Translating Research into Action: A Multi-Method Approach for Informing Substance Use Policy and Practice

By Cassandra Dorius, Shawn Dorius, Heather Rouse, Elizabeth Richey, Elizabeth Talbert, Kelsey Van Selous, and Darien Bahe

January, 2020

Acknowledgements

We gratefully acknowledge the help and support of our state collaborators, Betsy Richey (IDPH) and Kelly Davydov (IDHR), who were instrumental in the design and implementation of this project. We also appreciate and acknowledge the support and encouragement of the following individuals, without whom the project would not have been as successful:

**Iowa Department of Public Health:** Director Gerd Clabaugh, Betsy Richey, Janet Horras, DeAnn Decker, Julie Jones, Kevin Gabbert, Monica Wilke-Brown, Joe Caldwell, and Richard Nesselroad

**Iowa Department of Human Rights:** Kelly Davydov, Bill Brand, Lori Easterly, and Shane Kavanaugh (intern)

**Community Action and Outreach Partners:** Jay Hanson (Prairie Ridge Treatment Center); Becky Falck, Suzette Van Vark, and Deb Shubat (SEIDA); Sarah Ziegenhorn, Nick Sparr, and Tiffany Carter (IHRC).

**Early Childhood Iowa Integrated Data System Taskforce:** 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), and Amanda Winslow (DOE/DOM)

**Staff Support:** Rachael Voas

**Research Support:** Elizabeth Talbert

**Student & Postdoc Support:** Darien Bahe, Maya Bartel, Jessica Bruning, Dan Burdick, Melissa Denlinger, Shane Kavanaugh, Seulki Ku, Grant Manful, Kate McInroy, Kelsey Van Selous, and Taylor Voorhees.
Grant Related Products

Reports


Workshops


National Presentations


State and Local Presentations


Table of Contents

Executive Summary.................................................................................................................................................p5

Translating Findings in Action.................................................................................................................................p5

Key Takeaways from Data Collection Efforts........................................................................................................p7

Six Guiding Principles...............................................................................................................................................p8

Activity 1: Design Thinking Workshop ................................................................................................................p9

Activity 2: Data Discovery Workshop................................................................................................................p11

Activity 3: Interviews with Parents Who Have a History of Substance Use.........................................................p14

  Theme 1: Economic Vulnerability.........................................................................................................................p15

  Theme 2: Social Isolation and Stigma.......................................................................................................................p18

  Theme 3: Trauma, Coping, and Resilience.............................................................................................................p22

  Policy Bridge: Unpacking the Choice Vs. Disease Narrative.............................................................................p25

Activity 4: Quantitative Test of Ethnographic Findings.........................................................................................p29

Activity 5: Advancing Public Health Administrative Data Capacities.................................................................p33

Activity 6: Environmental Data Scan..................................................................................................................p42

Reference List...............................................................................................................................................................p44

Appendix 1 Design Thinking Report......................................................................................................................p45
Executive Summary

Over the past several decades, the popular press and government reports have given much attention to the harmful effects of the substance use epidemic on communities and states. These reports and other outlets often pay particular attention to the many powerful stories of individuals all across the country who have been damaged or lost their lives as a direct consequence of the substance use epidemic. To date, far less attention has been devoted to the effects of substance use on American families. Using a multi-method study design, and in partnership with IDPH leadership, we sought to identify the key concerns and ‘pain points’ of parents who use substances to better understand where policy and programming changes are needed to support Iowa families. This was accomplished by:

- conducting 41 ethnographic interviews of current and former substance using parents throughout the state of Iowa, and
- analyzing federal and state data to test the ethnographic results with quantitative data.

We were also tasked with testing the capacity of an integrated data system for understanding the impacts of substance use on Iowa families, and identifying additional indicators for an integrated data surveillance system to monitor substance use impacts. This was accomplished by:

- exploring the capacity for a statewide integrated data system to inform program and policy efforts related to family substance use in a popular home visiting program, and
- conducting an environmental scan of additional state and federal administrative data that could be used as part of an ongoing, real-time drug surveillance system in the future.

Translating Findings into Action

It can take years, or even decades, for health research to inform policy and practice. One of the goals of our IDPH-ISU partnership was to test new approaches for translating health research into practice on a much shorter timeline with a focus on how to better support the ‘whole person’ and ‘whole family’ related to substance use. To this end, we created two workshop opportunities where the findings of our studies could be reviewed, interpreted, and extended to inform future program development. This included a:

- Four-hour, facilitated, hands-on ‘Design Thinking Workshop’ to translate project findings into actionable strategies to improve effectiveness, return on investment, and outcomes for families who have complex needs and are served by many areas of state government.

- Three-hour facilitated ‘Data Discovery Workshop’ to inventory and screen data for future IDS use. This included identifying data within the Iowa’s Department of Public Health and other state systems, as well as public data sources that might provide valuable context on the lives of substance users. The data were prioritized for inclusion if they were assessed at the county level and met screening criteria.

The response to the workshops by participants was extremely positive. Respondents noted that: 1) Data often flow out, but results don’t get presented back to agency staff, and the workshop series provided administrators a chance to ask questions and provide clarifications of the findings being generated. (2) Program staff often lack the dedicated time to focus on developing new policies and programs. Facilitated discussions provided needed opportunities to improve programs and identify how to better work with substance using clients. And perhaps most importantly, (3) facilitating discussions for next steps helped IDPH to reduce the 17-year lag between health research and policy action. For example, participants at the Data Discovery Workshop identified 94 additional datasets for assessing substance use, set criteria for using data, and articulated the benefits of integrated data to monitor impacts of substance use on individuals and families. This learning has been already
shared with the Substance Use Bureau and their advisory board to begin developing a monitoring system for substance use in the state. The integrated data results are also being shared with legislators in the 2020 session as an example of how an integrated data system can be used to better support Iowa families. Further, six program ideas were generated in the Design Thinking Workshop that can be used to expand substance use programming efforts throughout the state. See Appendix 1 for full details. Items three and four below are currently being explored for follow-up efforts as a pilot project (#3) and needs assessment (#4). The six programming recommendations include:

1. One team proposed a Caring Community Concierge (CCC) program that links individuals and families leaving treatment services to CCC ambassadors that help to reintegrate recovering individuals into the community. The program would coordinate with existing community resources and foster peer-to-peer connections, all while modeling healthcare models of continued care.

2. A second team recommended Skilled Translation: A Second Chance Program focused on helping people who formerly used drugs to find employment by building on and rewards their existing skills. The program includes a skills assessment, job coaching, mentoring, and linkages to job opportunities that align with skills and interests. Participants who successfully move through Skilled Translation are eligible to become mentors in the program.

3. A third team proposed a Home Visiting Program (HV) that targets families with minor children in the home. This program facilitate connections between recovery services and individuals while they are still in treatment for the purpose of better managing the transition from treatment to recovery. It does this by fostering collaboration among treatment centers and the HV program, where individuals can develop a personal relationship with members of their future recovery community. The HV program will prioritize services for families in treatment.

4. A fourth team proposed Recovery Coaching Program (RC), with the goal to offer recovery coaching sessions and a post-treatment support network for Iowa families with history of substance use. The coaching session would include topics such as workforce development, medical aid, childcare, community outreach, life management skills, post recovery options, goal setting and others. If successful, the RC program would reduce the number of individuals that relapse and provide economic stability and critical life coaching to vulnerable Iowa families.

5. In a similar vein, team five recommended the Peer Support (PS) program, which utilizes community knowledge and parent experiences to develop a multi-layered peer support program with the goal of increasing support to families with substance use issues. Program supports are available to those in treatment and recovery.

6. The final team proposed The Helping Kids by Helping Families (HKHF) program that aims to help families with children during the post treatment phase by offering three essential supports: childcare, community connectedness, and parental coaching. Community engagement activities foster the development of durable social connections to existing community groups, including both religious and secular groups.
Core to the translation focus of the grant were the high quality findings produced through four distinct data collection efforts, each of which is described below and highlighted in the pages that follow. See Figure 1 for a depiction of the data collection and outreach process utilized in this project.

Key Takeaways from Data Collection Efforts

Interviews with Parents Who Have a History of Substance Use:
Ethnographic interviews reveal that families throughout Iowa have been devastated by substance use, even in cases where only a single family member is struggling with addiction. Three themes related to economic vulnerability, social isolation and stigma, and trauma and coping were found to be crucial across our respondents, often cyclically preceding and following substance use over the life course. Each of which is a key leverage point for future intervention. See page 14 for a full description.

Quantitative Test of Ethnographic Themes: The three ethnographic themes were tested with quantitative data to determine whether they successfully predicted ‘real world’ outcomes. We identified six markers of economic vulnerability, social isolation and stigma, and trauma that predict 46% of the variation in drug related deaths at the county level in Iowa, providing important pathways for future intervention. See page 29 for more details.

Test of Integrated Administrative Data Capacity: Using integrated administrative data, we identified several significant impacts of substance use on families with young children who participated in a popular home visiting program (MIECHV). Families who reported a history of substance use were significantly more likely to experience early and extensive disadvantage at the time of the child’s birth compared to other families. These same families were less likely to successfully complete the home visiting program, and were more likely to lose custody of their children during the course of the program. See page 33 for more details.

Environmental Data Scan for Future Integrated Data System (IDS) Use: An environmental data scan identified over 250 county-level, publically available indicators that could be used to monitor substance use across the State of Iowa. A report was produced that organized indicators by the themes of substance use, health, social isolation, economic vulnerability, trauma and coping, family, and demographic topics. For each of the 250 indicators, we provide a description of the measure with question wording and response categories, as well as the data set name, location, and where the variable can be found within the data set. See page 42 for details.
Six Principles Guided Our Project Efforts

Respondents are Experts

Respondents provide expert insight in understanding the causes and consequences of substance use. By assuming positive intent and trusting our respondents as the experts on the topic, we gained novel insights into substance use in Iowa. To reflect the expertise provided, respondents need meaningful incentives to match their participation.

Team Science Works

The team consisted of interdisciplinary faculty, staff, students, and partners from IDPH and IDHR. Team members went through rigorous training on ethics, interviewing, and engaging families with humility. This approach supported rapport building with participants and led to an improved understanding of the topic and high-quality interviews.

Foster Participation

Participants told us they wanted their voices heard to bring change to the state system. We committed to respondents to tell their stories in authentic ways and with a variety of stakeholders. This allowed the participants’ ideas to drive the discussion at workshops and avoided a cultural extraction approach to interviewing.

Identify People’s Pain Points

Policy and programming needs to be grounded in the pain points of people’s lives to make lasting change. The Iowans we spoke with were often vulnerable and felt underserved by the state system. By focusing stakeholder engagement on these pain points, we hope to support future treatment and recovery options.

Stay Connected

Continued connection to substance using populations allows IDPH to better target policies and programming to support families. To build and maintain these crucial pathways, trust must be gained. Families shared that neutral third parties (like a state university) made them feel safe to engage, and reducing stigma in communication promoted feelings of connection.

Data is a Valuable Resource

Qualitative and quantitative data were used iteratively to identify pathways and barriers to success. No single method can provide all of the insights needed, but through the use of qualitative interviews, linked state administrative data, and analysis of federal indicators, we uncovered a more holistic viewpoint of substance use in Iowa.
Activity 1: Design Thinking Workshop

**Description**
Half-day, facilitated, hands-on workshop to translate project findings into actionable strategies to improve effectiveness, return on investment, and outcomes for families who have complex needs and are served by many areas of state government.

**Attendees**
Executive leadership and representatives from Public Health, Education, Human Rights, Human Services; Legislative liaison; Academic researchers and students.

**Anticipated Outcomes**
Generate new ideas for leadership within and across the state agencies on how to better support the ‘whole person’ and ‘whole family’ related to substance use. Develop considerations for program staff on how to better work with substance using clients. And, reduce the time lag between research findings and action.

**Benefits**
1) Data often flow out but results don’t get presented back to agency staff, providing administrators a chance to ask questions and provide clarifications. 2) Program staff (even high level) don’t have time to develop policies and need dedicated time to engage in these discussions. 3) This process helps reduce the estimated 17-year lag between health research and policy action. 4) The mixed method results allows agency staff to better understand and empathize with the needs of substance users in Iowa and improve their data systems for further surveillance.

**Methodology Highlight**
Themes generated by design thinking workshop participants

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
<th>Group 5</th>
<th>Group 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Connections</td>
<td>Collaboration, Integration and Community Development</td>
<td>Incentives</td>
<td>Family Focus</td>
<td>Medical options</td>
<td>Person-centered strategies</td>
</tr>
<tr>
<td>Growth</td>
<td>Understanding Existing Resources</td>
<td>Peer to peer</td>
<td>Improve Family Health and Rehabilitation</td>
<td>Building support</td>
<td>Interpersonal (Connections) Strategies</td>
</tr>
<tr>
<td>Economic Access and Stability Access</td>
<td>Employment</td>
<td>Better jobs</td>
<td>Recovery Focus</td>
<td>Program</td>
<td>Institutional or Structural Change</td>
</tr>
<tr>
<td>Data</td>
<td>Developing New Resources</td>
<td>Housing access</td>
<td>Healthy Community Living</td>
<td>Disease education</td>
<td>Multilevel Interventions</td>
</tr>
<tr>
<td>Prevention</td>
<td>Executive functioning</td>
<td>Executive functioning</td>
<td>Foster Healthy Living</td>
<td>Buy ins</td>
<td></td>
</tr>
<tr>
<td>Appropriate Connecting to Resources</td>
<td>Health access</td>
<td>Support</td>
<td>Training</td>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Social Connections and Relationships</td>
<td>Strength Community</td>
<td>Targeted messaging</td>
<td>Direct Individualized Support</td>
<td>Targeted messaging</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Training</td>
<td>Training on Trauma-Informed Care</td>
<td>Training on Trauma-Informed Care</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>and Resilience</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


In the half-day *Design Thinking Workshop*, participants were guided through five creative thinking phases: gaining empathy, problem framing, ideation, developing ideas and communicating ideas.

**Phase 1 Gaining empathy:** Workshop participants were provided three personas (archetypes). The three personas, Melissa, Maria and Sam, and Bill collectively represent the experiences and challenges with substance use faced by individuals and families across the state of Iowa. Each persona was developed to represent two of the three key themes (social isolation and stigma, trauma and coping, or economic vulnerability). Example at right.

**Phase 2 Problem framing:** Participants were divided into six groups. Each group was provided with two personas and three of the problem statements. Each problem statement began with the phrase “How might we develop solutions that”:
1. reduce social isolation and stigma and promote economic stability?
2. will help overcome chronic resource deprivation and provide better job opportunities?
3. promote well-being and stability of Iowa families?
4. support youth in communities and discourages substance use?
5. help parents overcome the endless loop of intergenerational substance use issues?
6. help people cope with traumatic life events and reduce possibility of relapse?

**Phase 3 Ideation: Brainstorming solutions:** Based on personas and problem statements, participants generated ideas for policy and program improvements for individuals and families with substance use issues. After idea generation, participants were asked to group similar ideas into clusters, referred to as affinity diagrams. A total of 441 ideas were grouped into 38 clusters (see table on prior page). Ideas from each cluster were then reviewed and consolidated into seven broad themes that touched on the theme of community connections, healthy community living, institutional and structural reforms, development of new resources, employment and economic stability, and improvements targeting both individuals and whole families.

**Phase 4 Evaluating and comining ideas into strategies:** The goal of this phase was to develop program or policy level strategies that combine the various ideas generated during phase 3. A strategy template was provided to all groups to facilitate the discussion.

**Phase 5 Communicating solutions: Brand touch point analysis:** The goal of this phase was to communicate strategies developed in phase 4 as a series of positive experiences for individuals and families using a brand touch point analysis method. Participants were expected to visualize their ideas/strategies as brands trying to engage different customers. The aim is to support needs and expectations of families throughout the lifecycle of programs – from pre-engagement considerations to post-engagement challenges and encouraging continuing participation in programs. Touchpoints allow prospective individuals and families to gain knowledge on the programs and the benefits offered and help them make informed decisions for engaging in programs. Brand touch point template was provided to all groups. Due to lack of time, some groups were unable to develop more strategies or touchpoints. An example developed around home visiting is provided as an example below.

**Results of process:** By the end of the session, each team had developed and shared with the larger group a program idea that could address the problem statements provided in phase two and the themes identified by participants in phase three. Although distinct from one another in many ways, a unifying theme across the teams was the need to support families moving from treatment to recovery. Focusing on the recovery stage and finding new ways to reconnect people with their families, to a welcoming community, to the labor market, life coaches, and peer-to-peer support groups, for example, were all viewed as important ways to meet the needs of Iowa’s substance use recovery community.

A full description of the Design Thinking Workshop team recommendations can be found in Appendix 1.
Activity 2: Data Discovery Workshop

**DESCRIPTION**

Three hour facilitated ‘Data Discovery’ process to inventory and screen data for future IDS use. Included data within the IDPH and other state systems, as well as public data sources that might provide valuable context on the lives of substance users. The data were prioritized for inclusion if assessed at the county or lower levels of aggregation.

**ATTENDEES**

Public Health program managers and data staff from the Bureaus of Substance Abuse, Gambling, Violence Prevention, Suicide Prevention, and Maternal and Child Health; Epidemiologists; Academic researchers and students.

**ANTICIPATED OUTCOMES**

Generate analysis of utility and feasibility of available data. Analyze considerations for data quality when incorporating indicators into an IDS. Generate new analysis ideas for epidemiologists and new questions for research.

**BENEFITS**

Identified 94 datasets available to monitor substance use. Practiced screening data sets and identified goals to monitor use across state. Goals aligned across key themes of prevention, reducing stigma, and improving treatment, systems, and accuracy of data.

