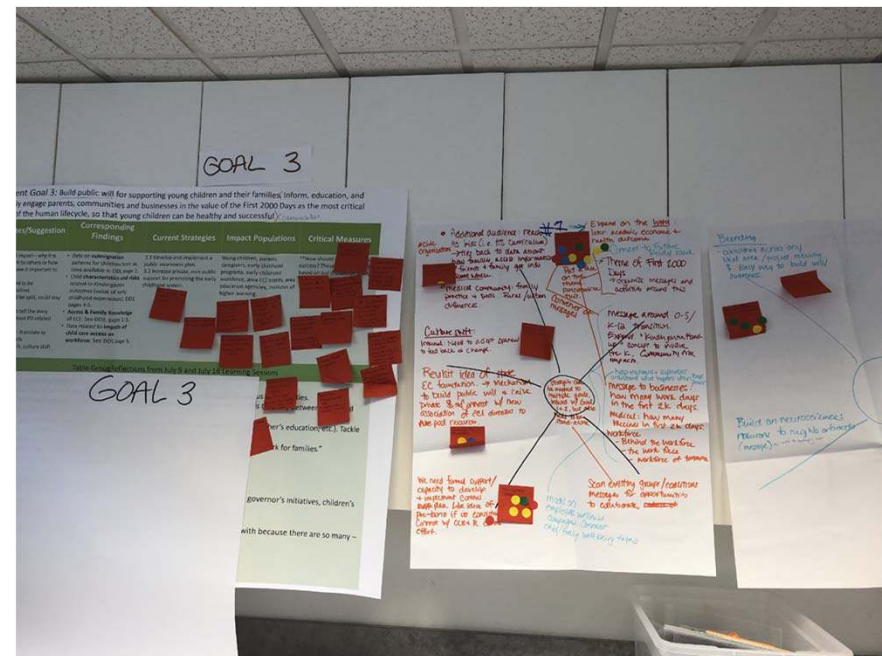
# Stakeholders: Brainstorming & Prioritizing

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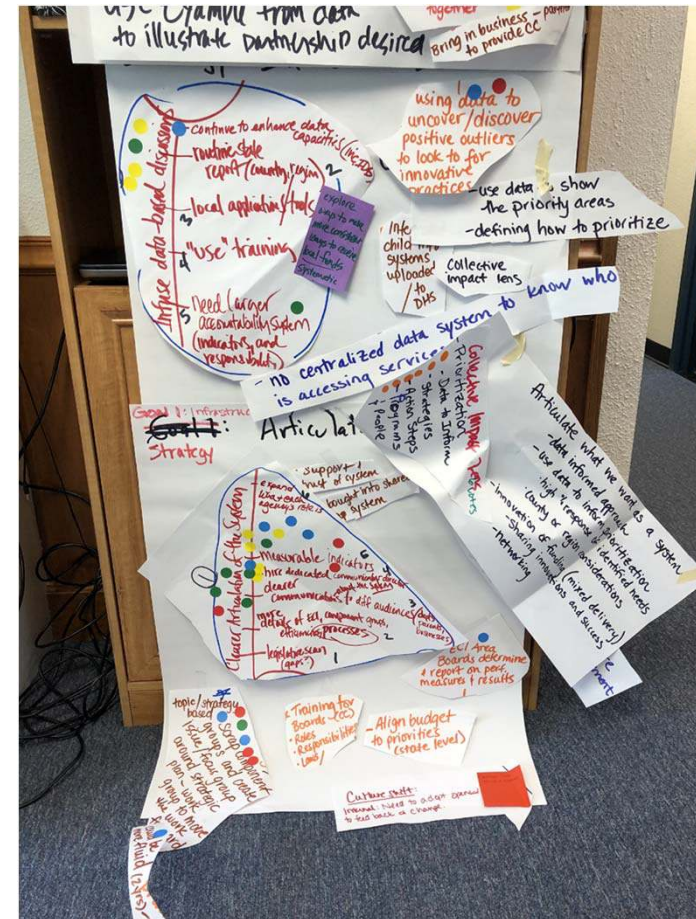




## Stakeholders: Brainstorming & Prioritizing



# PDG Core Team: Sorting & Assembling

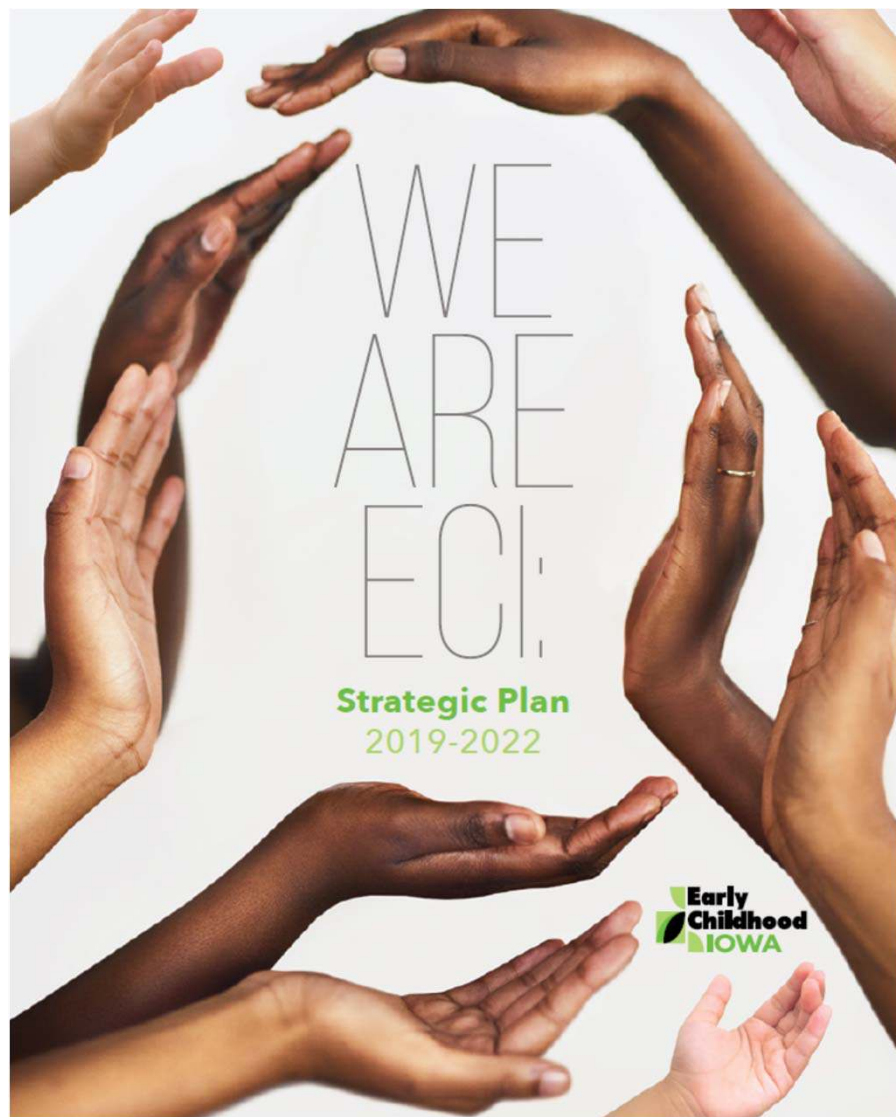


## Key Findings that Influenced our Strategic Plan

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- ☐ We need more, better, and diverse communications strategies infused across the system
- ☐ Learning Sessions process revealed needs for more training in data “use”
- ☐ Identified specific underserved populations that we need to prioritize for access and quality
- ☐ Focus on workforce needs to be a TOP priority if we are going to improve access and quality





## GUIDING PRINCIPLES

These are the central beliefs that guide our approach to analyzing our needs assessment data and defining the goals and strategies included in this plan.