**Methodology Highlight**

- **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.
In this workshop, participants were guided through a six-step Data Discovery process designed to identify and screen data for use in a public surveillance system for monitoring substance use in Iowa. The workshop format was originally developed by Dr. Sallie Keller at the Biocomplexity Institute, University of Virginia.

**Step 1: Examining factors impacting families:** Workshop participants were provided examples of internal and external factors impacting substance use in Iowa families. These factors included how laws, regulations, and availability of resources positively and negatively influenced families. Participants were asked to brainstorm additional factors impacting Iowa families. Participants discussed how lack of data, stigma related to substance use, and limited state resources impact Iowa families.

**Step 2: Exploring desired outcomes:** Participants were asked to consider their goals if a substance use monitoring system was created and effectively capturing data. Participants identified 27 goals. The list of desired outcomes related to five themes including desires to 1.) target prevention, 2.) improve treatment, 3.) reduce stigma, 4.) improve systems, and 5.) improve accuracy of data. Specific desired outcomes included increasing transitional housing opportunities, increasing number of people in treatment, identifying inefficiencies or redundancies in current substance use system, and effectively sharing data across departments.

**Step 3: Identify additional data domains:** Participants were provided examples of 5 data domains and 30 levels of analysis to help monitor substance use ‘hot spots’. Examples included the themes related to the findings from the ethnographic study, as well as general domains related to health and substance use. Participants then generated a list of over 50 levels of analysis. This list included unique domains such as consideration of the impact of disability and structural biases in the form of racism, sexism, and ageism among Iowa families.

**Step 4: Creating an inventory of available data:** The goal of this activity was to have participants identify datasets they are familiar with that can target surveillance of substance use and its effects on individuals and families. A list of datasets generated during this activity can be found on the next page. The list included unique datasets not previously identified in the environmental data scan such as Central Data Repository (CDR), Access to Recovery (ATR) data outcomes, Pregnancy Risk Assessment Monitoring System (PRAMS), and Iowa department of Public Health Data Reports such as Epidemiological profiles.

**Step 5: Screening considerations:** This activity was designed to help participants think about what types of factors impact the potential use of a dataset. Participants were provided with examples of factors that can be used to screen data such as cost, geography, accessibility, and representativeness of the dataset. Participants also identified how the data ownership and accessibility considerations such as geofencing may impact the feasibility of a data set.

**Step 6: Practice Screening:** This activity asked small groups to pick one dataset and practice the previous data screening techniques. Participants assessed Substance Use Treatment-Release From Treatment Dataset, Treatment Episode Dataset (TEDS), and Medicaid Claims Data along the previously identified data screening measures. A barrier for Medicaid Claims Data identified that the data is intensive to process and not representative of all Iowans. A barrier for the TEDs dataset was that it required legal agreements to access. Strengths identified for the TEDs dataset included that the data is updated every 7 days, the data has multiple responses from individuals across time, and it includes a wide array of demographic and treatment information. Substance Use Treatment-Release from Treatment Data also had numerous strengths including its ability to reflect longitudinal data and target those during intake and discharge from treatment.
A listing of potential data sets identified in Activity 4 is presented below:

**Substance Use & Health**
- Iowa Prescription Monitoring Program
- Central Data Repository (CDR)
- National Survey on Drug Use and Health (NSDUH)
- Iowa Youth Survey (IYS)
- Behavioral Risk Factor Surveillance System (BRFSS)
- Cannabidiol (CBD) Providers
- Hospital Association
- Medicaid-paid claims
- Use Title V/X &WIC Programs
- Outpatient/Inpatient Hospital Data (IPOP)
- Managed Care Organizations (MCO)
- National Outcomes Measures (NOMS)
- Treatment Episode Dataset (TED)
- Behavioral Health Barometer Report
- National Household Survey on Drug Abuse
- Inventory of Substance Abuse Treatment Services (I-STATS)
- Iowa Poison Control Center
- Emergency Medical Services Registry
- Center for Disease Control and Prevention
- Hospital Records
- 911 calls
- Emergency Room logs
- Substance Abuse Registry
- Substance Use Treatment Data-release from treatment
- Naloxone Administration data
- Iowa Tracking Program
- Crisis Center Data
- Board of Pharmacy Data

**Social Isolation**
- Iowa Youth Survey (IYS)
- Iowa Service Management and Reporting Tool (I-Smart)
- Youth Risk Behavioral Surveillance System (YRBSS)
- Central Data Repository (CDR)
- Vital Reports
- Your Life IA
- Recovery Iowa
- College/Regents Data
- Gambling Reports
- Regions Data
- Healthy Iowa
- Treatment Episode Data (TEDS)
- Substance Abuse and Mental Health Services Administration Performance Accountability and Reporting System
- Medical Data
- Naloxone Administration
- Emergency room data
- Iowa Correctional Offender Network
- Interfaith Alliance of Iowa

**American Association of Retired Persons (AARP)**
- National Association of Colored People (NAACP)-Chapter Level
- Services and Advocacy for GLBT elders
- One Iowa-LGBTQ
- Web-based Injury Statistics Query and Reporting System (WISQARS)
- Community Health Needs Assessment & Health Improvement Planning (CHNA & HIP)
- Homelessness Prevention Data
- Gambling Data
- Integrated Provider Network Claims
- Department of Education Suspensions and Expulsions (preschool-grade 12)

**Economic Vulnerability**
- Good will Salvation Army
- Criminal Juvenile Justice Planning (CJJP)
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Homeless Shelter Data System
- Community Meal Organizations
- Medical Examiner
- Poison Control Center
- Syringe Exchange
- Iowa Grants
- Access to Recovery (ATR) Data
- Drug courts
- Reports from Medicaid Claims
- Managed Care Organization Data (MCO)
- National Survey of Child Health
- Lutheran Social Services
- Barriers to Prenatal Care Survey
- Emergency Room Data
- Lawyers Associations
- Public Housing-Section 8
- Temporary Assistance for Needy Families (TANF)
- Family Investment Program (FIP)
- Family Development and Self Sufficiency (FADSS)
- Department of Human Services (DHS) – Child Care Assistance (CCA)
- Low Income Home Energy Assistance Program (LIHEAP)
- Epidemiological profiles
- Child and Adult Care Food Program
- Women Infant Children (WIC)
- Early Head Start and Head Start access
- Datasusa.io
- United Way ALICE Report Data
- Gender Equity Department of Human Rights
- Trauma and Coping

**Brain Injury Alliance**
- Emergency Rooms Data
- American Community Survey (ACS)
- Behavioral Risk Factor Surveillance System (BRFSS)-Adverse Childhood experiences
- National Child Abuse and Neglect Data System (NCANDS)
- Crime Victim Assistance Division (CVAD)
- Iowa Violent Death Reporting System
- National Intimate Partner and Sexual Violence Survey (NISVS)
- Web-based Injury Statistics Query and Reporting System (WISQARS)
- Police/Court records
- Domestic Violence Shelters
- Iowa Violent Death Reporting System
- National Organization of Asian Pacific Islanders Ending Sexual Violence
- Criminal & Juvenile Justice Planning

**Family/Individual Demographics**
- Vital Records
- Department of Human Services -child welfare
- Mandatory Reporters
- American Community Survey
- Family Development and Self Sufficiency
- Maternal, Infant, and Early Childhood Home Visiting (MIECHV)
- The National Survey on Child and Adolescent Wellbeing
- Healthdata.gov
- Tribal Health System Data
- Bureau of Indian Associations
- Iowa workforce needs assessment
- Iowa workforce development
- Resource and Patient Management System
- Adoption and Foster Care Analysis and Reporting System (AFCARS)
- Child and Adult Care Food Program
- Dependency Count Measures
- Tribal Child Welfare Data
- Bureau of Indian Affairs
- Title V needs assessment
- Dept. of Education School Climate Survey
- Dept. of Human Services childcare provider data
- Futures without violence
- The National Latin@ Research Center on Families and Social Change

**Your Choice**
- Justice Data Warehouse
- Conditions for Learning Survey
- Iowa School Health Profiles
- Disproportionate Minority Center (DMC)
- at Department of Human Rights (DHR)
- National Guard Data
Activity 3: Interviews with Parents Who Have a History of Substance Use

THEME 1
Economic Vulnerability
Participants frequently reported low education, unstable employment, and significant fines and fees related to prior substance use as barriers to obtaining and maintaining new jobs, purchasing transportation, and overall recovery.

THEME 2
Social Isolation & Stigma
Participants identified feelings of loneliness or wanting to ‘fit in’ as a reason for substance use initiation. Loneliness and isolation also precipitated relapse, especially after treatment. Perceived or real stigma stymied the formation of relationships and engagement with one’s community.

THEME 3
Trauma, Coping, & Resilience
Every participant we spoke with identified one or more experiences of severe trauma in their lives, often reporting that their initiation into substance use was an effort to cope with the event(s). Notwithstanding, strength and resilience were often evident, even after cycles of relapse.

POLICY BRIDGE
Choice Vs. Disease
Some participants believed their substance use was a choice, while others believed their substance use was a disease. Shifting the narrative from choice to disease provides new opportunities for engaging in a multigenerational approach to combat substance use.

Methodology Highlight
Themes were developed using an inductive, iterative coding process. First, interviews were recorded and transcribed verbatim by a professional transcription company. Next, trained research team members—almost all of whom had conducted the interviews themselves—reviewed the transcripts thoroughly, noting important themes related to substance use amongst Iowa families. In the first phase of coding, each transcript was read by two team members to ensure reliability of coding in the emergent themes. The team then met in person over a series of weeks to discuss the coding of the emergent themes and explore how emerging themes related to our understanding of the intergenerational nature of substance use in Iowa.

In the second phase of coding, the team leaders selected the most consistent and noteworthy themes uncovered in the first step of the process to systematically reassess across all transcripts and reviewers. Team members then recoded and reanalyzed the transcripts in their entirety using NVivo coding software. Again, each transcript was assigned to two coders to ensure inter-coder reliability. Frequent meetings about the thematic results continued to drive the second step of the analysis process, as coders were able to describe in more detail the importance of certain themes in the context of certain demographics, and the team was able to refine the core messages from the participants.

In addition to coding transcripts for themes, team members created profiles for each participant to holistically describe their experiences in a narrative format as well as answered a series of demographic questions about each participant based on transcript notes. Finally, field notes were created about the interview context to highlight items that may not have been captured on the recording.
Many of the people we interviewed describe a dependence on substances that was interwoven with chronic resource deprivation. This included extreme residential instability and homelessness (e.g., couch surfing, living out of cars and motels, losing homes), reliance on theft and charity to make ends meet, transportation hardship (e.g., loss of driving privilege or vehicle), pawning personal possessions, limited labor market opportunities (e.g., due to felonies, low wages, few marketable skills or training), and state-imposed fines and fees. Economic vulnerability often defined participants’ childhoods, and the experiences they had in the family context as children. Though economic vulnerability often preceded a participant’s substance use, the economic vulnerability that follows use—for participants and their dependents—was most tangible and consequential for participants.

The consequences of substances use clearly defined the experiences of economic vulnerability for many of our participants. These economic stressors were often described as pathways into substance use and catalysts for relapse. This was particularly true in the weeks following release from treatment—a time of growing concern for policy makers as this is when drug-related mortality is on the rise. A common misperception is that the first days and weeks after a successful period in treatment will be the most hopeful time in the life of a person recovering from substance use. Instead, the people we spoke with describe this time as often the loneliest, most financially difficult, and hopeless period in their lives, providing a novel and important social and economic account for high mortality in the weeks and months following release from corrections and treatment facilities.

The Long-term Financial Cost of Substance Use: Vincent and Elizabeth’s Story

Vincent and Elizabeth met when Vincent was 16 and she was 18 during a party at his parent’s house; mutual friends and siblings connected them. Both had already experienced the shadow of economic vulnerability, and Vincent, at least, had experienced his parent’s substance use. Elizabeth grew up in a trailer park with her mother, three sisters, and stepdad. Vincent had what he described as a “normal” childhood until he was about 13, when both of his parents lost their jobs as a result of their own rapidly escalating substance use. While his older sister used her meagre wages to buy his school materials, Vincent started noticing things disappearing around the house; when his father went to jail for the first time, Vincent was 18, and learned that his parents selling off the family’s possessions to afford illicit substances.

Elizabeth got a trailer and Vincent moved in with her around the time he graduated high school, after which he went to work for her dad. Vincent completed high school because Elizabeth encouraged him to stay the course even though many of his friends were skipping and dropping out. About a year after Vincent graduated, Elizabeth got pregnant: it was an unplanned pregnancy. Elizabeth stopped using substances for the pregnancy and up to a year after their daughter’s birth, though Vincent continued to use. Both Elizabeth and Vincent had an incredibly close relationship with Vincent’s mother. However, his mother passed away, and Vincent and Elizabeth both began to use heavily to deal with the grief of her death. Eventually, they moved into his mom’s house to save money. The substance dependence took a huge toll on the couple’s finances—Vincent’s meth addiction led him to try opiates, which he found made the meth withdrawal easier. He then started using a needle to administer his opiates, as he found that he could get a better high for less money. However, this switch made it harder for him to keep a job, and lack of funds led to criminal behavior:

I just couldn't hold down a job no more... And so since I couldn't hold down a job, I had to start you know stealing and you know committing crime to pay for my high. So that became a daily thing.

Elizabeth and Vincent split up for some time, and during this time Elizabeth went into treatment, taking her three children to the residential treatment with her. The couple is now together again, have both stopped using substances, and are trying to parent. However, they continue to struggle with the financial costs of their past substance use. Vincent says:

Like just cause when you're a recovering addict, you know you're going to have a lot of things from your past that follow you, you know, whether it be unpaid tickets, fines from things, um, fines from, you know, crimes that you've committed, any of those things. And if you don't pay 'em, they'll, they can take your license. They can take property. They can do things like that and when you're trying to get clean and build up your life, one small thing like that it can really, it can really, you know, ruin your mood and your outlook towards recovery and just make you want to give up.
Though neither Elizabeth nor Vincent have “give[n] up,” their ability to improve their financial situation and take part in several of life’s significant milestones—namely marriage—is still hindered by past issues with substance use and their subsequent fines. They have agreed not to get married until they pay off their fines, get their licenses back, and “have things the way it’s supposed to be when you get married.” The financial hardships described by Vincent, and echoed in different ways by many of our study participants, represent significant risk factors for substance use relapse. In the cycle of intergenerational substance use, economic vulnerability continues to be a reason for and consequence of this cycle.

The Cycle of Bad Jobs and Substance Use: Bill, Peter, and Sam’s Stories

Illicit substance use and bad jobs—another source of economic vulnerability for Iowans—are also associated in stories our participants tell. These bad jobs can be both a reason for and consequence of substance use. In several instances, respondents describe substance use as an integral, and rational, strategy to meet their financial and familial responsibilities. Bill describes how meth use helped him to reconcile the competing demands of long hours at the local meat packing plant and his desire to be a supportive husband and active, engaged parent:

My first week, when I worked in shipping, I worked seventy-nine hours that week and it was like...On the average, I worked sixty-nine to seventy-five hours a week. I never got to see [my family]. I worked second shift. I never got to see them ever. So that was part of the reason I used then was because I could come home and stay up and visit with [my partner] all night. At least, at least get to see her and then baby would get up to go to school in the morning, and I’d be able to see her you know. [...] But otherwise I’d fucking go in there and work twelve, thirteen hours, come home and go to bed and sleep right up until time to go. Get up to take a shower, get on my clothes and go to work. I missed everything.

Peter’s work stories were similar to those we heard from Bill—both described a physically and emotionally challenging workplace, with long hours—but in Peter’s case, he gave greater emphasis to the dangerous conditions and the ready availability of illicit substances in Iowa meat packing plants. Peter also reported that he and his coworkers from a variety of different communities often used drugs to get through the day; they often spent a large portion of their meager factory wages on any number of illicit substances flowing in and out of the workplace:

For sure, for sure. I mean like I, I don't think they hired you unless you were on drugs. I mean honestly, like they did not care. I mean like we were working some days seven days a week. You know. I also started get like...I, I, ah, resin burns on my arms from workin’ there. You know. So that’s when the...I don't know, the whole pain pill thing started, you know. And then you wouldn’t notice them or anything and if you're high on methamphetamine then you definitely didn't notice them. You know. But, yeah, I worked there about four years.

Bad jobs were not just a reason for substance use; a lack of access to good jobs was often the consequence of the cycle of substance use for our participants. Many—especially those who had frequent interactions with the criminal justice system—understood well the problem of working in jobs that were dangerous or difficult because they could not find stable, high-quality employment because of their criminal
record. Whereas jobs in the healthcare field are growing and relatively well-paid (and would promote economic security), felony records preclude many of our respondents from this kind of employment. Emily, for example, wants to be a Parent Partner because it is one of the few jobs she perceives her criminal history will allow her:

> I want to go back to college but regardless if I go back to college or not, like my background is going to stop me from getting any job that I want. And that's what sucks. It sucks bad. Cuz regardless, I mean regardless my backgrounds. And I don't know if I can get certain things expunged off my record if they do a background check. Because that's usually how it goes whenever I get hired for a good job. My background is what stops me when they do a background check. So, that's why I always get stuck working shitty ass jobs.

Substance use is strongly entwined with economic vulnerability in the lives of our respondents as both a cause and effect. For example, many people we interviewed with a dependence on substances have experienced chronic resource deprivation, including extreme residential instability and homelessness (e.g., couch surfing, living out of cars and motels, losing homes), reliance on theft and charity to make ends meet, transportation hardship (e.g., loss of driving privilege or vehicle), pawning personal possessions, limited labor market opportunities (e.g., due to felonies, low wages, few marketable skills or training), and state-imposed fines and fees. These economic stressors increase risk of substance use and often catalyze relapse. For example, when Vincent lost his job after becoming “clean” for a while, he faced a restart of the cycle of substance use:

> I lost my job, and once I lost my job, I lost my health insurance. So then I lost my ability to get suboxone. So then I started using opiates again. This time, um I dove back into using the needle and I started using heroin. Before when I was using opiates, I was mainly using you know like oxycontin, hydrocodone, dilaudid. I had never touched heroin, and this time, I, I had started hitting heroin real hard. And um...... I knew how much stronger it was, and I never actually had good access to it before....It was when I was up in [city], I found somebody that I could get access to it. Um and then once I started using that...I lost my job so basically, I lost my house, and I had to come move back down [here] with my dad. And you know...doing that also which was a dumb choice it also kept me in you know being connected to the drug circle. Um so that kept me using more. And let's see. Once I moved back in with my dad, you know I was using every day all day with him.

These economic difficulties wreak havoc on recovery. Amy describes poverty after leaving treatment:

> Like, you live there for three months, you have no job, no income or anything and like, when you leave, you're really...you don't...you know, you can't get a place to live without a job and you just leave and then you're like, well, now what? So a lot of my peers have relapsed after leaving because it's a lot to deal with.

**Policy Implications of Economic Vulnerability Findings**

Successful substance use programs and policies in Iowa will need to also address economic vulnerability to achieve a lasting change. Further, the timing of those economic supports might be most effective when administered during periods of transition. In particular, those first days and weeks after a successful period in treatment should be the most hopeful time in the life of a person recovering from substance use. Instead, we find this is often the loneliest, most financially difficult, and hopeless period, providing a social and economic account for high mortality in the weeks and months following release from corrections and treatment facilities. As Vincent reminds us, when a person recovering from substance dependence must focus on paying fines and recouping financial losses, as opposed to the possibilities that life without substances poses, hope diminishes, or even burns out.
Our study participants describe lives characterized by chronic social isolation, in which their social support networks are stunted or non-existent, often due to the ongoing and cyclical effects of substance use. Many participants told stories of isolated childhoods due to rural geography, lack of social ties, poor family relationships, or even mental health issues. Substance use often began for our participants in the formative high school years as a way to “fit in” and avoid social isolation. Isolation was also described as a consequence of substance use, as most of our study participants experienced acute social isolation stemming from incarceration, job loss, frequent stays in treatment/rehabilitation centers, and the loss of friends and family. This includes the loss of old, ‘clean’ friends during and after use; loss of high-risk substance use friendships during remission; forced or voluntary moves to new communities; little contact with churches or civic associations; and the attendant stigma associated with substance use and its effects (e.g., gaining an identity of felon or ‘addict’). Participants described how their own social isolation fed loneliness, depression, and social anxiety; limited their access to social support; and harmed job prospects, each of which increased the risk of future use and relapse.

Further, illicit substance use drove many of our participants to break ties with their nuclear and extended families (e.g., limit or have no contact with children, parents, and siblings; not attend family gatherings and events), reducing opportunities for family support and responsiveness with each successive wave of ‘the drug epidemic.’ For many, familial breaks were the result of self-exile initiated by respondents who felt stigmatized by family members. Alternately, isolation was also enforced by families, especially when non-using family members thought of substance use as a ‘contagion’ that might infect others if the substance user was allowed to participate fully in family events and activities. Divorces were frequently attributed to substance use, as were child separations, and histories of intimate partner violence. Finally, parent participants worried about how stigma and isolation resulting from their substance use might affect the experiences of their own children, and perpetuate the cycle of negative feelings and events that often precedes substance use. Taken together, these stories affirm that substance use not only negatively impacts the person who is actively using, but has ripple effects throughout the family system.

Using Substances to ‘Fit In’ with Friends and Family: Kelli, Elizabeth, and Veronica’s Stories

Many participants described childhoods, adolescences, and early adulthoods feeling isolated, unrooted, or otherwise different in their communities. This often led to early experimentation with alcohol and marijuana to “fit it”, as was the case for Kelli:

*I never really felt like I’d fit in anywhere, you know. And, um, I was pretty shy. Um, and I think that that had a lot to do with the way I reacted to different situations and scenarios and stuff in my life, and, um. So, I started, I started drinking at like a young age. [...] So, I was hanging out with people, uh, older people because they told me to like--Well I always used to hang out with older people. But they, I fit in better with them. I mean the kids my own age, um, or I was always, again, the one that was like shy or whatever. And I never, they would, I would get offered drugs a lot, but I never did it. Like I'd be like, "No, I, I don't think so." And then one day, um, I just decided like, okay, I'm gonna try it. And I remember it was, um, when my parents divorced, like when they separated. And, um, so I thought okay, I'm gonna try it and, and I liked it.*

Many of our participants described experiences using alcohol or marijuana to be cool, fit-in, or otherwise facilitate socialization in rather “boring” Iowa adolescences; often, their first entrée into ‘harder’
substances occurred when their inhibitions were lowered during use of alcohol or marijuana. Elizabeth describes how this happened for her:

Me and [my partner] lived out in the country and some guy came over when we were drinkin’ and he had [meth]. Which I didn’t even know this guy did it. He just kinda pulled it out. Yeah. And I tried it. [Sniffling] I think the alcohol kinda helped me try it with that one.

Veronica describes how her family used substances as a way of being together, often in contrast to being stigmatized and isolated by the community in general:

I feel like it became a bonding thing, like [...] We don’t play poker, or we don’t, you know. We don’t play board games. We smoke drugs, you know. That’s how we bond, you know. It's sad, but true. That's more what it was like, eventually when everybody came out and. It’s like, well I knew you did something, you know. Or I knew you did something. Um, and then that’s when I first took meth from my brother because he first knew, then oh, she smokes marijuana and then once we all came out it was just a free easy thing and we all just kind of smoked whatever, did whatever, you know. Smoke, chill.

**Stigma and Isolation Impact Recovery: Sam, Elaine, Lolly and Melissa’s Stories**

In the cycle of substance use and social isolation, stigma is also a byproduct of substance use. Sam and Bill describe their relationship as starting at a “drug house” with five years of heavy use and characterized by extreme social isolation. During that time, they were literally “off the grid”: they had no running water or electricity, and were able to afford rent only because they lived in a house more or less gifted to them from Bill’s mother. Five years into their relationship and after the birth of their daughter, they stopped using, with a few “slip ups” since. One of the ways Sam and Bill have attempted to make their move from the world of substance use to abstinence successful was a residential move to get away from the people they were using with, including the environment in which they had been using. Now the couple lives in a small town in southern Iowa, where they are struggling with new feelings of social isolation and stigma because of their past use. Sam acknowledges feelings of physical isolation, as well as social isolation, after their move:

That was a hard adjustment for me moving from a city to a small town like this not knowing. You know I mean I spent several years just back in the back bedroom. Didn’t come out. ... You know, not everybody agrees with--with what I've done in my life, you know. No matter what my story is people aren't always--especially in a small town like this, people don't really to accept that [laughter] so, you know.

Elaine describes how isolation played into her own strategy for recovery:

I also learned that if you want to be sober, it's [more than] just the dropping of drugs, it's the matter of a new mindset, a new lifestyle and letting every person go that you use drugs with no matter how much they mean to you and it's--it’s hard. It's definitely hard but it gets easier and I know people say it doesn't.

Many of our participants described acute social isolation (e.g., from incarceration, job loss, and frequent stays in rehabilitation centers) as a consequence of substance use. This isolation is particularly poignant when they transition back to the “real world” after treatment or when they stopped using substances. Though the observation of this isolation and judgement was outside the scope of our study, we take the respondents’ reports at face value that they perceive this judgement from their communities, and that they often self-isolate as a defense mechanism. This self-isolation defense may help them avoid relapse into substance use, but it leaves many of the people we talked to lonely and without much community. To the extent that they remain socially isolated, many will experience decreases in mental health, including social anxiety and depression.
This problem may be exacerbated in rural areas in the state. Lolly describes how treatment was a very positive experience, full of supportive people who had lived through substance use similar to her own, and who were able to support her in her recovery. When she returned to her hometown, however, she realized how isolated she had become from this support network, as they had spread out across the state. She felt judged by the people in town who knew about her struggles with illicit substance use:

*I just felt guilty or like everyone...I felt like, because this town is so small, like, everyone thought I was a piece of shit or something, you know. Because of what was going on, or...I just felt like I had a bad name at that time.*

Presently, however, Lolly’s isolation is impacting her mental, emotional, and financial health as well:

*I'm stuck here without a car. I don't have a job. I don't go to church. I'm going fucking crazy, honestly. I am. Like, I gotta do something. It's driving me nuts.*

Participants described social isolation from their own families as well as from larger communities. Some, like Melissa, have suffered the harmful effects of deep rifts with their families because of their illicit substance use. For many of our participants, an important part of the journey back from prolonged substance use is the attempt to repair damaged kin relationships. For others in our study, the journey required them to accept the loss of once close family members. Melissa started using alcohol and marijuana when she was about 14. At the beginning of her college years, Melissa’s friend offered her meth, and she tried it. She went to bed and “woke up a full-blown addict.” Melissa began using every day, and missed the death of her nephew to leukemia because she was cooking meth with her boyfriend. When her grandfather was dying of kidney cancer, she stole his pain pills and sold them to feed her substance dependence. Her family still feels resentment toward this time:

*There's some family members that point fingers at me for stealing my grandpa's pills and you know, I've kind of forgiven myself for that and I just have to accept that. Yeah, I stole those pills and as soon as they ask me about it, just comes out honest and you know, I did the next brave thing after doing all the wrong things.*

Melissa’s substance use—and eight drug charges that followed—led to the removal of her young daughter from her care. DHS placed Melissa’s daughter with her aunt, who ended up trying to adopt the child without being upfront about this with Melissa. The removal of her daughter was a wake-up call for Melissa. She went into treatment. After three months at House of Mercy, she was able to bring her daughter to live with her there and regain custody. Melissa has not used substances for the last two years, but is still terrified of losing her daughter again, even though she has completely changed her lifestyle. Her aunt and uncle are still some of the only family sources of support in Melissa’s life, due in no small part to the many burned bridges with other family members during her years of using.

Largely owing to stigma, but also attributable to concerns over drugs being a ‘contagion’ that would infect other family members, many of our study participants have been banished from their families (e.g., eliminating contact with kids, parents, and siblings, or disininviting from family gatherings and events). Divorces were attributed to substance use as well, as were child separations, domestic abuse, and loss of intergenerational contact with nuclear and extended family members. Lolly, for example describes how her family has been hesitant to include her in their larger life, even after she sought treatment for substance dependence:

*Even when I was in treatment, like, they were happy I was there, but got to go on a furlough, or whatever and I wanted to go to Christmas, because I hadn't been for the two years, and they were like that's good, you know, we'll see you there and like two days later they called me back and they were like “Oh we just think it's best if you don't come”. So, I don't know, I've just kind of tried to stay away from them because I'm never good enough or whatever and they just keep bringing me down, so.*
Post-Treatment Social Capital Deserts: Vincent and Maria’s Stories

When former users leave treatment programs, the social isolation and stigma they experience can be extreme. Our participants described the lonely shock of entering the world after recovery programs, and the lack of resources, connections, and support that they often faced. Though many treatment programs in the state provide substantial community and resources to their participants, they cannot continue to do so at the same level when participants finish. Many of our respondents moved back to homes far from their location of treatment, often without the support of close friends and family. Maria describes her struggle:

*I mean, it seems like things got worse when I got out of treatment, things got worse then before I was in treatment, or even in treatment, things got worse right after. And maybe that's the hardest part about relapse is just not—I mean it's so intensive in treatment. And then you just kinda’ get booted out like put in the cold and it's really fucking hard. It's really hard.*

Fortunately, some of our participants found needed support to connect them to important social capital and opportunities after leaving treatment. Vincent describes how important the support from a state program was for his recovery, as his family was no longer an option:

*If I wasn't able to get on that program up in [city], I don't know what would have happened cause they gave me free bus passes, helped me get clothes. Um, they just helped me do a bunch of stuff to kind of you know get a foothold in cause, in my position...Some people you know when they go through treatment, they have family behind 'em to help 'em out, you know what I mean? Maybe give them rides and stuff. I didn't, I didn't have that. And you know what I mean? I would have had no money. Like you can't ride a bus to go look for a job if you ain't got no money. You know what mean? Like sometimes you're in a very bad boat and some of the programs out there are lifesavers.*

Policy Implications of Social Isolation and Stigma Findings

Study participants describe lives characterized by chronic social isolation, in which social networks are stunted or non-existent due to the effects of substance use. This includes the loss of old, ‘clean’ friends during and after use; loss of high-risk substance use friendships during remission; forced or voluntary moves to new, foreign communities; little contact with churches or civic associations; and the attendant stigma associated with substance use and its effects (e.g., gaining an identity of being a felon or ‘addict’). Social isolation feeds loneliness, depression, social anxiety, limits social capital, weakens support networks and job prospects, and feeds acute boredom, each of which is a risk factor for relapse. The power of social isolation and stigma is present during the entire substance use cycle, from entrée, to “rock bottom”, to recovery, to staving off relapse.

Because social isolation and stigma are such integral parts of the cycle of substance use, successful policies and program should address the isolation that former substance users often experience, and find ways to incorporate them into productive and welcoming communities. This could include support for inclusive community spaces and recreation centers or other physical locations that outwardly combat social isolation. Such community building could both aid in recovery as well as provide a support to socially-isolated people most at-risk of entering the cycle of substance use for the first time. Recovery frameworks—whether in-patient, out-patient, or community-based—should include post-substance-use social capital building and network cohesion. Training for people who work with substance users should focus on appropriate language for communicating to clients—particularly using words that describe use rather than criminalizes behavior.
Theme 3: Trauma, Coping, and Resilience

Trauma was prevalent in the childhoods and life experiences of our study participants. In most cases, traumatic events—death of loved ones, abuse, chronic residential mobility, incarceration, unemployment—were perceived as causes of initial substance use, chronic substance use, and relapses following periods of remission. Many participants used the language of “coping” and wanting to be “numb” to trauma as reasons for substance use. Most participants describe licit and illicit substance use as coping strategies for dealing with life stressors.

Trauma was also often described as a consequence of substances use: participants’ own child removals, incarcerations, chronic mobility, and unemployment not only preceded but also followed periods of substances use. These events often triggered further substance use and more trauma. Notably, trauma for children and other close friends and relatives was often a consequence of a participants’ substance use. As a result, the substance use cycle of trauma and coping extended into other generations of Iowans.

With few exceptions, study participants report high levels of personal responsibility and accountability for their substance use and the consequences of their usage, even in light of substantial personal hardships. Despite it all, the individuals we spoke with displayed an impressive sense of resilience, determination to take care of themselves and children, and a desire to do good in the world. Like trauma and coping, resilience, a desire to do good, and a desire to seek a better life were important points in the cycle of substance use.

Loss, Abuse, and Other Trauma: Bill, Amy, Cornelius, Sam, and Maria’s Stories

Trauma was prevalent in the childhood and life experience of many of our study participants. Most describe licit and illicit substance use as a coping strategy for dealing with life stressors, of which there were myriad. For example, Bill found his father, to whom he was particularly close, dead when he was about 17-years-old. Bill, who occasionally used alcohol and meth recreationally, sank into chronic substance use:

*I lost my father. I lost my fuckin mind. I didn't give a shit about nothing I didn't want to live or nothin. Day in day out from that point on for ten years was spent in the pursuit of methamphetamine. Anything, cocaine, methamphetamine, alcohol, anything that would make it go away. Anything. I just could not deal with the grief. I didn't want to live or nothin. I didn't give a fuck. [...] I felt grief no doubt about it. I just didn't have any way to deal with it. I needed the distraction. That's the only way I could make the fuckin pain go away is to distract myself.*

Other participants detailed stories of losing friends, losing parents, of sexual or physical abuse at the hands of friends and family, and other traumatic, impactful experiences during their childhood. Family history was endemic to the population, with more than three-quarters of those we interviewed described a history of substance use in their family. Many participants detailed the substance use of their own parents as one type of traumatic childhood event that was an integral part of their entry into the cycle of substance use. Amy has spent her whole life in Iowa. She lived with her mother and her three siblings until age nine, when the children were taken away because of their mother’s illicit substance use and other reasons:

*I was like nine and my mom's house got raided or whatever so we went to a foster care for a few months and then after that we went...my grandparents got custody of us. And I don't...I guess I was too young to be really involved in much, but, um, we just stayed with my grandparents after that for a while.*
Around the time of the raid, Amy started smoking marijuana, and had already started smoking cigarettes that were easy to access in her mother’s house. By age 13 she was drinking, and by 15 she was smoking meth. Though Amy stopped all illicit substance use when she found out she was pregnant at age 16, she resumed after her second child was born. Recently, her youngest child (of five children) tested positive for meth and marijuana at birth, and Amy went to treatment. The treatment program eventually allowed the children to come live with her. Though Amy finds it hard to remain substance free because of her old networks and social isolation, she regularly attends NA meetings. Her mother, on the other hand, is still using.

Whereas trauma and coping may be one of the reasons people enter the cycle of substance use, this cycle also causes more trauma—and opportunities for coping—for themselves and their loved ones. Cornelius describes a “good upbringing,” where his parents were gainfully employed and he and his siblings suffered no particular trauma or abuse. When Cornelius was 13 his uncle passed away, and, because he saw other people doing it, “it seems like a good enough reason to start drinking.” This entry into substance use began a 30-year period of use, recovery, and relapse. During his using spells, trauma became a daily facet of Cornelius’ life:

And I found myself um in situations where I'd see kids get abused. And I wouldn't say anything. I knew it was wrong because I was not raised that way. And I knew this is not right. You know, I'd watch kids ah, but it'd be my son's mom. Her brothers. And on that side of his family, her brothers were probably eight and nine and they're breaking into houses because they don't have any food because it was a drug house. And I just succumbed to that. I feel comfortable there because I could do whatever I want, nobodies coming down on me. It's like everybody is leaving me alone. I'm waking up, there is cockroaches crawling on me and I'm just thinking, it's not supposed to be like this.