### CHILDREN AND FAMILIES ARE OUR "NORTH STAR"

Family voices are central to determining our plan, identifying its priorities and strategies, and deciding how to carry out our work. Effective partnerships with families allow us to truly understand needs and how best to address them. Further, the voices of all families must be heard, not just those our system serves.



### BRAIN SCIENCE

The decisions we make about what services to provide, when, and for whom are grounded in the science of brain development. A child's brain develops rapidly in the first three years of life, and ninety percent of the brain's architecture is developed by the age of 5. Research shows that early childhood experiences and relationships shape the architecture of the brain, and high-quality care produces long-lasting, positive outcomes for children.\*



### DIVERSE PARTNERSHIPS

We cannot do this work alone. We will engage families and community members throughout the process, learning in partnership as we go. We recognize that our goals and proposed actions require the input, expertise, and collaboration of multiple partners within and across our comprehensive early childhood system. Partners enter the work together as equals committed to a shared purpose.



### EQUITY

We embrace the mantra of "not about us without us" as we work toward equity within the early childhood system. We



### DATA IS A VALUABLE RESOURCE

We maintain high standards for data ethics while acknowledging that decision-making is more relevant and effective when we have better access to information. We commit to using data in service of the public good - to support Iowa's children and families.



### ACCOUNTABILITY

We will set bold, clear priorities for action, and we will do what we say we will do. We hold ourselves accountable for measurable action on the goals of this plan. We commit to transparency and inclusion throughout all phases of our work.

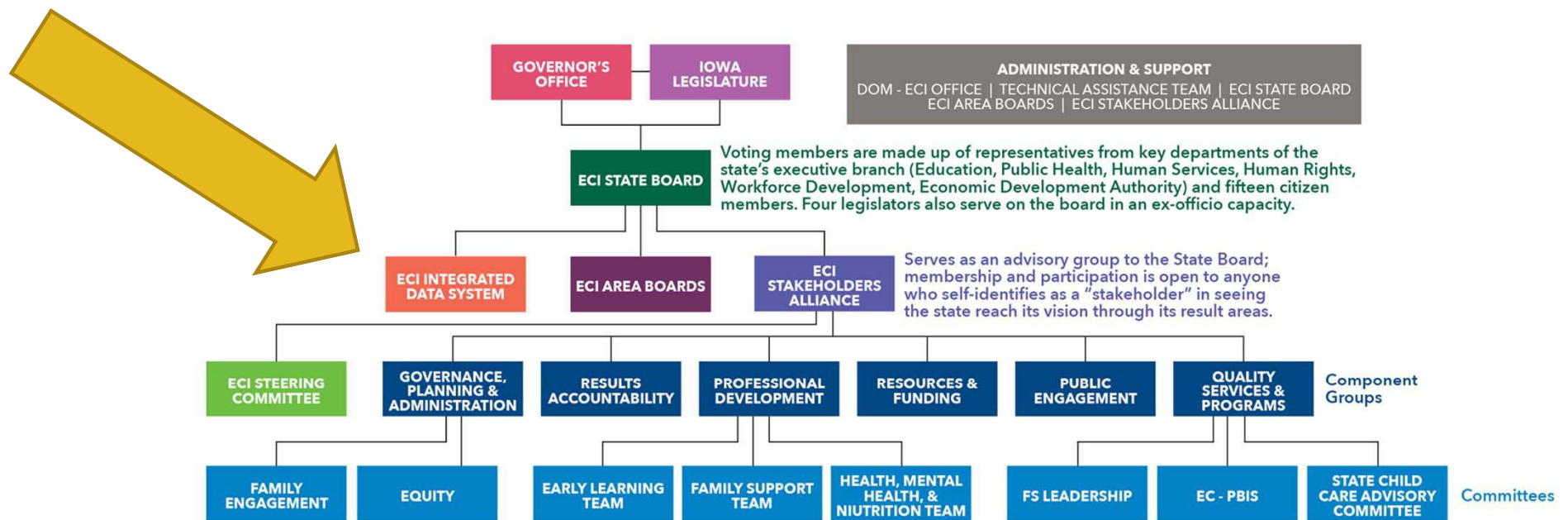
and families in our state vision includes "every child" which requires us to examine data for disparities by race, ethnicity, family income, geographic area, language, culture, different-abledness and other distinguishing characteristics in analyzing problems, identifying solutions and defining success.

\* For more information about the science of policy to practice, visit: [https://developingchild.harvard.edu/resources/three-early-childhood-development-principles-improve-child-family-outcomes/?utm\\_source=newsletter&utm\\_medium=email&utm\\_campaign=august\\_2019](https://developingchild.harvard.edu/resources/three-early-childhood-development-principles-improve-child-family-outcomes/?utm_source=newsletter&utm_medium=email&utm_campaign=august_2019)

For full report of the Strategic Plan: <https://earlychildhood.iowa.gov/document/we-are-eci-strategic-plan-2019-2022>

# A Living Plan

## HOW THE CURRENT SYSTEM IS STRUCTURED



# Moving ECI's IDS forward one step at a time

5

PDG grant renewal submitted November 2019 with IDS focus

4

Ongoing stakeholder feedback and enhancements to best serve young children and their families, including IDS motivated work

3

ECI Component Groups engaged in 'next step' planning, including IDS related projects

2

- Federal approval of Needs Assessment (no revisions!); awaiting Strategic Plan approval
- Unanimous State approval of Needs Assessment & Strategic Plan

1

*Memorandum of Agreement* signed by 7 Directors & Iowa State



## IOWA'S VISION:

*Every child, beginning at birth, will be healthy & successful.*

# Thank You

### ***ECI Preschool Development Grant (PDG) Core Team:***

Shanell Wagler (PDG PI) & Amanda Winslow (Iowa Department of Management; DOM); Kelly Davydov (Iowa Department of Human Rights; DHR); Tom Rendon & Mary Breyfogle (Iowa Department of Education; DE); Ryan Page (Iowa Department of Human Services; DHS); Rick Roghair (Iowa Association for the Education of Young Children; IAAEYC); Cassandra Dorius & Heather Rouse (Iowa State University; ISU).

### ***PDG Needs Assessment, IDS, and Data Analysis Partners - Iowa State University:***

*Department of Human Development and Family Studies.* Heather Rouse, Cassandra Dorius, Christine Lippard, Carla Peterson, Ji Young Choi (faculty leads); Rachael Voas (program manager); Quentin Riser, Maya Bartel, Seulki Ku, Jessica Bruning (graduate and post-doctoral research assistants); Allison Gress, Emma Kelley, Kaitlyn Facile, Lexi Flake (undergraduate research assistants).