Many of our respondents described similar substance-use-induced traumatic experiences that defined their lives while they were using. Often, the respondent’s children are negatively impacted by the residential and family instability that stems from substance use. Sam describes this “spiral”:

Um, so therefore, things just kind of spiraled out of control for me and then next thing I know, um, I don't have any rights to my daughter anymore and, um, when something like that happens, you continue to bury yourself in your use to forget about it and I think that's what I did for many years, um, many years and throughout periods of time of quitting and going back using and quitting and going back to using throughout my life.

The various traumas that preceded the cycle of substance use for our participants are now often present in the lives of their children. Maria’s father was an alcoholic, and her sister introduced her to meth. By age 11, Maria was using marijuana and alcohol regularly. Maria had children early in her life and has since lost custody of them to their father, due to her substance use. Now, the two oldest live with their father and his new wife, and Maria describes how it is difficult to watch their childhood unfold much like hers did:

Like their home life? Oh because it's like me watching me all over again. […] Like you know but I can't literally help them or take them away. But um so yeah, it's just kind of shitty there. Just literally I just see my, them living my life like when I was little. It sucks.

Resilience and Accountability: Bill, Tony, and Kelli’s Stories

Though the life histories and experiences of many of our participants and their families are often underlined by trauma, there is an incredible amount of resilience and accountability exemplified by the individuals themselves. In citing these traumatic events, our participants were rarely attempting to place blame or otherwise avoid responsibility. On the contrary, the Iowans we spoke with embodied core American values of personal responsibility and accountability for their actions. With few exceptions, study participants report high levels of personal responsibility and accountability for their usage, despite substantial hardships beyond their own
control. Despite it all, the people we spoke with showed an impressive resilience, determination to take care of themselves and children, and a commitment to do good in the world. Bill describes this well:

And like I said you gotta grow up sometime. Something's got to be more important than that and then your wife and your family's got to be more important than drugs your drug and your drug than your vices. So that's why I made the decision I mean shit uh she had been fuckin clean for oh a long time and fuckin slipped up. It is what it is. You stumble and fall and you get back up and move on.

Bill’s attitude, to just get back up and keep trying is emblematic of the attitude of many people with whom we spoke. Tony describes how his substance use and recovery has made him the person he is today:

Um, actually it's turned into more of a positive, I think. I think with um, obviously it was negative at first. But it also gives you a broader life perspective. You're going to meet a lot of shady characters and learn a lot about life through that lifestyle. Which I think it was a great learning experience. And then also with ah, um, being able to beat it, subdue it, I guess. Ah, cuz they say your never really over it. Um, it's pretty fulfilling, I guess. The part about finding a higher power was way sooner and had a better outlook I'd probably have a completely different life. But I don't know. As far as it goes, I really wouldn't want to change much of it, other than the fact that I'd rather quit sooner. [laughs] And made better choices. I guess I've made a lot of mistakes.

Kelli, similarly, sees her traumatic experiences with substances as a way that she might be able to make a positive change in her world. Hope keeps her going:

Like, and that's where we get our, our strength from, is from somebody else who's experienced it and did it clean and what did they do. Like what did you do, and that's, that's, that's what gives me hope is that there's always--I can't go through something in my life that somebody else hasn't went through and done it clean. And that's the same way that I can help somebody else through something that I've been through, because I did it clean. So, that's what gives me hope.

Working hard, taking responsibility, helping others find a workable path, and never giving up on the hope of substance use remission and reunification with family members is among the single most unifying attributes of the people we interviewed.

Policy Implications of Trauma, Coping, and Resilience Findings

A wraparound model of treatment in which the mental, physical, and emotional needs are identified and met may be the most effective way to address past trauma, as well as to stave off of conditions that may lead to that trauma in future generations. Given the intergenerational nature of substance use, policy and programs should consider treating the whole family, not just the individual substance user (and treating children prior to removal). Participants in our study who were able to get treatment with their custodial children told us that this experience was incredibly important in their recovery, as well as their children’s well-being. Jessica explains:

I had also had my children placed in the treatment center with me...so I had had my children back in my care for a couple of months before I graduated treatment. But, I also had gotten some services set up not just for my children, but for myself because of all of the trauma that I've endured in my life and they have endured a lot of trauma.

Finally, building on the resilience of people who use or have used substances can enhance programs and policy for substance use recovery in Iowa. The humor, candor, accountability, and desire to help others that many of our participants brought to our interviews should inform a strengths-based approach to recovery and relapse avoidance.
Cultures are defined, in part, by narratives, and the culture surrounding substance use is no different. The entrenched narrative among the Iowan’s we spoke with is that substance use and dependence are choices, while the emergent narrative preferred by IDPH is that they are a disease. We found evidence of both narratives used by our participants, though ‘choice narrative’ was the far stronger and taken-for-granted of the two. We heard frequent reference to the need for people with substance dependence to hit rock-bottom or otherwise experience an extreme event so as to ‘decide’, ‘choose’, or ‘see the need’ for behavioral change. This choice narrative often relies on the individual person who uses substances seeing the direct ‘consequences’ of their actions and making an informed choice to do less harm to themselves and those around them. This reactive behavior of hoping and waiting for individuals with substance dependence to hit rock-bottom is a high-risk strategy that leads to increased mortality incidence, child removals, incarcerations, unemployment, and homelessness, each of which is attended by high collateral damage to families and communities.

The disease narrative relies more on the understanding of one of the main “causes” of drug use: a genetic predisposition to use substances. When participants use this language, they discuss the need to manage the disease, not cure it. The choice inherent in the disease narrative is the acceptance of the disease as a lifelong companion, something to monitor, avoid exacerbating, and live with. The disease approach to substance use is a proactive method to life management as opposed to a reactive response to certain circumstances and events.

Family history of substance use was endemic among our study participants and was seen as a personal risk factor driving participant’s own use as well as the (mostly) anticipated substance use of their children. Almost every participant described a history of alcoholism in their family, and many reported having parents or close family members with other substance dependencies, ranging from marijuana to methamphetamine and heroine to opiates. Participants suggested that genetic factors likely predisposed them to their own substance dependence and this left many to worry that these same risks would have similar negative impacts on their children. Despite the understanding of the genetic link between generations of people who use substances, many of our respondents did still not internalize the disease ideology, instead discussing how they made choices to stop using at certain “rock bottom” points in their lives.

The narratives of choice and disease have different implications for how a substance user’s family may navigate the cycle of substance use. Whereas a family that considers substance use a “choice” often feels hurt, rejected, or put-off by a member who cycles in and out of periods of use, families who consider substance use a symptom of a disease may be better able to weather the emotional burdens of the cycle. Our data suggests that the support of family and other significant people in the lives of people who use substances may help in recovery and continuing sobriety. This support seems to be much more likely and steady if the family approaches substance use with a disease ideology.

Additionally, participants’ own children might benefit personally from their parents’ internalization of disease ideology. There was a widespread belief among the parents in our study—all of whom currently use substances or have a history of substance dependence—that substance use in childhood and adolescence is common, even normal, and generally unavoidable. Most hoped that by being open with their children about the harmful effects of excess usage and by discouraging more than recreational/or experimental substance use, their children would not repeat their mistakes. Unfortunately, this approach does not seem to be working among Iowa families, as there was evidence of an emergent third generation of children using substances.

To the extent that public health can replace choice ideology with disease ideology, treatment services and interventions may come earlier and with greater effect than what we have seen to date. This is not to disparage choice altogether. Rather, we recommend replacing the ‘choice’ to stop using substances and to become a better person with the ‘choice’ to seek treatment for a condition that is unrelated to a person’s worth. The change in ideology could impact the people who use substances to choose to seek treatment earlier, as well as the particular intervention used that addresses the long-term disease, and ultimately to the strength and understanding of their support networks of family, friends, and larger community. If substance dependence is a disease, people should stop waiting or hoping for a ‘stage 4’ diagnosis or hitting “rock bottom” before they are willing to act.
All of our participants came to a moment, at some point in their cycle of substance use, when they acknowledged there was a serious problem. How they saw that moment, however, and the reason for it varied amongst two distinct narratives: substance use as a choice an individual makes, or substance use as a disease to which an individual succumbs. Vincent and Elizabeth both discuss moments of complete turns away from illicit substances, toward a life of family, sobriety, and growth. However, they use very different narratives to describe these moments. Elizabeth, who went to her first treatment after a DUI, eventually found sobriety during a second stint at Hope House, where she was able to live residentially with her children. Describing her experience of stopping to use, she says:

*I wanted to be a better person. So I made the choice to try to stop using drugs and stuff.*

Vincent describes his own removal from the culture of illicit substance use without the same kind of choice narrative. During the peak of his using, Vincent and his dad were using so frequently that Vincent was committing crimes to make enough money to keep them getting high. Though he had been in jail before, for a felony intimate partner violence charge, Vincent’s stealing for money to access illicit substances finally caught up with him. He faced a choice between a long-term jail or long-term treatment. He did not choose to get off illicit substances, per se, but chose one of two options that both required this of him.

*And it's crazy because you know the whole time I'm running, I don't want to get arrested. Once I finally get arrested and I get in that jail cell, I feel this huge relief over my shoulders knowing that I finally am you know I'm trapped. Like I can't go out and get high. I don't have to go commit crime no more. Even though I'm going to go through the withdrawal, it's still a relief 'cause I know I'm going to, I'm going to get off the drugs.*

To Elizabeth, ending her substance use was a choice she personally made. Vincent, on the other hand, situates his end of substance use as forced. More often, we heard reference to the need for users to hit rock-bottom or, like Vincent’s time in jail, experience an extreme event so as to ‘decide’, ‘choose’, or ‘see the need’ for behavioral change. The choice narrative centers around the idea of negative ‘consequences’ for the substance user and those close to them. Bill describes rock-bottom like this:
Somewhere along the way everybody's got a rock bottom. Sometimes that rock bottom isn't their exact rock bottom. They have to do...it's got to be something you know. You know the more times that you get devastation through that I think...For me, you know I mean the more devastation I get over that drug, the easier it is for me to walk away from it. Um I don't know. I mean you've got to want a better life and if you don't, and if you don't have anything to live for or a better life to look at, look for...You know, if you don't have the ability to do so then, then you know...We know a lot of people that, that could have been so many things.

The rock-bottom narrative also comes out in stories of mothers who “choose” to stop substance use as soon as they realize they are pregnant. Many of our participants who are mothers described this process, particularly in their first pregnancies. Victoria, for example, actually asked a friend to get her pregnant with her third child so she could stop using.

I [got] pregnant with Mark who I've known my whole life, since I was five years old. And I basically told him I wanted him to give me a baby so I could stop doing drugs because I don't want to do them anymore. So I did, he did.

Likewise, Amy didn’t use until after her second child was born. This kind of ‘moment of enlightenment’ happens to many women when they first become pregnant. Participants who are parents often describe their rock-bottom as when the choice is between substance use and their children—at least in the short term, or the first time, they “choose” the children. As Ashley says, she stopped substance use because:

My kids. Getting my kids back. Knowing that I had one last chance, um, with both of them basically.

Most described a history of alcoholism in their family and many had parents or close family members who also had illicit substance dependence. Participants worried that they, and their children, might be predisposed to alcoholism or dependence given this history. Despite this basic understanding of the disease narrative, there was little evidence that any of nearly 40 parents in our study intended to advocate for substance use abstinence to their children so they could avoid the ‘disease’ altogether. On the contrary, there was widespread belief among the people we interviewed that children’s alcohol and substance use is normal and generally unavoidable. To combat this ‘choice,’ most participants hoped that by being open with their children about the harmful effects of excess usage and by discouraging anything more than recreational or experimental substance use, their children would not repeat their mistakes. Unfortunately, this approach doesn’t seem to be working. Our data found evidence of an emergent third generation of substance use in Iowa families. Hoping that this third generation makes a ‘better choice’ than their parents did—as opposed to avoiding behaviors that exacerbate a genetic and/or biological condition—is an approach that lacks understanding of how deadly a disease substance use can be. On the other hand, some of the children and family members we heard about had stronger beliefs about choice than their drug using parent or relative. Michelle describes a text message her daughter sent to her:

Um, my daughter sending me a [text] message that says, "Mom why can't, why's meth so important to you? Why can't you choose," you know, it that really, that stuck with me all this time.

This same daughter continues to be wary of her mother’s sobriety and recovery, as she does not accept the disease narrative. Michelle, however, has come to see that, as her rock-bottoms got lower and lower (at one point she was hospitalized for a life-threatening infection), she was powerless to combat the disease with choice:
She [my daughter] says it's not a disease. I don't know where I stand on that, because I know I had a choice, and I hold a whole lot of guilt for that. But there was a point where it came to, where I couldn't stop though too and I truly believe that. There was nothing in me that could stop me and I think that face infection and just everything, the way it turned out was what saved my life, you know. But, that's all I got.

As opposed to focusing on the choices a substance user has made and the ‘consequences’ of those choices, the disease narrative of substance use focuses more on the biological and genetic ‘reasons’ behind a substance user’s illness. Indeed, substance use conceptualized as a disease—as opposed to a series of poor choices—may be a better way to at once get substance users the immediate medical attention they need, and to put in place social and physical supports to maintain an abstinent lifestyle, as opposed to simply making a discrete choice to stop using. For example, Cornelius describes the liberation his parents may have felt in finally conceptualizing his substance use as a disease, not a choice:

> It was easier for em just to you know, after a point in time you know it's like what do you do? They had to have felt helpless, you know. And it's one thing when you're taking those substances and you're helpless against it. But now, that's affected somebody who did not make that choice. Who had no, you know what I mean, nothing to do with any of that. And here they're ah, experiencing the wrath of that disease and how that spreads out, you know it's like, wow.

Hoping and waiting for individuals with substance dependence to hit rock-bottom is a high-risk strategy that leads to increased mortality incidence, child removals, incarcerations, unemployment, and homelessness, each of which is attended by high collateral damage to families and communities. Michelle, for example, describes hitting rock-bottom multiple times, and how each time it got a little worse:

> Because I can always, it's not necessarily my bottom because I can always make a new bottom. Every single time I went in I was at the bottom. But this time I was at a new bottom, you know, and I knew death was coming.

Abby suggests thinking about substance dependence as a disease to control, not completely overcome:

> Cause the disease doesn't care if you're white, black, rich, poor, doesn't care where you came from. It affects everybody the same. I mean, for the most part, you know? Which, is sad, you know? I've seen many people die. I've had people in my family die from alcoholism. It's, it's a killing disease. It's kinda like dementia. You know? You can take your dementia drugs and it can control it to a certain extent and then, or diabetes even. You can take your insulin, but it's not gonna cure it. It's just gonna help maintain your life.
Activity 4: Quantitative Test of Ethnographic Findings

TEST 1
Which theme best predicts drug overdose deaths?

Social capital (a measure of social isolation) and pain pills per capita were the strongest predictors of drug mortality, followed by economic vulnerability and family disunity (a measure of trauma and coping). Collectively, the seven constructs accounted for 40% of the variation in country drug death rates in Iowa.

TEST 2
What items in each theme best predict drug overdose deaths?

Among each grouping of variables, child poverty (economic vulnerability), number of religious organizations (social isolation), and non-marital birth rates (trauma and coping) were most predictive of overdose deaths. The refined models explained 46% of the variation in county-level death rates due to substance use.

TEST 3
Which counties are most at risk for drug overdose deaths?

No single set of policies will work equally well in all 99 counties of Iowa. We map predicted drug mortality rates across Iowa counties to identify high value geographic targets for substance use intervention efforts.

Methodology Highlight

We wanted to understand why some Iowa counties had high drug mortality rates while others had low mortality rates and to assess what might drive these differences. To do this, we identified county-level risks of drug mortality risks that corresponded to what we learned from our respondents, including issues of poor health, economic vulnerability, low social capital, family disunity, physical inactivity, and access to drugs. We then regressed drug overdose death rates on the measures corresponding to our study themes.

The dependent variable is drug overdose deaths, defined as the number of deaths due to drug poisoning per 100,000 in the population by county of residence of the deceased. Drug overdose mortality rates were estimated by pooling the number of deaths over a three-year period (2015-2017), and then dividing total deaths by the average number of people at risk during the same time period.

The independent variables included county-level measures of poor health, economic vulnerability, low social capital, family disunity, physical inactivity, and access to drugs. Poor health was measured with three variables, including a county-level measure of a self-rated health (% reporting poor or fair health) and measures of the average number of physically and mentally unhealthy days in the last month. Economic vulnerability was measured with four variables, including the child poverty rate, the unemployment rate, average income at the 20th percentile of the county income distribution, and education measured as the share of the county population reporting at least some college education. Low social capital was measured as the total number of associations per capita, including civic, religious, business, political, professional, and recreational organizations. Family disunity was measured with four variables, including the teen birth rate, the percentage of single parents in the county, non-marital (wedlock) births as a share of all births, and the county marriage rate. Physical inactivity was measured as the percentage of adults in the county that report having been physically inactive in the last month. Access to drugs was measured using the number of legally sold pain pills per capita, as recorded by the drug enforcement agency. We also included a variable that controlled for differences in population size across Iowa counties.
In keeping with our interest of engaging with participants in the study as valued collaborators, we focused the next step of our study—testing qualitative findings using quantitative data—on the social and contextual factors identified by our study participants as being strongly related to their own substance use history. Participants described their lives, from childhood to the present, using words, phrases, stories and autobiographical narratives that suggest the social and familial context is a fundamental cause of substance use onset, escalation of substance use, and relapse following periods of substance use remission. Some of the causes and consequences of substance use described by our participants included poor health, economic vulnerability, low social capital, family disunity, physical inactivity, and easy access to controlled substances. Because these factors simultaneously predict substance use behavior and often result from substance use, a vicious cycle is activated in the lives of many people with substance use disorders. The vicious cycle that attends substance use increases mortality risk, raises barriers to recovery, and increases the likelihood of intergenerational transmission of substance use behaviors.

For this stage of the study design, our goal was to explain why some Iowa counties had high drug mortality rates while others had low mortality rates and to understand which of the insights that our participants shared might drive these differences. To this end, we regressed drug overdose death rates on six variables that measure concepts identified by our study participants. The independent variables included county-level measures of poor health, economic vulnerability, low social capital, family disunity, physical inactivity, and access to drugs. We also included a variable that controlled for differences in population size across Iowa counties (see below).

Figure 2. Explanatory model of county-level substance use mortality rates

Bivariate analysis showed that counties with poor health, high incidence of economic vulnerability, family disunity, physical inactivity, and above-average access to drugs tended to also have high drug overdose death rates. Multivariate regression analysis showed that low social capital was associated with a high drug overdose death rate. Among the several factors measured, social capital and pain pills per capita were the strongest predictors of drug mortality risk, followed by economic vulnerability and family disunity. Collectively, the seven variables we measured accounted for 40% of the variation in county drug death rates.

We also estimated a series of regression models to understand which indicators of economy, social capital, and family structure mattered most. Results show that among the four indicators of economic vulnerability, the child poverty rate was the most strongly associated with drug overdose deaths. Among the several categories of association we measured, religious organizations per capita had the strongest negative
effect on drug mortality rates. Put simply, counties with a high per capita rate of churches had below average number of deaths and this difference was beyond chance. In terms of family disunity, the rate of non-marital fertility, sometimes referred to as out-of-wedlock births, was the most strongly associated with drug deaths (see figure on next page). These refined models explained 46% of the variation in county drug death rates.

Our analysis suggests that speaking directly with, and listening to the experiences of, people who used drugs is an effective public health monitoring activity and an important missing link in IDPH’s ongoing substance use surveillance efforts. The risk factors and social contexts described by the people we spoke with turned out to be remarkably strong predictors of drug overdose mortality risk. Future efforts to engage with people on the substance use disorder spectrum will provide valuable and possibly even novel insights into substance use prevention, treatment and recovery.

Figure 3. County-level correlates of drug overdose death rates

Using the model results described above, we calculated predicted drug mortality rates for each Iowa county. While these variables strongly indicated an impact in the rate of drug overdose deaths, not all counties are impacted the same and no single set of policies will work equally well in all 99 counties of Iowa. The map on the next page highlights predicted drug mortality rates across Iowa counties. Counties shaded in red are high on risk factors that make them especially vulnerable to drug overdose mortality. In the context of limited state resources, the high-risk counties identified in the map below might be viewed as high value targets for substance use intervention efforts.

Our findings agree with prior social epidemiological research that identifies the social context as a fundamental cause of health risk and inequality in health risk. Attention to the fundamental causes of substance use disorders and substance use mortality, including economic vulnerability, communities experiencing chronically poor health and low physical activity, and a pharmaceutical environment that has often saturated at-risk communities with highly addictive, powerful pain pills, is likely to yield positive returns to public health investments.
Figure 4. Predicted Drug Mortality Rates
Activity 5: Advancing Public Health Administrative Data Capacities

**BUILD IDPH DATA CAPACITY**
Collect, document, and profile relevant data elements within public health data systems that contain information about family and child health and substance use history.

**TEST INTEGRATION SYSTEM CAPACITY**
Test data integration protocols with particular attention to equity in scientific algorithms.

**ANALYZE INTEGRATED DATA**
Analyze integrated data and document strengths and limitations of the IDS approach.

**DISSEMINATE FINDINGS**
Communicate findings within a community of relevant stakeholders to determine how findings could be translated into practical recommendations.

**Methodology Highlight**

Prior environmental scans of existing state administrative data about families with substance use histories revealed two data sources that contained information about substance use history and could be accessed through existing legal data sharing agreements between the IDPH and ISU: (1) DAISEY home visiting records contained information in caregiver reports about prior history of family substance use; and (2) Vital Statistics Birth records contained information about prenatal smoking and also provided the population-based with which to compare the integration cohort.

Detailed data profiling, descriptive analyses, and missing data analyses were conducted with each dataset separately to document data quality and inform the integration protocols. Using probabilistic and deterministic matching of variables including child first name, last name, date of birth, gender, and race/ethnicity these two datasets were integrated at the child level for any family who participated in home visiting for one calendar year in the federal MIECHV program (i.e., 2017). Descriptive and multivariate analyses included a sample of 755 families in the final integrated dataset that included home visiting records and vital statistics birth records. Findings were then shared with a variety of community audiences, including IDPH MIECHV program leadership, IDPH Departmental leadership, and invited stakeholders across Iowa systems to discuss what was learned about the IDS as well as about families experiencing substance use in Iowa. Findings were also shared at the National Association for Public Policy and Management conference in November 2019 as part of a symposium showcasing the use of state IDS for program and policy work.

Variables for the study were coded to analyze birth risks (pre-term or low-birth weight, teen motherhood, low maternal education, single motherhood, inadequate prenatal care, poverty, and tobacco use), home visiting enrollment characteristics (child age at enrollment, prenatal enrollment, and enrollment duration), home visiting outcomes (successful completion of program and average number of visits per month), and demographics (child age, gender, parent race and ethnicity, and number of siblings). Many items were dichotomized as yes or no, the child/parent did not exhibit this characteristic, to facilitate counting birth risk factors and examining the likelihood of multiple program outcomes.
This project provided a novel opportunity to explore the use of administrative data about families experiencing substance use challenges, with a focus on data collected and maintained by the Iowa Department of Public Health. The purpose of these activities was to explore capacity for a statewide integrated data system (IDS) to inform program and policy efforts. To this end, we tested the capacity of our newly implemented Early Childhood IDS to integrate records across two public health data systems that had previously been identified to contain information about family substance use.

Since 2016, Iowa partners including IDPH and ISU have been building a plan for an IDS to establish the legal, technical, scientific, and business processes for administrative data from public service systems to be integrated and used to inform policy and practice. Using two years of national training and technical assistance from Actionable Intelligence for Social Policy (www.aisp.upenn.edu), Early Childhood Iowa (ECI) partners implemented the first phase of this plan by securing legal agreements and commencing data sharing to conduct three demonstration projects. The current project was one of those demonstrations, designed to test the capacity of Iowa’s Early Childhood Integrated Data System (IDS) to understand cross-systems characteristics and service utilization patterns of families with substance use histories. It included work to (1) collect, document, and profile relevant data elements within public health data systems that contain information about family and child health and substance use history; (2) test data integration protocols with particular attention to equity in scientific algorithms; (3) analyze integrated data and document strengths and limitations of the IDS approach; and (4) communicate findings within a community of relevant stakeholders to determine how findings could be translated into practical recommendations. For an overview of this approach, please see the methodology highlight on prior page.

Three primary questions guided the analytic work using the integrated dataset:

1) What are the characteristic differences between families in home visiting programs who do or do not have histories of substance use?
2) Are there different home visiting service utilization patterns and outcomes for families with histories of substance use compared to those without such histories?
3) What are the primary factors that affect successful home visiting program completion?

Question 1: What are the characteristic differences between families in home visiting programs who do or do not have histories of substance use?

The analytic sample included 755 families. Table 1 provides descriptive information about the sample, with relative distributions of characteristics by families with and without substance use histories. The majority of children in this sample were under age three, though the range included 0 – 71 months. Caregiver reports indicated that 22% (n=171) of families had a history of substance use/abuse prior to enrollment in home visiting programs. Further, mothers of children in MIECHV home visiting programs with a family history of substance use are significantly more likely than those without such history to be non-Hispanic white. Mothers with a history of substance use are less likely to be non-Hispanic black, Hispanic, or other, compared to those without a history of substance use.

Figure 5 includes birth characteristics of children in families with and without histories of substance use. Mothers with family history of substance use had significantly higher rates of poverty at child birth, prenatal tobacco use, to be unmarried at child birth. There was no statistically significant difference in pre-term/low birth weight, teenage mothers, low maternal education, and inadequate prenatal care.

Figure 6 provide information about cumulative risk. For this indicator, each individual risk (poverty, unmarried mother, low maternal education, birth to teen mother, preterm/low birthweight, inadequate prenatal care, and smoking during pregnancy) were summed to create a cumulative risk index. Figure 6 shows that children in families with a substance use history have significantly more risks compared to children without such history, with nearly 64% of them having 3 or more compared to 44% with no substance use history.
Table 1. Description of the sample

<table>
<thead>
<tr>
<th></th>
<th>Mean/prop</th>
<th>SD</th>
<th>Mean/prop</th>
<th>Mean/prop</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
<td>All</td>
<td>Substance use</td>
<td>Non-Substance use</td>
<td></td>
</tr>
<tr>
<td>n = 755</td>
<td>n = 171</td>
<td>n = 584</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child male</td>
<td>0.53</td>
<td>0.50</td>
<td>0.53</td>
<td>0.53</td>
<td>ns</td>
</tr>
<tr>
<td>Mother White</td>
<td>0.74</td>
<td>0.44</td>
<td>0.89</td>
<td>0.69</td>
<td>* b</td>
</tr>
<tr>
<td>Mother Black</td>
<td>0.14</td>
<td>0.34</td>
<td>0.05</td>
<td>0.16</td>
<td>* a</td>
</tr>
<tr>
<td>Mother Other</td>
<td>0.12</td>
<td>0.33</td>
<td>0.05</td>
<td>0.14</td>
<td>* a</td>
</tr>
<tr>
<td>Mother Hispanic</td>
<td>0.16</td>
<td>0.37</td>
<td>0.09</td>
<td>0.18</td>
<td>* a</td>
</tr>
<tr>
<td>No sibling</td>
<td>0.49</td>
<td>0.50</td>
<td>0.51</td>
<td>0.48</td>
<td>ns</td>
</tr>
<tr>
<td>1 sibling</td>
<td>0.26</td>
<td>0.44</td>
<td>0.27</td>
<td>0.26</td>
<td>ns</td>
</tr>
<tr>
<td>2 or more siblings</td>
<td>0.25</td>
<td>0.43</td>
<td>0.22</td>
<td>0.26</td>
<td>ns</td>
</tr>
</tbody>
</table>

Note. Data include matched samples of VS and DAISEY MIECHV children who were born between 2010 and 2018 in Iowa and participated in the MIECHV in 2017. Estimates are unweighted. Significant differences between families with substance use history and non-substance users are estimated by unpaired two-sample t-tests: * Ha = diff > 0 or b Ha = diff < 0. *p < .05.

Figure 5. Birth characteristics by family history of substance use

Note. Data include matched samples of Iowa children who were born between 2010 and 2018 and participated in the MIECHV in 2017. Estimates are unweighted. *Significant differences between families with substance use history and non-substance use are estimated by unpaired two-sample t-tests.
Table 2 presents the prevalence and co-occurrence of each birth risk and family history of substance use. Among families with a history of substance use, higher portions of them also experienced poverty (97.08%), had unmarried mothers (75.44%), used tobacco (59.65%) compared to the entire population of families in the MIECHV cohort. Among families experiencing poverty at the time of the child’s birth, 68.83% of them had unmarried mothers. For families with unmarried mothers, 95.87% of them experienced poverty at birth. Families with low maternal education also had high rates of experiencing poverty (96.95%) and having unmarried mothers (71.76%). Among families with teenage mothers, high percentage of them also experienced poverty (96.43%) and had unmarried mothers (96.43%). Families with preterm/low birth weight infants also had high rates of experiencing poverty (94.05%) and having unmarried mothers (71.43%). Among families with inadequate prenatal care, high percentage of them also experienced poverty (93.33%), had unmarried mothers (66.67%) and used tobacco (73.33%). Families with tobacco use in pregnancy tended to experience poverty (95.80%) and have unmarried mothers (74.81%).

Question 2: Are there different home visiting service utilization patterns and outcomes for families with histories of substance use compared to those without such histories?

The next set of analyses examined home visiting service utilization patterns and outcomes. Table 3 presents home visiting program participation characteristics by family substance use history. T-test comparisons were used to examine differences between families with and without substance use history.

There were seven possible ways for a family to terminate services. Families who completed program or who exited the program due to child’s age were identified as “successful completion of the program.” Families who moved out of the service area, could not be located, were no longer interested in the service, were too busy, or had lost parenting rights were identified as “unsuccessful completions of the program”. Findings suggest that families with a history of substance use have a lower rate of successful program completion (14%) than those without a history of substance use (28%). There was no statistically significant difference in child age at enrollment, prenatal enrollment, enrollment duration, and the number of visits per month between the two groups. Findings presented in Figure 7 indicate that children with families with substance use history were more likely to be unable to be contacted or indicate they were no longer interested in services than families without such history. They also have nearly 4 times higher rates of having parental rights terminated or lost – 7.22% compared to less than 2% of those without substance use histories.
Table 2. Co-occurrence of family substance use history and child birth characteristics

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(22.65)</td>
<td>(93.91)</td>
<td>(67.42)</td>
<td>(17.35)</td>
<td>(11.13)</td>
<td>(11.13)</td>
<td>(1.99)</td>
<td>(34.70)</td>
</tr>
<tr>
<td>1. Family substance use history</td>
<td>-</td>
<td>97.08*</td>
<td>75.44*</td>
<td>15.79</td>
<td>8.77</td>
<td>10.53</td>
<td>2.92</td>
<td>59.65*</td>
</tr>
<tr>
<td>2. Poverty at birth</td>
<td>23.41*</td>
<td>-</td>
<td>68.83*</td>
<td>17.91</td>
<td>11.42</td>
<td>11.14</td>
<td>1.97</td>
<td>35.40</td>
</tr>
<tr>
<td>3. Unmarried mother at birth</td>
<td>25.34*</td>
<td>95.87*</td>
<td>-</td>
<td>18.47</td>
<td>15.91*</td>
<td>11.79</td>
<td>1.96</td>
<td>38.51*</td>
</tr>
<tr>
<td>4. Low maternal education</td>
<td>20.61</td>
<td>96.95</td>
<td>71.76</td>
<td>-</td>
<td>-</td>
<td>12.98</td>
<td>3.82</td>
<td>40.46</td>
</tr>
<tr>
<td>5. Birth to a teen mother</td>
<td>17.86</td>
<td>96.43</td>
<td>96.43*</td>
<td>-</td>
<td>-</td>
<td>7.14</td>
<td>2.38</td>
<td>20.24*</td>
</tr>
<tr>
<td>6. Preterm/low birth weight</td>
<td>21.43</td>
<td>94.05</td>
<td>71.43</td>
<td>20.24</td>
<td>7.14</td>
<td>-</td>
<td>8.33*</td>
<td>40.48</td>
</tr>
<tr>
<td>7. Inadequate prenatal care</td>
<td>33.33</td>
<td>93.33</td>
<td>66.67</td>
<td>33.33</td>
<td>13.33</td>
<td>46.67*</td>
<td>-</td>
<td>73.33*</td>
</tr>
<tr>
<td>8. Tobacco use in pregnancy</td>
<td>38.93*</td>
<td>95.80</td>
<td>74.81*</td>
<td>20.23</td>
<td>6.49*</td>
<td>12.98</td>
<td>4.20*</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. Numbers in parentheses represent the population percentage. Numbers represent percentages of children within a risk group (row) who also experienced each of the other risks (column). Significant chi-square differences (p<.05) are indicated (*).

Table 3. Home visiting program participation characteristics by family substance use history

<table>
<thead>
<tr>
<th></th>
<th>Mean/prop</th>
<th>SD</th>
<th>Mean/prop</th>
<th>Mean/prop</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
<td>All</td>
<td>Substance use</td>
<td>Non-Substance use</td>
<td></td>
</tr>
<tr>
<td>n = 755</td>
<td>n = 171</td>
<td>n = 584</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Successfully completed the program</td>
<td>0.25</td>
<td>0.43</td>
<td>0.14</td>
<td>0.28</td>
<td>*</td>
</tr>
<tr>
<td>Child age (months) at enrollment</td>
<td>6.65</td>
<td>13.21</td>
<td>5.71</td>
<td>6.92</td>
<td>ns</td>
</tr>
<tr>
<td>Prenatal enrollment</td>
<td>0.40</td>
<td>0.49</td>
<td>0.42</td>
<td>0.40</td>
<td>ns</td>
</tr>
<tr>
<td>Enrollment duration</td>
<td>20.39</td>
<td>16.95</td>
<td>19.43</td>
<td>20.69</td>
<td>ns</td>
</tr>
<tr>
<td>Number of visits per month</td>
<td>1.06</td>
<td>1.02</td>
<td>1.12</td>
<td>1.04</td>
<td>ns</td>
</tr>
</tbody>
</table>

Note. Data include matched samples of VS and DAISEY MIECHV children who were born between 2010 and 2018 in Iowa and participated in the MIECHV in 2017. Estimates are unweighted. *Significant differences between families with substance use history and non-substance users are estimated by unpaired two-sample t-tests at p < .0
Figure 7. Reason for program discharge by substance use history

No contact or could not locate
- Substance-use History: 28.87%
- Non-Substance Use: 25.24%

No longer interested in services
- Substance-use History: 17.53%
- Non-Substance Use: 14.06%

Moved out of service area
- Substance-use History: 15.65%
- Non-Substance Use: 12.37%

Too busy
- Substance-use History: 8.31%
- Non-Substance Use: 5.15%

Parental rights were terminated or lost
- Substance-use History: 7.22%
- Non-Substance Use: 1.92%

Other
- Substance-use History: 14.43%
- Non-Substance Use: 6.71%

Note. Data include matched samples of VS and DAISEY MIECHV children who were born between 2010 and 2018 in Iowa and participated in the MIECHV in 2017. Estimates are unweighted. * indicates significant differences between those that completed the home visiting program and those that did not are estimated by unpaired two-sample t-tests at $p < .05$.