This work was made possible by the Preschool Development Grant Birth to Five (Grant Number 90TP0030-01-00) from the Office of Child Care, Administration for Children and Families, U.S. Department of Health and Human Services as part of a grant totaling \$2,190,119 with 0% financed with non-governmental sources. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Office of Child Care, the Administration for Children and Families, or the U.S. Department of Health and Human Services.

## Questions or comments about Iowa's Early Childhood Integrated Data System?

Please email us:

Cass Dorius

[cdorius@iastate.edu](mailto:cdorius@iastate.edu)

Heather Rouse

[hlrouse@iastate.edu](mailto:hlrouse@iastate.edu)









Iowa Department of Public Health  
Protecting and Improving the Health of Iowans

# From Data to Action: Leveraging State-University Partnerships to Drive Translational Research

Betsy Richey, Cassandra Dorius, Shawn Dorius & Heather Rouse

November 9, 2019

APPAM Annual Meeting, Denver, CO

# Time Lags in Translating Health Research Into Practice

It can take years, or even decades, for health research to inform policy and practice.

One of the goals of our agency-academy partnership is to test new approaches for translating health research into practice on a much shorter timeline.



The answer is 17 years, what is the question: understanding time lags in translational research

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## DECLARATIONS

### Competing interests

None declared

### Funding

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### Ethical approval

Not applicable

### Guarantor

JG

### Contributorship

ZSM designed, conducted and analysed the literature review, and drafted and revised the paper; JG initiated the project, drafted and revised the paper, and has led a number of studies cited that attempted to measure lags; SW revised the paper

## Summary

This study aimed to review the literature describing and quantifying time lags in the health research translation process. Papers were included in the review if they quantified time lags in the development of health interventions. The study identified 23 papers. Few were comparable as different studies use different measures, of different things, at different time points. We concluded that the current state of knowledge of time lags is of limited use to those responsible for R&D and knowledge transfer who face difficulties in knowing what they should or can do to reduce time lags. This effectively 'blindfolds' investment decisions and risks wasting effort. The study concludes that understanding lags first requires agreeing models, definitions and measures, which can be applied in practice. A second task would be to develop a process by which to gather these data.

## Introduction

Timely realization of the benefits of expensive medical research is an international concern attracting considerable policy effort around 'translation'.<sup>1,2</sup> Policy interventions to improve translation respond to a vast empirical literature on the difficulties of getting research across research phases and into practice.<sup>3-11</sup>

Both literature and policy tend to assume that speedy translation of research into practice is a good thing. Delays are seen as a waste of scarce resources and a sacrifice of potential patient benefit.<sup>12</sup> Although some lag will be necessary to ensure the safety and efficacy of new interventions or advances, in essence we should aim to optimize lags. One recent study (of which JG and SW were co-authors) estimating the economic benefit of cardiovascular disease (CVD) research in the UK between 1975 and 2005, found an internal rate of return (IRR) of CVD research of 39%.<sup>13</sup> In other words, a £1.00 investment in public/charitable CVD research produced a stream of benefits

equivalent to earning £0.39 per year in perpetuity. Of this, 9% was attributable to the benefit from health improvements, which is the focus of this paper. (The remaining 30% arise from 'spillovers' benefiting the wider economy.) This level of benefit was calculated using an estimated lag of 17 years. Varying the lag time from 10 to 25 years produced rates of return of 13% and 6%, respectively, illustrating that shortening the lag between bench and bedside improves the overall benefit of cardiovascular research. What is notable is that all the above calculations depended upon an estimated time lag; estimated because, despite longstanding concerns about them,<sup>14</sup> time lags in health research are little understood.

It is frequently stated that it takes an average of 17 years for research evidence to reach clinical practice.<sup>1,5,15</sup> Balas and Bohen,<sup>16</sup> Grant<sup>17</sup> and Wratschko<sup>18</sup> all estimated a time lag of 17 years measuring different points of the process. Such convergence around an 'average' time lag of 17 years hides complexities that are relevant to



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## SUBSTANCE USE AMONG IOWA FAMILIES: AN INTERGENERATIONAL MIXED METHOD APPROACH FOR INFORMING POLICY AND PRACTICE

- Use a two-generational lens to understand the family context
- Include both rural and urban populations
- Test IDS governance and procedures with at least two IDPH data sets
- Conduct face-to-face, in depth interviews with adults who have a history of substance use



## STUDY PURPOSE

Use social research to identify opportunities for substance use health interventions



Improve understanding of the dynamics of rural substance use



Strengthen IDPH surveillance of substance use with IDS & ethnographic assessments



Understand multi-generational impacts of substance use and family risk to help IDPH develop strategies to identify and support families harmed substance use

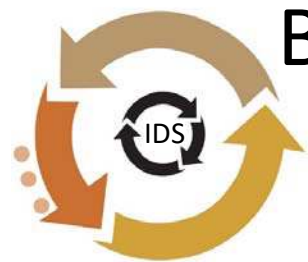
## ETHNOGRAPHIC APPROACH

- Interviewed 41 adults and 3 couples
- Semi-structured, recorded interviews (60-90 mins)
- Interview protocol focused on the social context of substance use
  - Family
  - Community
  - Church
  - Occupation