Figure 8. Child birth characteristics and prenatal enrollment by program completion

Tobacco
- Completed: 19%
- Did Not Complete: 40%

Unmarried mother
- Completed: 13%
- Did Not Complete: 54%

Low maternal education
- Completed: 11%
- Did Not Complete: 20%

Teen mother
- Completed: 14%
- Did Not Complete: 1%

Inadequate prenatal care
- Completed: 4%
- Did Not Complete: 1%

Pre-term/low birthweight
- Completed: 10%
- Did Not Complete: 14%

Prenatal enrollment
- Completed: 45%
- Did Not Complete: 34%
Question 3: What are the primary factors that affect successful home visiting program completion?

Given the identified differences in program completion rates for families with and without substance use histories, further examination of the relationships between birth characteristics and home visiting program patterns was conducted. This analysis used the dichotomous variable of program completion [0=not completed (i.e., all other reasons rather than “completed program or child aged out”) and 1=successful completion (i.e., completed program or child aged out)].

Figure 8 shows that many of the birth characteristics were differentially related to program completion rates. Families where mothers used tobacco while pregnant, were unmarried, had low education (e.g., < high school diploma), and who had inadequate prenatal care were less likely to complete the program. Families who were enrolled prenatally were more likely to complete the program.

To examine unique relations between child and family characteristics and home visiting outcomes, multiple logistic regression was used. This approach is helpful for considering multiple predictors simultaneously. Given the amount of co-occurrence among risks and characteristics, this approach was ideal to understand unique relationships among variables. This analysis produces odds ratios, which are interpreted as the likelihood of an outcome for a child with a given characteristic compared to the likelihood of that same outcome for a child without that characteristic. An odds ratio of 1.0 indicates equal likelihood (i.e., no difference). Odds ratios of less than 1.0 indicate a decreased likelihood of the event occurring while odds ratios greater than 1.0 indicate an increased likelihood of the event occurring. Statistically significant odds ratios are noted in Table 3 and suggest that children born with 2 or more siblings (compared to those with no siblings at birth), with unmarried mothers at birth, whose mothers used tobacco during pregnancy, who were younger at the time of enrollment, and who had longer enrollment durations were less likely to complete the program. Compared to families postnataally enrolled, those who were prenatally enrolled were 1.72 times more likely to complete the program. Also, families with mothers who breastfed the child were 2.10 times more likely to complete the program.

This evaluation of child and family characteristics related to home visiting program utilization patterns and outcomes provided insight about differences among families with and without histories of substance use. It also used integrated administrative data from IDPH home visiting and vital statistics birth records as one of the first tests of Iowa’s Early Childhood Integrated Data System (IDS). As such, it provided important information about the capacity of integrated administrative data to inform program evaluation work for the Iowa Department of Public Health, and suggests opportunities for enhancing data relevance for future programmatic work.
Table 3. Family characteristics predicting home visiting program retention, \( n = 326 \)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Odds Ratio</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of substance abuse</td>
<td>0.56</td>
<td>(0.24)</td>
</tr>
<tr>
<td>Child male</td>
<td>1.17</td>
<td>(0.41)</td>
</tr>
<tr>
<td>Mother Black (^a)</td>
<td>0.55</td>
<td>(0.27)</td>
</tr>
<tr>
<td>Mother other (^a)</td>
<td>0.46</td>
<td>(0.29)</td>
</tr>
<tr>
<td>Mother Hispanic (^b)</td>
<td>1.83</td>
<td>(0.97)</td>
</tr>
<tr>
<td>1 sibling (^c)</td>
<td>1.12</td>
<td>(0.50)</td>
</tr>
<tr>
<td>2 or more siblings (^c)</td>
<td>0.35</td>
<td>(0.18)*</td>
</tr>
<tr>
<td>Pre-term/Low birthweight (^d)</td>
<td>1.90</td>
<td>(1.04)</td>
</tr>
<tr>
<td>Teen mother (^e)</td>
<td>1.43</td>
<td>(0.79)</td>
</tr>
<tr>
<td>Low mother education (^f)</td>
<td>0.44</td>
<td>(0.23)</td>
</tr>
<tr>
<td>Unmarried mother (^g)</td>
<td>0.44</td>
<td>(0.19)</td>
</tr>
<tr>
<td>Poverty (WIC/Medicaid) (^h)</td>
<td>0.54</td>
<td>(0.40)</td>
</tr>
<tr>
<td>Inadequate prenatal care (^i)</td>
<td>0.34</td>
<td>(0.74)</td>
</tr>
<tr>
<td>Tobacco use (^j)</td>
<td>0.33</td>
<td>(0.13)**</td>
</tr>
<tr>
<td>Child age at enrollment</td>
<td>1.14</td>
<td>(0.03)***</td>
</tr>
<tr>
<td>Prenatal enrollment</td>
<td>3.93</td>
<td>(1.72)**</td>
</tr>
<tr>
<td>Enrollment duration (months)</td>
<td>1.11</td>
<td>(0.02)***</td>
</tr>
<tr>
<td>Average number of visits per month</td>
<td>0.97</td>
<td>(0.24)</td>
</tr>
<tr>
<td>Breastfeeding at any time</td>
<td>4.05</td>
<td>(2.10)**</td>
</tr>
<tr>
<td>Constant</td>
<td>0.03</td>
<td>(0.03)***</td>
</tr>
</tbody>
</table>

Pseudo R-squared 0.40

Note. Data were restricted to caregivers enrolled in MIECHV in 2017; estimates are unweighted; Pseudo R-square is provided as a reference; reference categories are as follows: \(^a\) White; \(^b\) non-Hispanic; \(^c\) no sibling; \(^d\) healthy weight and gestational 40 weeks; \(^e\) mothers’ age 20 and older at child’s birth; \(^f\) mothers with a high school degree or more; \(^g\) mothers married at child's birth; \(^h\) mothers with first prenatal care visit in first trimester and at least 4 prenatal care visits during pregnancy; \(^i\) mothers not receiving WIC and not using Medicaid as delivery payment; and \(^j\) mothers not smoking during pregnancy. \(^*\) \( p < .10 \); \(^*\) \( p < .05 \); \(^**\) \( p < .01 \); \(^***\) \( p < .001 \).

Findings and Implications for Substance Use Policy and Programming

Specific findings from this work suggest two important patterns that could be used to inform public health approaches to working with families experiencing substance abuse problems. First, children who are born into families with a history of substance use experience significantly more risks that are evident at birth. They are more likely to be born to unmarried mothers, to mothers who smoked during pregnancy, and more likely to be enrolled in WIC or Medicaid at the time of birth compared to children without family histories of substance use. They also have greater numbers of cumulative risk, with 64% experiencing three or more risks at birth compared to 45% without family histories of substance use. Where this study was comprised entirely of families involved with the MIECHV home visiting program, the comorbidities among risks suggest opportunities to further coordinate services and potentially garner additional resources to support children in these programs who experience multiple risks.

The second key finding is that families with substance use histories are less likely to complete the MIECHV home visiting program as it was designed (i.e., full service completion as directed at intake or the target child ages out appropriately). While this is not entirely surprising, understanding some of the reasons for family disconnection with this important public health service in the context of substance use history is particularly relevant for policy and program responses. Findings suggest, for example, that families with substance use histories have nearly 4 times the rate of having their parental rights terminated compared to...
families without substance use histories. They are also more likely to be “lost” in the system – where caseworkers are unable to locate families with substance use histories midway through the program. Combined, these findings suggest a need for more intensive connections with these families, and potentially different types of home visiting services to ensure they are receiving the parental supports they need to ensure their family can stay together. These findings could be used to garner additional resources to do such work through recent opportunities presented by the 2018 Family First Prevention Services Act. This Act offers additional resources through the child welfare system to support families at risk for child removal. Where the Iowa Departments of Public Health and Human Services seek to coordinate services and garner additional federal dollars to support at-risk families, the identification of families entering MIECHV home visiting programs with histories of substance use could be a prioritized solution.

**Implications for Enhancing Capacity of Iowa’s Early Childhood Integrated Data System**

One of the purposes of this project was to test data integration and communications strategies proposed by the Early Childhood Iowa (ECI) IDS Taskforce for use in prioritized system enhancement work. Findings suggest three important areas of IDS future development for consideration: data integration processes, programming to understand service utilization patterns, and limitations in data captured by administrative data systems.

First, our data integration test identified limitations in current data collection efforts that inform future integrations. Vital statistics birth records, for example, collect information about parents as “parent A” and “parent B” rather than identifying roles such as mothers, fathers, or foster parents. Race/ethnicity data in birth records are also limited, as they pertain only to the parent(s) identified on the record. No race/ethnicity of the child is noted on birth records. DAISEY home visiting data are limited in that they do not collect child gender. Each of these limitations do not prohibit records from being integrated, though they do limit the ability to verify and validate matches where inconsistent values and variables are found across systems.

Second, the creation of program enrollment ages, lengths of enrollment, and completion variables using DAISEY records was a good test of how the IDS can utilize rich information that is linked to program dates and child birth dates to understand timing, duration, and sequencing of services. One of the unique purposes of the IDS is to help state and local leaders better understand longitudinal patterns in services, identify gaps in services for vulnerable children, and make connections between programs by understanding factors that precede or follow service utilization. This project allowed the IDS data team to generate programming code using dates that will be useful in future efforts to dig deeper into service utilization timing, duration, and sequencing.

Third, the use of self-report substance abuse history data from DAISEY records identified opportunities for future improvements in data collection and use. The primary variable used in this study to identify families with a history of substance use was collected from caregiver reports at the time of home visiting enrollment. Prior work with IDPH MIECHV team revealed that sometimes such reports are collected by home visitors in non-standardized ways. Additional training, particularly around the sensitivity of asking families about experiences such as substance use, may be warranted to ensure these data are of high quality and inform practical use. It also suggests that additional sources of data about family substance use history may prove more fruitful for identifying more rich information about the type, timing, nature, and extent of substance use. DAISEY caregiver reports, for example, do not indicate which family member experienced substance use problems, whether or not the substance use was directly observed or experienced by the child, or how long ago the substance use experiences were prior to home visiting program enrollment. Future work to identify sources of data within public service systems that captures more details about substance use and its associated outcomes or co-occurrences would be helpful.
Activity 6: Environmental Data Scan

**STEP 1**
Review Literature

Academic articles and government reports were reviewed to identify indicators utilized by others to study substance use. Ethnographic study results identified additional pain points in need of substance use surveillance.

**STEP 2**
Scan Data Environment

Scanned federal, state, and NGO-produced data bases to locate indicators across ethnographic study themes.

**STEP 3**
Record Potential Surveillance Variables

Recorded publicly available variables available at the county level of aggregation. Indicators, data sources, and locations were compiled and recorded, resulting in over 250 variables across substance use themes.

**STEP 4**
Engage Stakeholders

Data scan results were shared during a Data Discovery Workshop to representatives from five Bureaus within Iowa’s Department of Public, Epidemiologists, Academic researchers, and students.

**Methodology Highlight**

An environmental data scan was completed to identify county-level, publically available indicators that could be used to monitor substance use across the State of Iowa. To do so, the team reviewed literature related to substance use, considered emerging findings from the qualitative interviews described previously, and reviewed academic and governmental articles, reports, and websites related to substance use. This review included exploration of materials such as The Geography of Social Capital in America with The Social Capital Project, Pain in The Nation with Trust for America’s Health and Well Being Trust, and Measuring Mobility with U.S. Partnership on Mobility From Poverty, Sanford Social Psychological Answers to Real-world Questions, and The Urban Institute. The team also reviewed data portals commonly used by The Iowa Department of Public Health, including the Behavioral Risk Factor Surveillance System, the Iowa Youth Survey, the United States Census Bureau’s American Community Survey, and the Center for Disease Control and Prevention’s Wide-ranging Online Data for Epidemiologic Research.

In total, the environmental data scan includes information about over 250 county level variables that could be used to monitor substance use in Iowa. The report produced is organized by the themes of substance use, health, social isolation, economic vulnerability, trauma and coping, family, and demographic topics. And includes references that indicate specifiers for the variables, as well as the data set name, location, and where the variable can be found within the data set.

Although, the environmental data scan is extensive, it is not an exhaustive list of all possible variables that could be utilized to monitor substance use. A draft of the environmental data scan was shared with the Iowa Department of Public Health during the Data Discovery workshop and served as an example of variables and datasets that could be utilized to monitor substance use in Iowa. As a result, experts in the field performed their own data discovery with help from the Iowa State team.
An example of substance use indicators identified in the environmental data scan is provided in the text and footnote below. For a full review of the over 250 indicators collected, see the technical report, “Environmental Data Scan: Substance Use and its Correlates in Iowa’s 99 Counties” by Dorius, Dorius, Rouse, and Van Selous.

### Environmental Data Scan Highlight

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Variable</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance Use</td>
<td><strong>Marijuana</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• primary marijuana use/type in past 30 days (18+)¹</td>
<td>Iowa Youth Survey. Section B Question B39</td>
</tr>
<tr>
<td></td>
<td>• primary reason or marijuana use in past 30 days (18+)²</td>
<td>Iowa Youth Survey. Section B Question B40</td>
</tr>
<tr>
<td></td>
<td>• ever used/used in last 30 days (students in grades 6, 8, 11)³ ⁴</td>
<td>Iowa Youth Survey. Section B Question B41</td>
</tr>
<tr>
<td></td>
<td>• age when first tried (students in grades 6, 8, 11)⁵</td>
<td>Iowa Youth Survey. Section B Question B42</td>
</tr>
<tr>
<td>Drug Distribution System</td>
<td>• number of oxycodone and hydrocodone pills distributed per person per year by distributor, pharmacies, and manufacturer⁶</td>
<td>Drug Enforcement Environment Administration Pain Pill Database. Retrieved October 21, 2019, from <a href="https://www.dea.gov/clan-lab">https://www.dea.gov/clan-lab</a></td>
</tr>
<tr>
<td></td>
<td>• monthly Iowa liquor Sales by zip code, store, category, volume (liters &amp; gallons), cost, and retail value⁷</td>
<td>Iowa Department of Commerce, Alcoholic Beverages Division. Retrieved October 21, 2019, from <a href="https://data.iowa.gov/Sales-Distribution/Iowa-Liquor-Sales/m3tr-qhgy">https://data.iowa.gov/Sales-Distribution/Iowa-Liquor-Sales/m3tr-qhgy</a></td>
</tr>
<tr>
<td></td>
<td>• drugs labs by county⁸</td>
<td>Iowa Department of Commerce, Administration Pain. Retrieved October 21, 2019, from <a href="https://data.iowa.gov/Sales-Distribution/Iowa-Liquor-Products/gckp-fe7r">https://data.iowa.gov/Sales-Distribution/Iowa-Liquor-Products/gckp-fe7r</a></td>
</tr>
<tr>
<td>Drinking and Driving</td>
<td>• Operating While Intoxicated (OWI) driver’s license revocations¹¹</td>
<td>Iowa Operating While Intoxicated (OWI). Retrieved October 21, 2019, from <a href="https://iowadot.gov/mvd/stats/owirevocations.pdf">https://iowadot.gov/mvd/stats/owirevocations.pdf</a></td>
</tr>
<tr>
<td>Substance Related Mortality</td>
<td>• alcohol-impaired driving accidents by blood alcohol content¹²</td>
<td>Iowa Department of Transportation, National Clandestine Laboratory Register. Retrieved October 21, 2019, from <a href="https://fars.nhtsa.dot.gov/States/StatesAlcohol.aspx">https://fars.nhtsa.dot.gov/States/StatesAlcohol.aspx</a></td>
</tr>
<tr>
<td>Substance Related Crime</td>
<td>• drug/narcotic violations and drug equipment violations¹⁴</td>
<td>Iowa Department of Transportation, National Clandestine Laboratory Register. Retrieved October 21, 2019, from <a href="https://fars.nhtsa.dot.gov/States/StatesAlcohol.aspx">https://fars.nhtsa.dot.gov/States/StatesAlcohol.aspx</a></td>
</tr>
<tr>
<td></td>
<td>• type of drug offense¹⁵</td>
<td>Iowa Department of Transportation, National Clandestine Laboratory Register. Retrieved October 21, 2019, from <a href="https://fars.nhtsa.dot.gov/States/StatesAlcohol.aspx">https://fars.nhtsa.dot.gov/States/StatesAlcohol.aspx</a></td>
</tr>
</tbody>
</table>

¹ Primary type of marijuana use in past 30 days (smoke, eat, drink, vaporize, dab, other, don’t know/not sure, refused, not asked/missing) (18+). Behavioral Risk Factor Surveillance System. Module: 7 Question 2

² Primary reason for marijuana use in past 30 days (medical, non-medical, both, don’t know/not sure, refused, not asked/missing) (18+). Behavioral Risk Factor Surveillance System. Module: 7 Question 3

³ Ever used marijuana (pot, grass, hash, bud, weed). Data includes information by county, grade, and gender for grades 6, 8, 11. Iowa Youth Survey. Section B Question B39

⁴ Used marijuana (pot, grass, hash, bud, weed) in past 30 days. Data includes information by county, grade, and gender for grades 6, 8, 11. Iowa Youth Survey. Section B Question B40

⁵ Age when first tried marijuana (pot, grass, hash, bud, weed). Data includes information by county, grade, and gender for grades 6, 8, 11. Iowa Youth Survey. Section B Question B41

⁶ Number of oxycodone and hydrocodone pills distributed per person per year by distributor, pharmacies, and manufacturer.