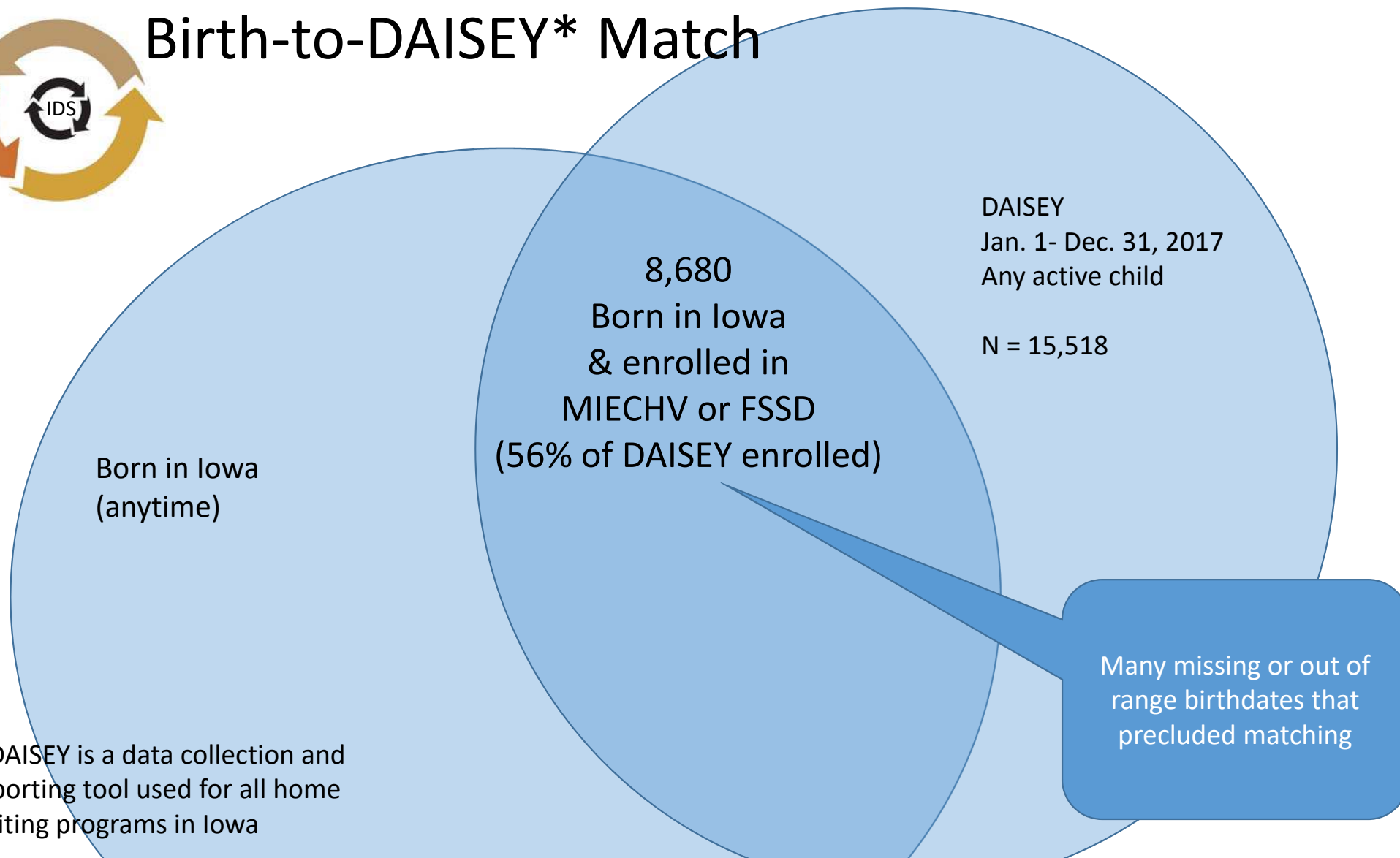


## THEMES: DRIVERS OF SUBSTANCE USE

- Social isolation & stigma
- Economic vulnerability
- Trauma & coping
- A choice versus disease accountability narrative



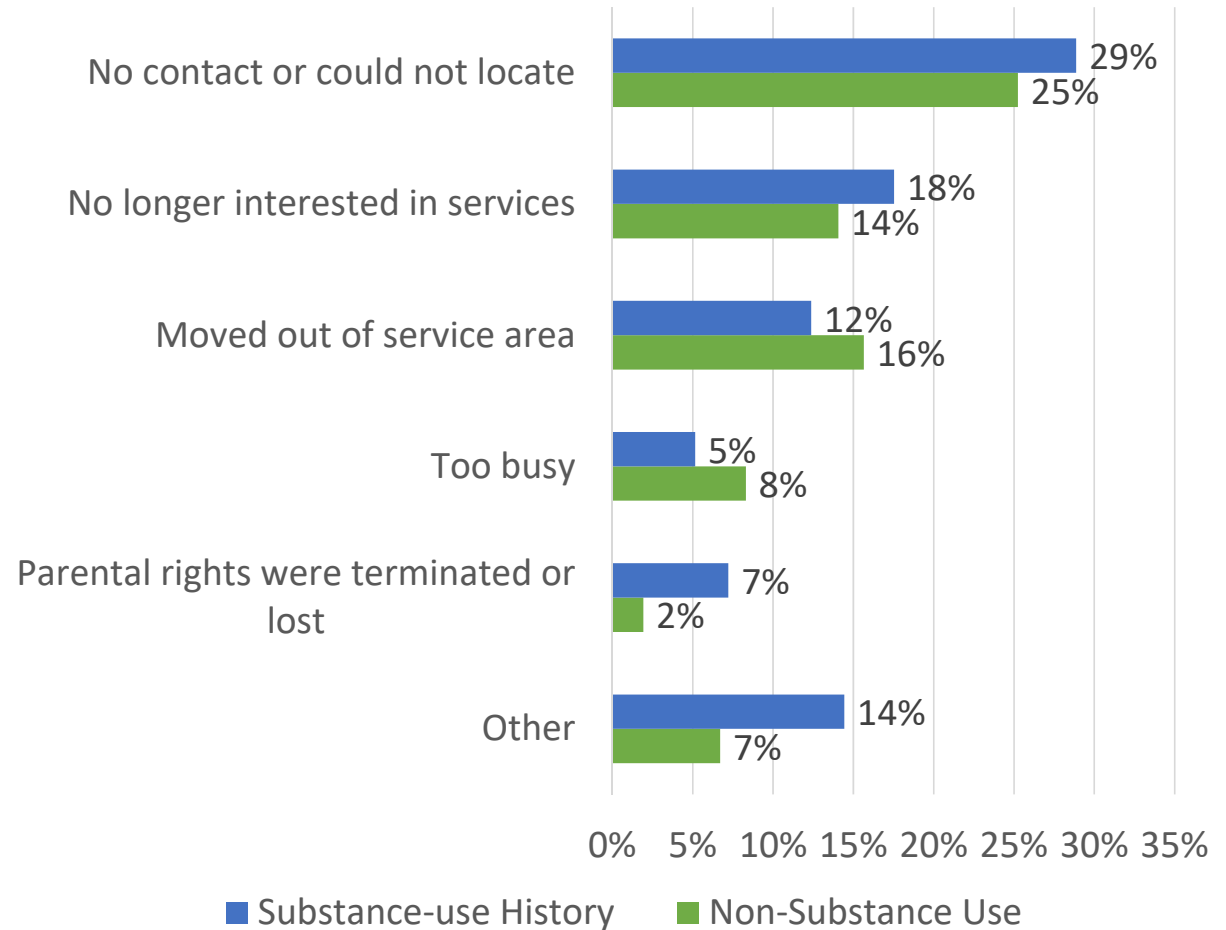
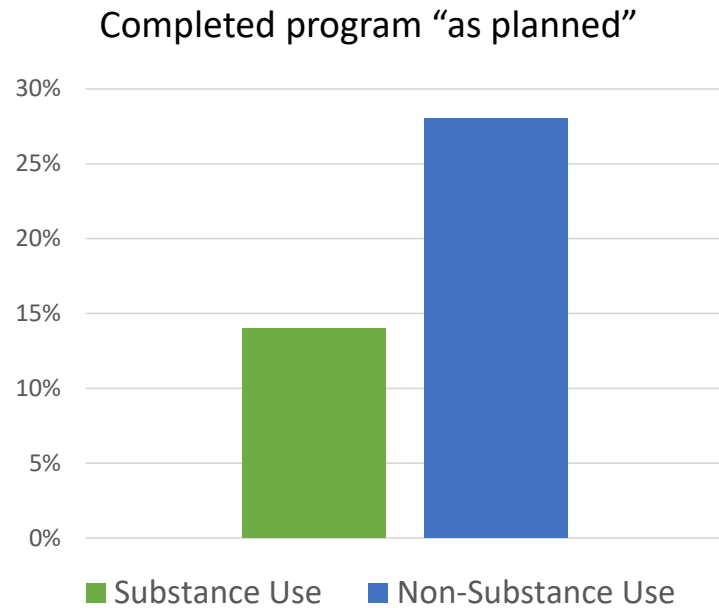
# Birth-to-DAISEY\* Match



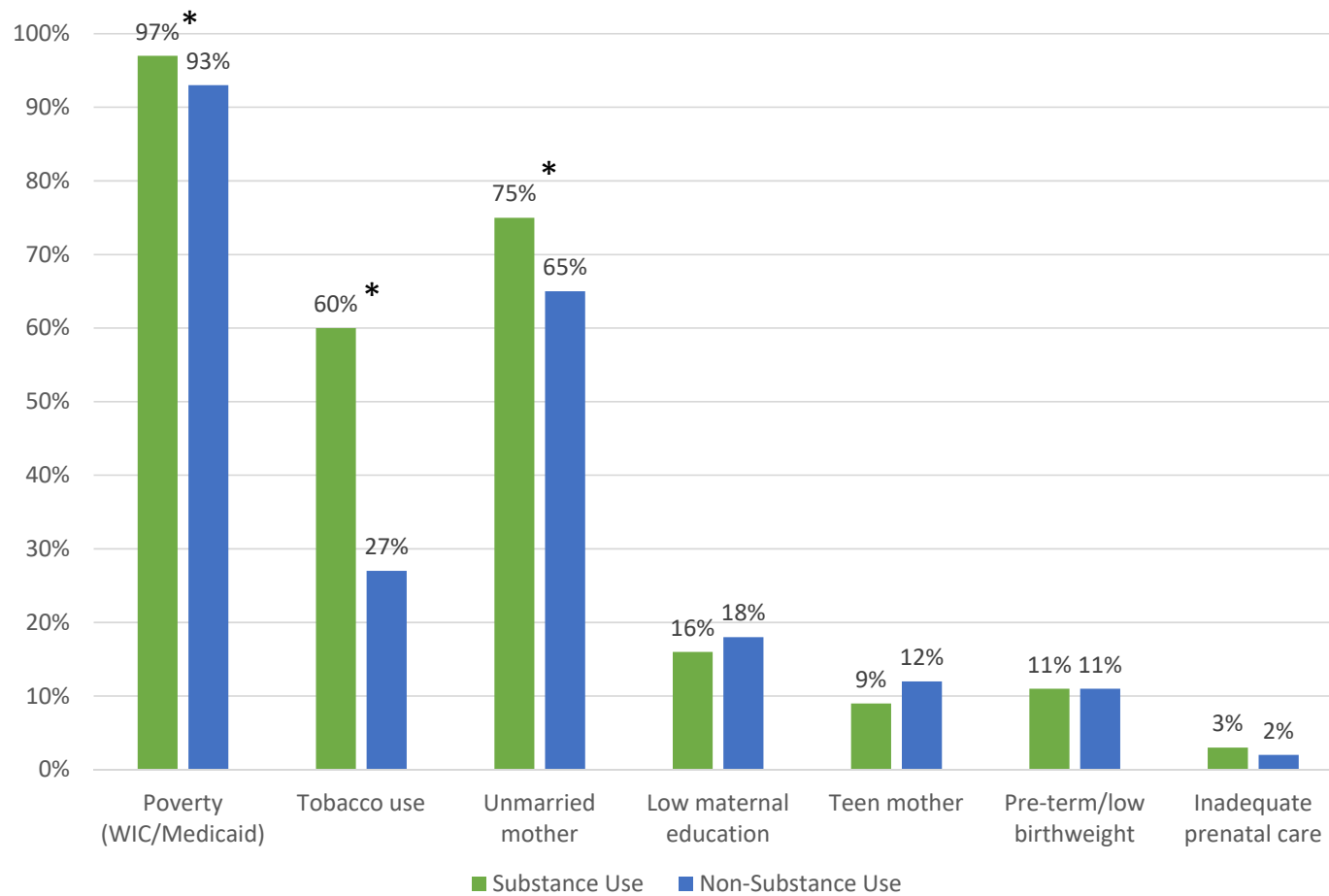
\* DAISEY is a data collection and reporting tool used for all home visiting programs in Iowa