⁷ Monthly Iowa liquor sales by zip code, store, category, volume (liters & gallons), cost, and retail value.

⁸ Iowa Liquor Stores. Data shows zip code, city, state, address, store name etc. Updated monthly. Iowa Liquor Stores.

⁹ Iowa Liquor Products. Data shows product item number, category type, description, vendor, vendor name, volume of bottle (ml), bottle cost, bottle retail cost, age proof, number of bottles in pack, etc. Iowa Liquor Products.

¹⁰ Iowa Liquor Products. Data shows product item number, category type, description, vendor, vendor name, volume of bottle (ml), bottle cost, bottle retail cost, age proof, number of bottles in pack, etc. Iowa Liquor Products.


¹⁴ Number of reported group A offenses by reporting agency. Data table includes number of offenses reported by county police offices. Data includes crime type and rate per 100,000 of crime against persons, crime against property, and crime against society for Iowa county. Federal Bureau of Investigation's Uniform Crime Reporting located with Iowa Department of Public Safety. Table 1

¹⁵ Number of reported group A offenses by reporting agency. Data table includes number of offenses reported by county police offices. Data includes crime type and rate per 100,000 of crime against persons, crime against property, and crime against society for Iowa county. Federal Bureau of Investigation's Uniform Crime Reporting located with Iowa Department of Public Safety. Table 14
Reference List


Appendix 1. Design Thinking Report

Created by Tejas Dhadphale
Email: tejas@iastate.edu

Objective:
This report provides a summary of findings from the Design Thinking workshop conducted on November 14, 2019. The goal of the workshop was to develop specific ideas for policy and program improvement for individuals and families with substance use issues.

About the Design Thinking Workshop:
Design Thinking is a creative approach to solving problems. Design thinking approach and methods integrate diverse perspectives and personal creativity to provide meaningful solutions to real world problems of varying scales and complexities.

Participants were guided through the convergent-divergent design thinking process. The double-diamond design thinking process includes phases of problem framing, developing insights, brainstorming solution and prototyping and communicating ideas. The following figure shows the double diamond process.

Figure 1: Double diamond design thinking process
Workshop outline and methods:
In this workshop, participants were guided through five design thinking phases: gaining empathy, problem framing, ideation, developing ideas and communicating ideas.

Phase 1 Gaining empathy
The goal of this phase was to understand key challenges faced by individuals and families with substance use issues. Team led by Dr. Dorius presented the findings from the ethnographic assessment study conducted by Iowa State University (ISU) between October 15, 2018 – August 31, 2019. The report includes findings from in-depth interviews conducted with 41 men and women across the state of Iowa. Based on the interviews, three key personas were developed for this workshop. Personas are archetype characters created based on research to highlight the needs and wants of specific users groups. The three personas created for the workshop were used to provide context and highlight the challenges faced by individuals and families with substantiated cases of substance use.

Phase 2 Problem framing
Participants were divided into six groups. Each group was provided with two personas and three problem statements. Each groups used a set of three problem statements to generate ideas. The following questions were outlined:

Problems statements outlined for group 1, 2 and 3
The first three groups focused on developing ideas to reduce social isolation, promote economic stability, well-being and stability for Iowa families. The teams focused on the following questions:

1. How might we develop solutions that reduce social isolation and stigma and promote economic stability?
2. How might we develop solutions that will help overcome chronic resource deprivation and provide better job opportunities?
3. How might we develop solutions that promote well-being and stability of Iowa families?

Problems statements outlined for group 4, 5 and 6
The other three groups focused on developing ideas to cope with traumatic life events, reduce possibility of relapse and address intergenerational substance use issues. The teams focused on the following questions:

1. How might we develop solutions that support youth in communities and discourages substance use?
2. How might we develop solutions that help parents overcome the endless loop of intergenerational substance use issues?
3. How might we develop solutions to cope with traumatic life events and reduce possibility of relapse?
The questions were developed based on six key themes identified from the ethnographic assessment study:

1. Social Isolation and Stigma
2. Economic Vulnerability
3. Stability and Well-being of Iowa Families
4. Trauma, Coping, Accountability, Resilience
5. Intergenerational Substance Use and Abstinence Parenting
6. Competing Substance Use Narrative: A choice or a Disease

These themes were used to develop personas and to brainstorm policy and/or program level improvements.

**Phase 3 Ideation: Brainstorming solutions**
In this phase, participants used the lotus-blossom technique to brainstorm solutions at an individual, program and policy level. Participants collectively generated 441 ideas. After initial brainstorming, participants were asked to group similar ideas together to create affinity diagrams or clusters. Each group of ideas was given a title that summarized the overall theme of the cluster. 441 ideas were grouped into 38 key themes (many overlapping themes across groups). Appendix A provides a list of ideas generated during the workshop.

**Phase 4 Developing and combing ideas into strategies**
This phase focused on narrowing down and combing ideas into programs or policies. The goal was to combine ideas to develop robust human-centered solutions. Each group was provided a strategy sheet to develop and communicate program and/or policy level improvements.

**Phase 5 Communicating solutions: Brand touch point analysis**
The goal of touch point analysis is to develop a series of positive experiences for individuals and families with substantiated cases of substance use. The aim is to support needs and expectations of families throughout the lifecycle of programs – from pre-engagement considerations to post-engagement challenges and encouraging continuing participation in programs. Touchpoints allow prospective individuals and families to gain knowledge on the programs and the benefits offered and help them make informed decisions for engaging in programs. Each group outlined program structure, locations, resources and agencies required to successfully implement policies or programs level improvements. At the end of the workshop, groups shared their strategies with each other.

**What does this report include?**

Three personas.
Problem statements.
Key themes (cluster of ideas) and consolidated themes from the workshop.
Strategies (combination of different ideas) and touchpoints
Phase 1 Gaining empathy: Personas
Workshop participants were provided three personas (archetypes). The three personas, Melissa, Maria and Sam and Bill collectively represent the experiences and challenges with substance use faced by individuals and families across the state of Iowa. Each persona was developed to represent two key themes (see below; Figure 2).

<table>
<thead>
<tr>
<th>Persona Name</th>
<th>Represents the following key themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melissa</td>
<td>Economic Vulnerability</td>
</tr>
<tr>
<td></td>
<td>Stability and Well-being of Iowa Families</td>
</tr>
<tr>
<td>Maria</td>
<td>Trauma, Coping, Accountability, Resilience</td>
</tr>
<tr>
<td></td>
<td>Intergenerational Substance Use and Abstinence Parenting</td>
</tr>
<tr>
<td>Sam and Bill</td>
<td>Social Isolation and Stigma</td>
</tr>
<tr>
<td></td>
<td>Trauma, Coping, Accountability, Resilience</td>
</tr>
</tbody>
</table>

Short descriptions of personas

Melissa
Melissa is in her 30’s and identifies as Latina and White. She grew up in rural Iowa with three siblings. Her childhood was marked by family substance use, residential instability and sexual abuse. Melissa has two children that were taken away from her due to history of substance use. She wants to overcome economic instability (fines, child support) and is looking for high quality and sustained employment.

Maria
Maria is 32 and identifies as White. She lives in rural Iowa with her two children. Her unstable childhood and prolonged abuse led to substance use. Maria’s son Matt has now started buying substance – that has led to the endless loop of intergenerational substance use, residential instability and economic vulnerability.

Sam and Bill
Samantha and Bill live in a small town in Southern Iowa. Sam and Bill have faced acute social isolation and stigma during the post-treatment phase. As a family, they are looking for a support structure that offers civic and religious engagements. Sam and Bill are looking for better employment that would reduce working hours and a social network that will reduce social isolation.

Detailed descriptions of each personas is provided below.
Name: Melissa  
Age: 30  
Race/ Ethnicity: White/ Latina  

Background  
Lives in rural Iowa, 3 siblings, 2 children (taken away into foster care)  
Family substance use  
Residential instability  
Sexual abuse  

Key Issues  
• Economic vulnerability  
• Well-being and stability for family  

Pain points  
• No driver's license  
• Owes to child support  
• Pending fines  
• Financial insecurities  
• Chronic resource deprivation  
• Limited labor market opportunities due to past record  
• Fighting for custody of children.  
• Economic stressors increase risk of substance use and often catalyze relapse.  

Impact on family  
• Substance being a 'contagion' that would infect other family members; Melissa banished from her family.  
• Loss of intergenerational contact with nuclear and extended family. Loss of family support structure.  
• Impact of Melissa's past on her children. The constant fear of losing her children again, even though she has completely changed her lifestyle.  

What does Melissa need?  
• Overcome economic stressors (fines, child support).  
• Programs that support better job opportunities.  
• Overcome fear of losing child custody.  
• A social structure to understand her situation and emotionally support her family.
Name: Maria  
Age: 32  
Race/Ethnicity: White  

Background  
Lives in a rural Iowa, 2 children, 2 sisters  
Working at a local sandwich franchise, Economic vulnerability  
Unstable childhood resulted in substance use  
Abuse from family members, introduced to substance by sister  

Key Issues  
- Intergenerational Substance Use  
- Trauma, Coping, Accountability & Resilience  
- Wellbeing & stability of Family  

Pain points  
- Maria’s childhood was marked by family substance use, residential instability and sexual abuse.  
- Maria intentionally became pregnant to escape her abusive family.  
- Traumatic events (death of father and abuse from partner) in life resulted in chronic substance use.  
- Maria wants to go back to school and look for a high quality employment.  
- Maria has not used substances for the last 2 years.  

Impact on family  
- Maria lost custody of kids due to chronic substance use.  
- Family was split and children now live away from her.  
- Maria finds it difficult to watch her children go through similar events in life.  
- Substance use has resulted in economic challenges for her family.  
- Maria’s son Matt has now started buying substance.  
- As a mother, she is trying to get help for Matt. She feels stuck in an endless loop of family substance use issues, residential instability and economic vulnerability.  
- Maria has experienced three generations of substance use.  

What does Maria need?  
- A support system that will help cope with intergenerational substance use.  
- A mechanism to cope with traumatic events to avoid relapse.  
- A program to help overcome financial insecurities and better job opportunities.  
- A program that supports and educates youth (and prevent substance use).
Name: Sam and Bill  
Age: 30/35  
Race/ Ethnicity: White

Background  
Lives in a small town in Southern Iowa, 1 daughter  
Working in meat packing plant  
Lived in a “drug house” for years  
Move away to get away from people

Key Issues  
- Acute Social Isolation & Stigma  
- Trauma, Coping, Accountability & Resilience

Pain points

- Feel judgment from others  
- Cannot attend religious gatherings (church) or civic engagement  
- Judgement has resulted in self isolation  
- Self-Isolation as a defense mechanism  
- Isolation causing mental health issues, social anxiety and depression

- Treatment was a positive experience: Full of supporting people who have gone through the same experience. Feel isolated after returning from treatment. No support network after treatment.  
- Meat packaging job requires long hours and six day weeks. Results in less time with family and greater self-isolation. Risk of relapse.  
- Lack of high quality employment due to previous criminal record.

Traumatic events and coping

- Bill lost his father and other loved ones at an early age.  
- This resulted in abuse from other family members and an unstable living condition.  
- Traumatic events and loss of loved ones resulted in initial substance use, chronic substance use and replaces following periods of remissions.  
- Sam and Bill acknowledge their past and take full personal responsibility and accountability for their actions.

What do Sam and Bill need?

- A support network that will help them overcome self-isolation.  
- A support structure after treatment for civic engagement and religious gatherings.  
- Opportunity for high quality employment.  
- Reduced work hours to facilitate increased family time and less isolation.  
- A mechanism to cope with traumatic events to avoid relapse.  
- A system that acknowledges and supports positive behavior.

Phase 2 Problem framing
Participants were divided into six groups. Each group was provided with two personas and three problem statements. The following table shows personas, key themes and problem statements provided to the groups.

Groups 1, 2 and 3 were provided with the following:

<table>
<thead>
<tr>
<th>Persona</th>
<th>Key themes</th>
<th>Problem Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melissa</td>
<td>Economic Vulnerability, Stability and Well-being of Iowa Families</td>
<td>7. How might we develop solutions that reduce social isolation and stigma and promote economic stability?</td>
</tr>
<tr>
<td>Sam and Bill</td>
<td>Social Isolation and Stigma, Trauma, Coping, Accountability, Resilience</td>
<td>8. How might we develop solutions that will help overcome chronic resource deprivation and provide better job opportunities?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9. How might we develop solutions that promote well-being and stability of Iowa families?</td>
</tr>
</tbody>
</table>

Groups 4, 5 and 6 were provided with the following:

<table>
<thead>
<tr>
<th>Persona</th>
<th>Key themes</th>
<th>Problem Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maria</td>
<td>Trauma, Coping, Accountability, Resilience, Intergenerational Substance Use and Abstinence Parenting</td>
<td>1. How might we develop solutions that support youth in communities and discourages substance use?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. How might we develop solutions that help parents overcome the endless loop of intergenerational substance use issues?</td>
</tr>
<tr>
<td>Sam and Bill</td>
<td>Social Isolation and Stigma, Trauma, Coping, Accountability, Resilience</td>
<td>3. How might we develop solutions to cope with traumatic life events and reduce possibility of relapse?</td>
</tr>
</tbody>
</table>
Phase 3 Ideation: Brainstorming solutions

Based on personas and problem statements, participants generate ideas for policy and program improvements for individuals and families with substance use issues. After idea generation, participants were asked to group similar ideas into clusters (affinity diagrams). A total of 441 ideas were grouped into 38 clusters. The following tables shows number of clusters and ideas generated by each group. All ideas and clusters are included in Appendix A.

<table>
<thead>
<tr>
<th>Idea Clusters</th>
<th>Group number</th>
<th>No. of ideas</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 clusters</td>
<td>1</td>
<td>90 ideas</td>
</tr>
<tr>
<td>8 clusters</td>
<td>2</td>
<td>69 ideas</td>
</tr>
<tr>
<td>7 clusters</td>
<td>3</td>
<td>54 ideas</td>
</tr>
<tr>
<td>5 clusters</td>
<td>4</td>
<td>48 ideas</td>
</tr>
<tr>
<td>10 clusters</td>
<td>5</td>
<td>120 ideas</td>
</tr>
<tr>
<td>4 clusters</td>
<td>6</td>
<td>60 ideas</td>
</tr>
</tbody>
</table>

The following tables shows clusters created by each groups.

<table>
<thead>
<tr>
<th>Group 1 Clusters</th>
<th>Group 2 Clusters</th>
<th>Group 3 Clusters</th>
<th>Group 4 Clusters</th>
<th>Group 5 Clusters</th>
<th>Group 6 Clusters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Connections</td>
<td>Collaboration, Integration and Community Development</td>
<td>Incentives</td>
<td>Medical options</td>
<td>Person-centered strategies</td>
<td></td>
</tr>
<tr>
<td>Growth</td>
<td>Understanding Existing Resources</td>
<td>Peer to peer</td>
<td>Building support</td>
<td>Interpersonal (Connections) Strategies</td>
<td></td>
</tr>
<tr>
<td>Economic Access</td>
<td>Employment</td>
<td>Better jobs</td>
<td>Program</td>
<td>Institutional or Structural Change</td>
<td></td>
</tr>
<tr>
<td>Stability Access</td>
<td>Developing New Resources</td>
<td>Housing access</td>
<td>Disease education</td>
<td>Multilevel Interventions</td>
<td></td>
</tr>
<tr>
<td>Data</td>
<td>Executive functioning</td>
<td>Health access</td>
<td>Buy ins</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevention</td>
<td>Health access</td>
<td>Strengthen Community</td>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appropriate Connecting to Resources</td>
<td>Social Connections and Relationships</td>
<td>Recovery Focus</td>
<td>Targeted messaging</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Person-centered strategies</td>
<td>Institutional or Structural Change</td>
<td>Healthy Community Living</td>
<td>Training</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ideas from each cluster were reviewed. Clusters from group 1, 2 and 3 (provided with the same personas; Melissa and Sam and Bill) were consolidated. Similarly, clusters from group 4, 5 and 6 (provided with the same personas; Maria and Sam and Bill) were also consolidated. The synthesis of ideas and cluster shows seven broad themes. The following table shows consolidated themes.
<table>
<thead>
<tr>
<th>Consolidated themes from groups 1, 2 and 3</th>
<th>Consolidated themes from groups 4, 5 and 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Themes</td>
<td></td>
</tr>
<tr>
<td>1. Community connections and development</td>
<td>4. Improvements at an individual and family level</td>
</tr>
<tr>
<td>2. Employment, economic access and stability</td>
<td>5. Healthy community living</td>
</tr>
<tr>
<td>3. Developing new resources</td>
<td>6. Institutional and structural change</td>
</tr>
<tr>
<td></td>
<td>7. Multilevel interventions</td>
</tr>
</tbody>
</table>

**Phase 4 Evaluating and combing ideas into strategies**
The goal of this phase was to develop program or policy level strategies that combine the different ideas generated during phase 3. Strategy template was provided to all groups.

**Phase 5 Communicating solutions: Brand touch point analysis**
The goal of this phase was to communicate strategies developed in phase 4 as a series of positive experiences for individuals and families using a brand touch point analysis methods. Participants were expected to visualize their ideas/strategies as brands trying to engage different customers. The aim is to support needs and expectations of families throughout the lifecycle of programs – from pre-engagement considerations to post-engagement challenges and encouraging continuing participation in programs. Touchpoints allow prospective individuals and families to gain knowledge on the programs and the benefits offered and help them make informed decisions for engaging in programs. Brand touch point template was provided to all groups. The following table shows the number of strategies and touch point templates developed by each group. Due to lack of time, some groups were unable to develop more strategies or touchpoints.