# Completion of Home Visiting Program, by Type

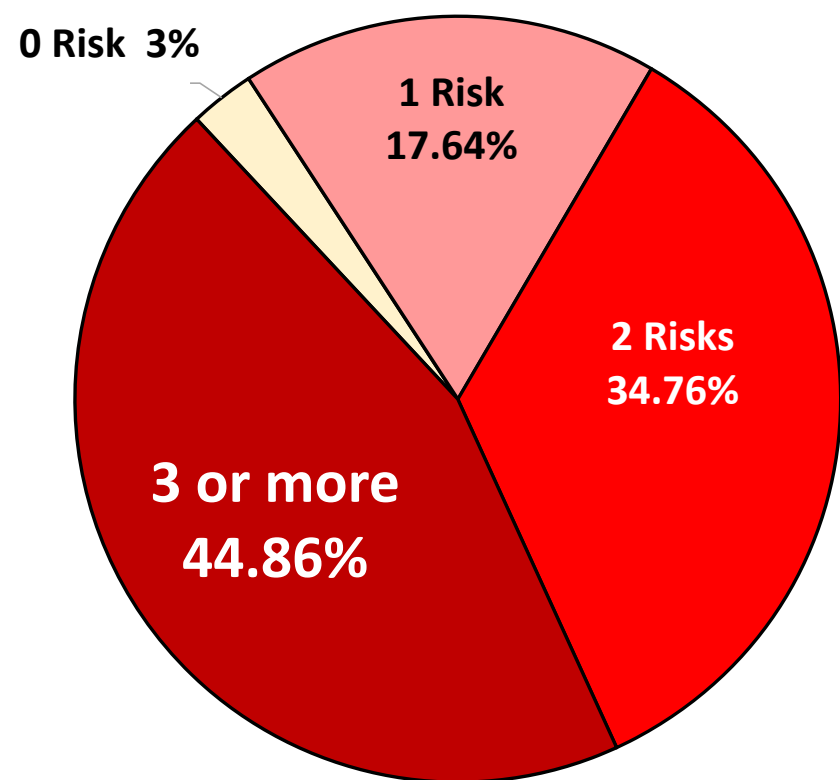


# Birth Characteristics by Substance Use History

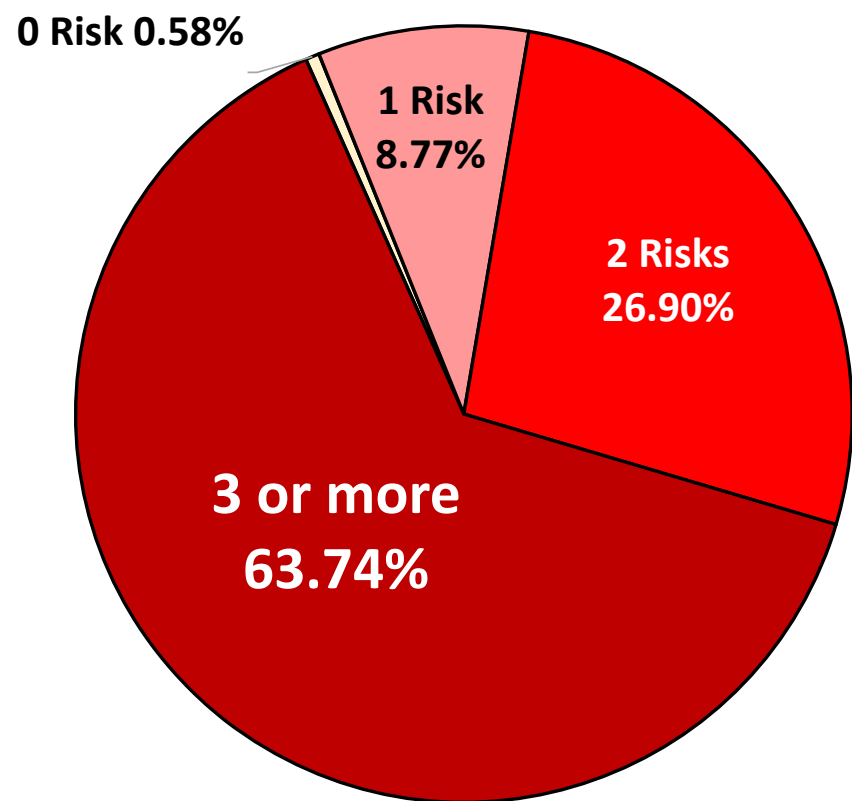


# Cumulative Birth Risks by Substance Use History

**Non-Substance Use**



**Substance-use history**



## TRANSLATING RESULTS TO ACTION

- **Workshop #1: Data Discovery**

- *Purpose:* Identify potential data for an IDS capable of monitoring substance use and its impacts on individuals and families & develop criteria for screening data for future use

- **Workshop #2: Design Thinking**

- *Purpose:* Develop, evaluate, and communicate strategies for developing solutions for individuals and families with substantiated cases of substance use.

## Workshop #1: Data Discovery

*How can the Iowa Department of Public Health better monitor drug use and its impacts on individuals and families throughout our state?*

### DATA DISCOVERY WORKSHOP AGENDA

Location: Urbandale Public Library, 3520 86<sup>th</sup> Street  
Date: October 29, 2019  
Time: 1 pm – 4 pm  
Convener: Betsy Richey, IDPH

#### Agenda Items

1:00 pm – 1:15 pm	Introduction to the day and one another	Betsy Richey & Cass Dorius
1:15 pm – 1:45 pm	How can integrated data systems be used to help monitor drug use among individuals and families in Iowa?	Heather Rouse
1:45 pm – 2:10 pm	What do Iowa parents say about their own drug use and its impacts on themselves and their families?	Shawn Dorius
2:10 pm – 2:20 pm	What data is available to help IDPH learn more about drug use and its impacts?	Kelsey Van Selous
2:20 pm – 2:30 pm	Break	
2:30 pm – 3:50	Data Driven Discovery Workshop. Materials provided by Dr. Sallie Keller and The Social Decision Analytics Division, Biocomplexity Institute, University of Virginia	Cass Dorius
3:50 pm – 4:00 pm	Wrap up and talk about next steps	Betsy Richey & Cass Dorius

#### Additional information

The goal of this workshop is to identify ways IDPH can better monitor drug use and its impacts on individuals and families throughout our state. Workshop results will be provided to IDPH as a report. If you have any questions, please email [cdorius@iastate.edu](mailto:cdorius@iastate.edu) or [betsy.richey@idph.iowa.gov](mailto:betsy.richey@idph.iowa.gov).



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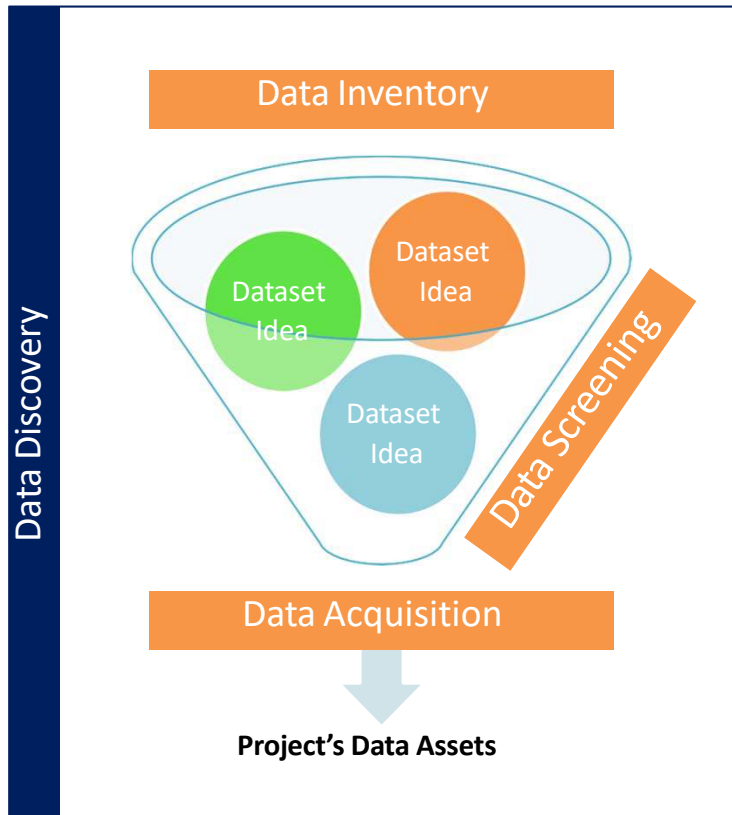
Workshop Activities Supported by 2018 IDPH-CDC Subaward: Dorius, C., Rouse, H.L., & Dorius, S.F. Substance Use among Iowa Families: An Intergenerational Mixed Method Approach for Informing Policy and Practice. Iowa Department of Public Health, subaward from the Centers for Disease Control. 10/15/2018-11/30/2019. (Total Award \$2,390,000; Subaward \$215,000).

## Who attended?

- Epidemiologists
- Program managers & data staff
  - Substance abuse
  - Gambling
  - Violence prevention
  - Suicide prevention
  - Maternal and child health
- Academic researchers & students



# Data Discovery: Process and definitions



Adopted from materials provided by Dr. Sallie Keller, The Social Decision Analytics Division, Biocomplexity Institute, University of Virginia

- **Data Discovery** is the open-ended and *continuous process* by which potential datasets are identified.
- **Data Inventory** refers to the broadest, most far-reaching 'wish list' of information pertaining to your 'big' question.
- **Data Screening** is an evaluative process by which eligible datasets are sifted from the larger pool of candidate datasets.

How would you use a substance use monitoring system to support programming or policy efforts?

Create  
performance  
measures

Create accurate and  
data-informed  
framing of issues

Make it accessible  
to others to  
address related  
issues

Develop  
community  
partnerships



What other information domains should we consider to help us monitor 'hot spots' of substance use and its effects?



Substance Use  
& Mortality

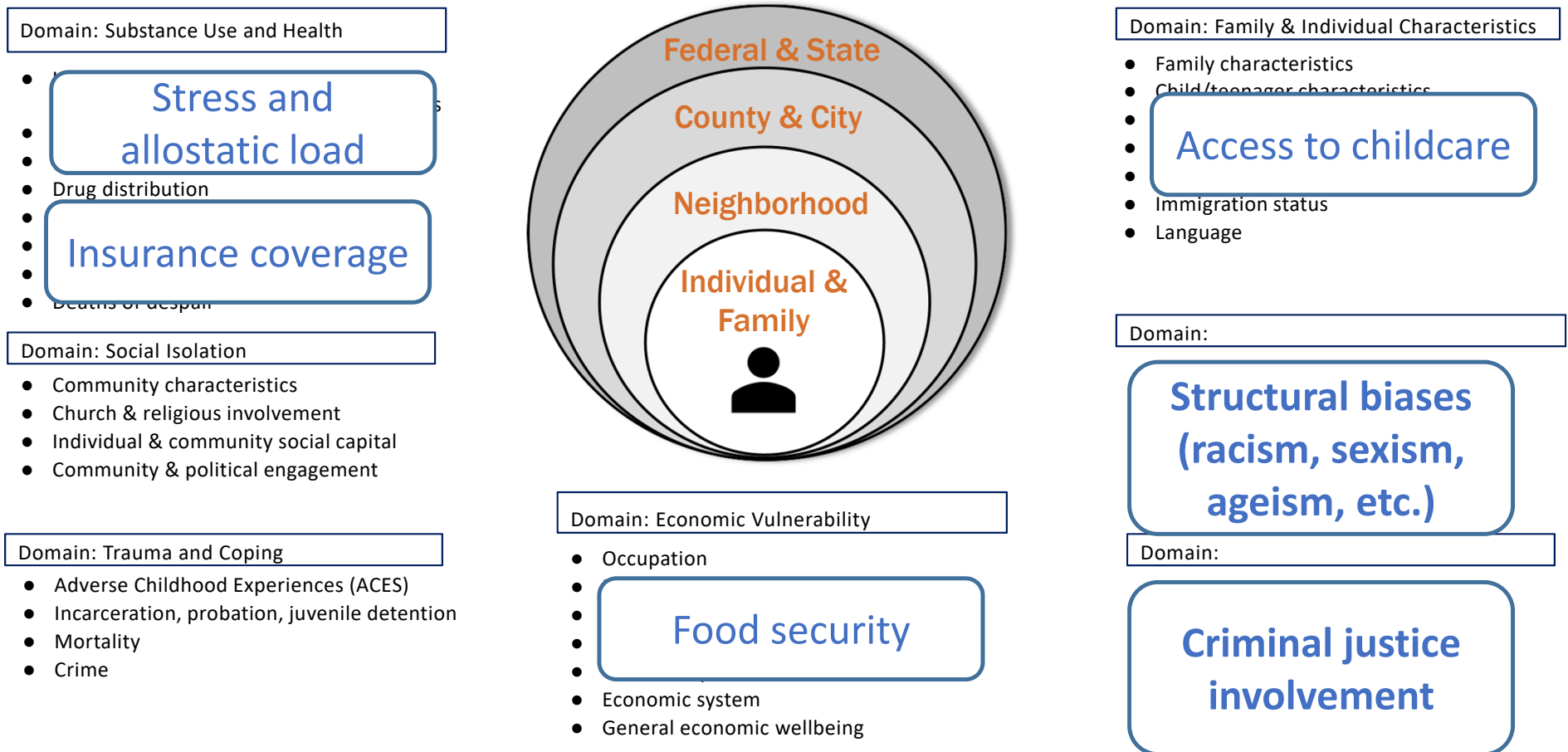
Economic  
Vulnerability

Mental and  
Physical  
Health

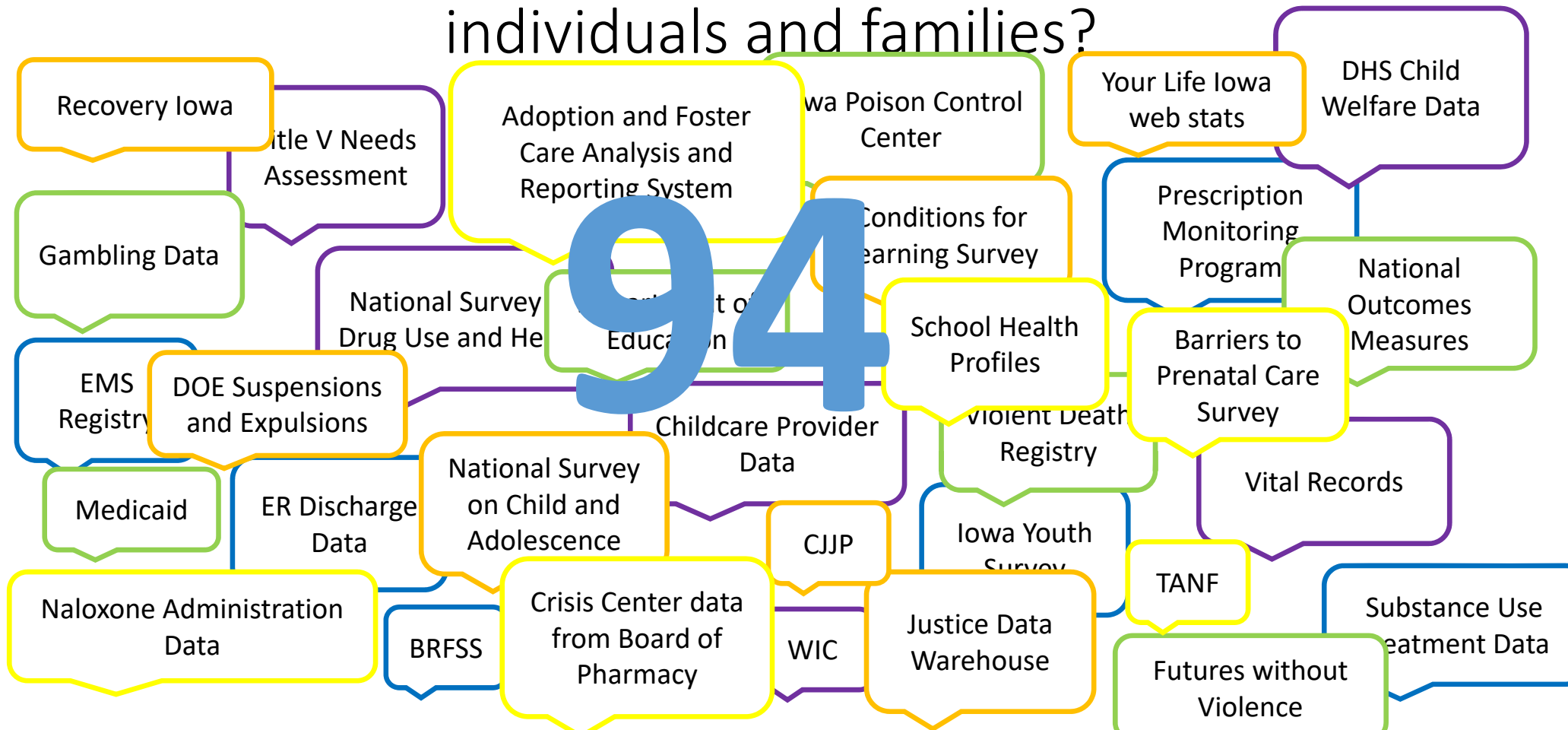
Social  
Isolation

# Data Inventory: Consider all relevant domains

*What informational domains at play? What are your levels of analysis?*



What data sets do you know of that would help us monitor substance use and its effects on individuals and families?