<table>
<thead>
<tr>
<th>No. of Strategies</th>
<th>Group number</th>
<th>No. of touch points</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>2</td>
</tr>
</tbody>
</table>

The following sections reports six strategies and touchpoints developed participants.
## Strategy 1

### Title of the program
Caring Community Concierge (CCC)

<table>
<thead>
<tr>
<th>Key Themes</th>
<th>Personas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Connectedness</td>
<td>Melissa</td>
</tr>
<tr>
<td>Community supports (at all levels)</td>
<td>Sam</td>
</tr>
<tr>
<td>Well-being and stability</td>
<td>Bill</td>
</tr>
</tbody>
</table>

### How does the program work? (Different aspects and structure of program)

The Caring Community Concierge (CCC) program will provide targeted service specific to different individuals and families. The goal is to leverage existing conditions to create a human-touch case management system that works at different levels.

First, the program assesses needs of individuals during treatment and looks for issues of isolation and possibility of relapse. Second, the program leverage existing connections in the community to provide a caring concierge system at a community level. Ambassadors within the community will be identified and introduced through the program. The goal of the ambassadors and the CCC is to provide targeted solutions to the needs of individuals and families. The CCC program will involve other families and support agencies to ensure there is continued connections with individuals who need assistance.

The last phase will include utilizing former clients (individuals who have benefitted from the program) to support new clients and become ambassadors in the CCC program. This program will required central administration oversite and support.

### Key benefits
Centralized resources to help create a system of continued care (this strategy mimics the healthcare model of prevent – track – intensive – post recovery)

- Encourage community engagement
- Preparing former clients to engage with communities and work as liaisons
- Acknowledging the diverse needs of individuals and catering to it.

### Resources required
Human connectors
Access to faith services and employers
Connections to institutions

### Departments involved
Public (PH/Ed/HS)
Privates (providers)
Volunteer to connect to people in
## Strategy 1: Touchpoints

<table>
<thead>
<tr>
<th>Touch points</th>
<th>Pre-engagement</th>
<th>During-engagement</th>
<th>Post-engagement</th>
</tr>
</thead>
</table>
| Program structure             | • Assessing existing connections  
• Service creation with different levels  
• Targeted service based on different individuals/families  
• Advertisement of concierge service  
• Develop assessment structure                                                                                                                                          | • Human touch concierge  
• Case management (at an individual/family level)                                                                                                                             | • User former clients to support new clients with central admin oversight and support |
| How the program works         | • While in treatment (Trx); assess for needs. Look for issues of isolation/relapse  
• Ambassadors introduced in the program                                                                                                                                 | • Concierge/liaison for targeted approach based on needs                                                                                                 | • Cycle of connections instead of cycle of abuse                                                        |
| Identifying/retaining individuals/families | • Referral from Trx and community centers                                                                                                                                                                     | • Continued connection with individuals – involve other family members and support agencies                                                                 |                                                                                                         |
| Different agencies            | • PH/HS/Education  
• Providers  
• Actual connections in that community                                                                                                                                                                                 | • Umbrella/local partner focus                                                                                                                              |                                                                                                         |
| Resources/locations for implementing program | • In Trx + transition plan created/client driven                                                                                                                                                                  | • Local – Go to – go with – go in                                                                                                                           | • Good benefits to individuals, families, community and agencies                                        |
Strategy 2

Title of the program
Skill Translation: A Second Chance Program

Key Themes
- Workforce integration
- Social isolation
- Economic vulnerability

Personas
Melissa, Sam and Bill
Recovered individuals looking for employment and stability

How does the program work? (Different aspects and structure of program)

The Skill Translation (ST) program will target recovered individuals looking for employment. The program will translate individuals’ past skills into professional skills through job coaching, mentoring leading to steady recovery and long term economic stability. The program will work at three levels:

Level 1: This level includes skill assessment for recovered individuals (resiliency – measure- assess)
This includes employment skills, social skills to outreach possibilities.

Level 2: This includes job coaching and structuring the implementation program. Individuals after recovery can enroll into the SK program and will be provided job coaching and mentoring.

Level 3: Job opportunities: This includes providing a list of competencies required by individuals to get employment. The list of competencies required will circulated in treatment centers, community venues, faith-based locations, and within state and federal

Key benefits
- Conducts individual skill assessment and matches individuals to job opportunities
- Potentially creates a continuity of employment
- Economic stability over time

Resources required
- On-demand providers
- List of interested employers

Departments involved
- PHS/DOJ
- On-board employers for job placements
### Strategy 2: Touchpoints

<table>
<thead>
<tr>
<th>Touch points</th>
<th>Pre-engagement</th>
<th>During-engagement</th>
<th>Post-engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program structure</td>
<td>• Prevention outreach</td>
<td>• Individual skill assessment with positive reframe – job coaching – job opportunity – mentorship throughout the process</td>
<td>• Peer mentors to engage individuals</td>
</tr>
<tr>
<td></td>
<td>• Skill assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How the program works</td>
<td>• Identify employers with needs for suitable workshops</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Develop peer mentors to help in the process</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• During prevention outreach provide need to individuals in need – through recovery mode + support of organizational system models – with lead to opportunity of growth</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Alumni connect events – celebrate 1st, 2nd and 3rd year of engagement</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• “Second chance” policy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Community recognition for positive programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifying/retaining individuals/families</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Different agencies</td>
<td>• PHS/DOJ</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• On-board employers for job placements</td>
<td></td>
</tr>
<tr>
<td>Resources/locations for implementing program</td>
<td>• Pilot community partners, employers, mental health providers.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Locating funding, locating employers with wellness resource assessment of employers and people</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Events planned to celebrate alumni connections, second chance programs and community recognition programs</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Strategy 3

<table>
<thead>
<tr>
<th><strong>Title of the program</strong></th>
<th><strong>Home Visiting Program (HV)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key Themes</strong></td>
<td></td>
</tr>
<tr>
<td>Home Visiting</td>
<td></td>
</tr>
<tr>
<td>Executive functioning</td>
<td></td>
</tr>
<tr>
<td>Goal setting</td>
<td></td>
</tr>
<tr>
<td>Social connections = family experience</td>
<td></td>
</tr>
<tr>
<td><strong>Personas</strong></td>
<td></td>
</tr>
<tr>
<td>Melissa, Sam and Bill</td>
<td></td>
</tr>
<tr>
<td>Families with children (and substance abuse)</td>
<td></td>
</tr>
</tbody>
</table>

### How does the program work? (Different aspects and structure of program)

The Home Visiting (HV) program will specifically focus on families with children. The goal of the program is to connect with individuals while in treatment and build collaboration among treatment centers and the HV program. HV program will prioritize services for families in treatment.

The program will start in the treatment facility and the first visit will be completed first day of post-treatment experience. The program aims to strengthen the ability of individuals to 1) develop and meet social connection needs through the HV program and 2) then transfer this “relationship” to informal supports (family, friends and community). The program heavily relies on a collaborative network between individuals, families, communities, treatment centers and agencies.

Required policy changes: 1) Allow HV to travel to treatment center, 2) change frame for eligibility: ditch “households” and serve family, and 3) prioritize HV services for families in

### Key benefits

Support individuals during the most important recover stage: the post-treatment phase
Capitalize on potential that could otherwise be lost
Expand workforce by building executive functioning
Mitigate/reduce costs of child welfare and other systems

<table>
<thead>
<tr>
<th><strong>Resources required</strong></th>
<th><strong>Departments involved</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires time and collaboration</td>
<td>PHS/MH</td>
</tr>
<tr>
<td>PD/training/coaching</td>
<td></td>
</tr>
<tr>
<td>MH consultation from HV</td>
<td></td>
</tr>
<tr>
<td>Willing individuals and families to conduct HVs</td>
<td></td>
</tr>
</tbody>
</table>
# Strategy 3: Touchpoints

<table>
<thead>
<tr>
<th>Touch points</th>
<th>Pre-engagement</th>
<th>During-engagement</th>
<th>Post-engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program structure</td>
<td>• HV connecting to treatment centers (HV providers + funders lead this effort)</td>
<td>• First meet at treatment center</td>
<td>• Continue monitoring</td>
</tr>
<tr>
<td>How the program works</td>
<td>• Enhance policies</td>
<td>• First day out of treatment have home visits (over dinner)</td>
<td>• HVs gradually tapered off</td>
</tr>
<tr>
<td>Identifying/retaining individuals/families</td>
<td>• Pay for collaboration and planning</td>
<td>• Connect with champions</td>
<td>• Share ways to re-join the program</td>
</tr>
<tr>
<td></td>
<td>• Training for HV staff</td>
<td>• Second generation model HV</td>
<td>• Families and individuals can become peer mentors for other families</td>
</tr>
<tr>
<td></td>
<td>• Marketing materials</td>
<td>• Transition plan transfer to social/informal supports</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Curricula</td>
<td>• Phased in – gradual phase out incentive plans</td>
<td>• Incentive for participating in the program</td>
</tr>
<tr>
<td></td>
<td>• HV = aftercare – built into the treatment plan</td>
<td>• Financial literacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Foster family at treatment plan</td>
<td>• Fostering family continues and is tapered out</td>
<td>• Training families and/or community members for conducting HVs</td>
</tr>
<tr>
<td></td>
<td>• Identify incentives for goals</td>
<td>• Door not closed – group based engagement</td>
<td></td>
</tr>
</tbody>
</table>
Strategy 4

Title of the program
Recovery Coaching Program (RC)

Key Themes
Economic stability
Everyday life coaching
Community integration

Personas
Maria, Sam and Bill
Individuals and families post treatment

How does the program work? (Different aspects and structure of program)

The Recovery Coaching (RC) program aims to help individuals and families during the post treatment phase. The goal of the program is to offer recovery coaching sessions and post-treatment support network for Iowa families.

The coaching session will include topics such as workforce development, medical aid, childcare, community outreach, life management skills, post recovery options, goal setting and others. The RC program will connect with individuals in the treatment facilities. Provide assistance during treatment will ensure individuals follow-up and enroll in the recovery coaching sessions. Sessions will be tapered off after individuals find employment or are reasonable stable. If successfully implemented the RC program will protect individuals from relapse, provide economic stability and critical life coaching.

Key benefits
Coaching when it’s most needed; post treatment
Coaching on diverse topics
Resulting in stable income and economic stability
Protect against relapse

Resources required
Training required for coaches
Connections with treatment facilities

Departments involved
IDPM/RCO
## Strategy 4: Touchpoints

<table>
<thead>
<tr>
<th>Touch points</th>
<th>Pre-engagement</th>
<th>During-engagement</th>
<th>Post-engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program structure</td>
<td>• Referral (TX) support assistance</td>
<td>• Community knowledge</td>
<td>• Open door policy</td>
</tr>
<tr>
<td>How the program works</td>
<td>• Offer assistance to new individuals in recovery</td>
<td>• Coaching offered on different topics</td>
<td>• Individuals return for refresher coaching or advanced coaching</td>
</tr>
<tr>
<td></td>
<td>• Individuals attend coaching sessions after treatment</td>
<td>• Coaching takes into account past skills and future employment prospects</td>
<td>• Successful clients are celebrated</td>
</tr>
<tr>
<td></td>
<td>• Coaching varies based on individuals’ needs</td>
<td>• Coaching centered in communities or easily accessible places</td>
<td>• Successful cases are communicated within the community for recognition and promotion of the program</td>
</tr>
<tr>
<td></td>
<td>• Coaching sessions connect with employers and small business</td>
<td>• Recovery coaching is incentivized to promote participation</td>
<td></td>
</tr>
<tr>
<td>Identifying/retaining individuals/families</td>
<td>• TX, DOC, DHS</td>
<td>• Daily methods and hours</td>
<td></td>
</tr>
<tr>
<td>Different agencies</td>
<td>• IDPM/RCO</td>
<td>• RCO</td>
<td></td>
</tr>
<tr>
<td>Resources/location for implementing program</td>
<td>• Urban setting • SOR funding</td>
<td>• Urban, SOR, IDPM, private sector</td>
<td></td>
</tr>
</tbody>
</table>
Strategy 5

Title of the program
Helping Kids by Helping Families (HKHF)

Key Themes
Community groups  
Social connections  
Serve children and families

Personas
Maria, Sam and Bill  
Families with children

How does the program work? (Different aspects and structure of program)

The Helping Kids by Helping Families (HKHF) program aims to help families with children during the post treatment phase. The goal of the program is to help children by supporting the entire family. The program works at different level and is catered for all members of a family.

The program will support the following aspects:
1. Affordable childcare: Childcare will include meal plans and activities for children of different ages. It will encourage older children to engage and mentor younger children.

2. Religious and non-religious programming: This will include social connections, community outreach, and access to community groups for families with both religious and non-religious beliefs. Families will be provide information regarding upcoming events and ways for civic engagement.

Key benefits
Reduce social isolation  
Connectivity and support systems  
Family engagement  
Avoid relapses

Resources required
Space, facilitators, incentives, transport and childcare

Departments involved
DOT  
Communities
Strategy 5: Touchpoints

<table>
<thead>
<tr>
<th>Touch points</th>
<th>Pre-engagement</th>
<th>During-engagement</th>
<th>Post-engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program structure</strong></td>
<td>• Social media campaign</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How the program works</strong></td>
<td>• Reaching out to mothers, families and communities</td>
<td>• Childcare with meals and activities</td>
<td>• Satisfaction surveys</td>
</tr>
<tr>
<td></td>
<td>• Communicating the program and its benefits</td>
<td>• Older adults mentoring younger children</td>
<td>• Repeat and re-engage</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Support group for mothers</td>
<td>• Pay it forward: get involved in mentoring and create support groups within the community</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Incentives for bringing friends or families</td>
<td>• Peer mentoring</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Incentives for communities to implement the program</td>
<td></td>
</tr>
<tr>
<td><strong>Identifying/retaining individuals/families</strong></td>
<td>• Families with children who need childcare</td>
<td>• Taper off support from agencies and sustain the program using community connections and resources</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Using existing resources to support children in the community</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Supporting children will prevent intergeneration substance use</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Resources/location for implementing program</strong></td>
<td>• Libraries, community centers, faith-based locations,</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Strategy 6**

<table>
<thead>
<tr>
<th><strong>Title of the program</strong></th>
<th>Peer Support Program (PS)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key Themes</strong></td>
<td><strong>Personas</strong></td>
</tr>
<tr>
<td>Connecting with people</td>
<td>Maria, Sam and Bill</td>
</tr>
<tr>
<td>Social connections</td>
<td>Families with children</td>
</tr>
<tr>
<td>Prevent relapse</td>
<td></td>
</tr>
<tr>
<td>Community building</td>
<td></td>
</tr>
<tr>
<td><strong>How does the program work?</strong> (Different aspects and structure of program)</td>
<td></td>
</tr>
<tr>
<td>The Peer Support (PS) program utilizes community knowledge and parent experiences to develop a multi-layered peer support program. The goal is to support families with SA issues, in-and and post-treatment.</td>
<td></td>
</tr>
<tr>
<td>The program aims to hire individuals after treatment to ensure financial stability. The program will provide tiered treatment and support structure. Affinity groups will be created based on treatment, community and employment prospects. Participants in the program will support each other. The program will utilize community knowledge and parent experiences to build a network of peer support.</td>
<td></td>
</tr>
<tr>
<td><strong>Key benefits</strong></td>
<td></td>
</tr>
<tr>
<td>Someone to listen</td>
<td></td>
</tr>
<tr>
<td>Prevent relapse/overdose</td>
<td></td>
</tr>
<tr>
<td>Community building</td>
<td></td>
</tr>
<tr>
<td>Address economic vulnerability</td>
<td></td>
</tr>
<tr>
<td><strong>Resources required</strong></td>
<td></td>
</tr>
<tr>
<td>Ask people what gaps they experienced and get robust feedback</td>
<td></td>
</tr>
<tr>
<td>Resiliency training sessions</td>
<td></td>
</tr>
<tr>
<td><strong>Departments involved</strong></td>
<td></td>
</tr>
<tr>
<td>HDS, HC</td>
<td></td>
</tr>
</tbody>
</table>
### Strategy 6: Touchpoints

<table>
<thead>
<tr>
<th>Touch points</th>
<th>Pre-engagement</th>
<th>During-engagement</th>
<th>Post-engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program structure</strong>&lt;br&gt;How the program works</td>
<td>• Awareness building partnerships with other organizations/services</td>
<td>• Non judgmental&lt;br&gt;• Resiliency building&lt;br&gt;• Coping skills</td>
<td></td>
</tr>
<tr>
<td><strong>Identifying/retaining individuals/families</strong></td>
<td>• Connect with treatment facilities&lt;br&gt;• Connect with schools&lt;br&gt;• Connect with community leaders and centers</td>
<td>• Create connections&lt;br&gt;• Provide supports&lt;br&gt;• Meet people where they are – personalize and adapt</td>
<td>• Become mentors reach out to others ongoing role and support for everyone</td>
</tr>
<tr>
<td><strong>Different agencies</strong></td>
<td>• Agencies to refer and inform</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Resources/ location for implementing program</strong></td>
<td>• Release from treatment&lt;br&gt;• Direct outreach&lt;br&gt;• Referrals from HDS, HC, ER&lt;br&gt;• Law enforcement</td>
<td>• Flexible and convenient locations&lt;br&gt;• Move from home visiting model to more community based structure</td>
<td>• Become mentor and get paid, ongoing generational support&lt;br&gt;• Workforce development – advance in employment for mentors</td>
</tr>
</tbody>
</table>