What information about the data will help you determine their fit?

How fine grained a geography is needed?

How difficult are the data to access?  
Are legal agreements required? Is there a fee for use?

How frequently are the data collected?

What is the data quality?  
Are there gaps or other concerns?

# Outcomes

- Analysis of utility and feasibility of available data
- Considerations for program staff on data quality
- New analysis ideas for epidemiologists
- New questions for research



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## Workshop #2: Design Thinking

*How might we develop policies and programs to better support individuals and families with substantiated cases of substance use?*

### DESIGN THINKING WORKSHOP AGENDA

Location: Grant Room, Jessie Parker Building  
Date: November 14, 2019  
Time: 8 am – 12 pm  
Convener: Betsy Richey, IDPH

#### Agenda Items

8:00 am – 8:10 am	Introduction to the day	Betsy Richey
8:10 am – 9:00 am	Overview of findings from mixed-method study	Cass Dorius Kelsey Van Selous Darien Bahe Shawn Dorius Elizabeth Talbert
9:00 am – 10:00 am	Design Thinking Workshop, Part 1	Tejas Dhadphale
10:00 am – 10:15 am	Break	
10:15 am – 11:45 am	Design Thinking Workshop, Part 2	Tejas Dhadphale
11:45 am – 12:00 pm	Wrap up and next steps	Cass Dorius

#### Additional information

The goal of this workshop is to translate project findings into actionable strategies to improve effectiveness of programs, increase the state's return on investment, and support the individuals and families whose complex needs are served by many areas of state government. Workshop results will be provided to IDPH as a report. If you have any questions, please email [cdorius@iastate.edu](mailto:cdorius@iastate.edu) or [betsy.richey@idph.iowa.gov](mailto:betsy.richey@idph.iowa.gov).



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Workshop Activities Supported by 2018 IDPH-CDC Subaward: Dorius, C., Rouse, H.L., & Dorius, S.F. Substance Use among Iowa Families: An Inaugural Mixed Method Approach for Informing Policy and Practice. Iowa Department of Public Health, subaward from the Centers for Disease Control. 10/15/2018-11/30/2019. (Total Award \$2,500,000; Subaward \$215,000).

## Who will attend?

- Agency executive leadership
  - Public Health
  - Education
  - Human Rights
  - Human Services
- Program leaders
- Legislative liaison
- Academic researchers & students



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# Design Thinking: Process

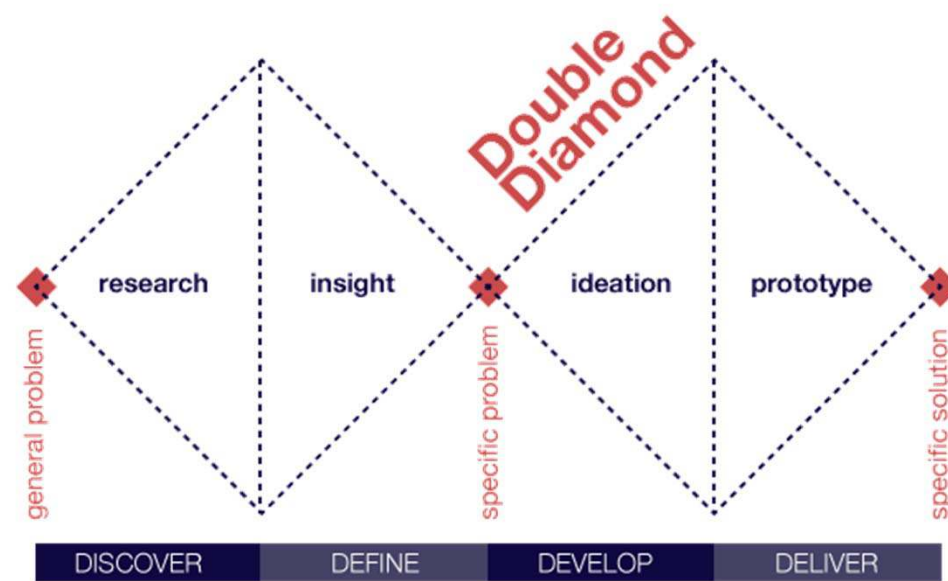
Design Thinking is a creative problem solving process represented by the Double Diamonds at left. People are led through activities where issues are explored widely and deeply (divergent thinking) and then are asked to take focused action (convergent thinking). This happens in **four basic steps**:

*Step one:* Empathize & frame problems

*Step two:* Brainstorm ideas

*Step three:* Develop & evaluate strategies

*Step four:* Communicate policies & programs



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## Anticipated Outcomes

- New ideas generated for leadership within and across the state agencies on how to better support the ‘whole person’ and ‘whole family’ related to substance use
- Considerations for program staff on how to better work with substance using clients
- Reduce the time lag between research findings and action



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# Thank You

## ***ECI Integrated Data System Taskforce:***

Shanell Wagler & Amanda Winslow (Iowa Department of Management; DOM); Betsy Richey (Iowa Department of Public Health; IDPH); Kelly Davydov (Iowa Department of Human Rights; DHR); Tom Rendon (Iowa Department of Education; DE); Tammi Christ & Ryan Page (Iowa Department of Human Services; DHS); Marion Kresse (BooST); Cassandra Dorius & Heather Rouse (Iowa State University; ISU).

## ***Ethnography, IDS, and Data Analysis Partners - Iowa State University:***

Cassandra Dorius, Heather Rouse, Shawn Dorius (faculty leads); Rachael Voas (program manager); Elizabeth Talbert (Research Associate); Melissa Denlinger, Taylor Voorhees, Kelsey Van Selous, Quentin Riser, Maya Bartel, Seulki Ku, Jessica Bruning (graduate and post-doctoral research assistants); Darien Bahe, Dan Burdick, Grant Manful, Kate McInroy (undergraduate research assistants).

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# Wrapping up

Thank you for being here today!

If you have any questions about the workshops or project results, please email:

Betsy Richey

[betsy.richey@idph.iowa.gov](mailto:betsy.richey@idph.iowa.gov)

Cass Dorius

[cdorius@iastate.edu](mailto:cdorius@iastate.edu)



# Common Themes

- **Listening for shared priorities**
- **Standardizing process to make collaboration easier and more routine**
- **Communication! Learning exchanges or sessions to digest findings together**
- **Getting creative about funding for these partnerships**

# Questions?

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# THANK YOU

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