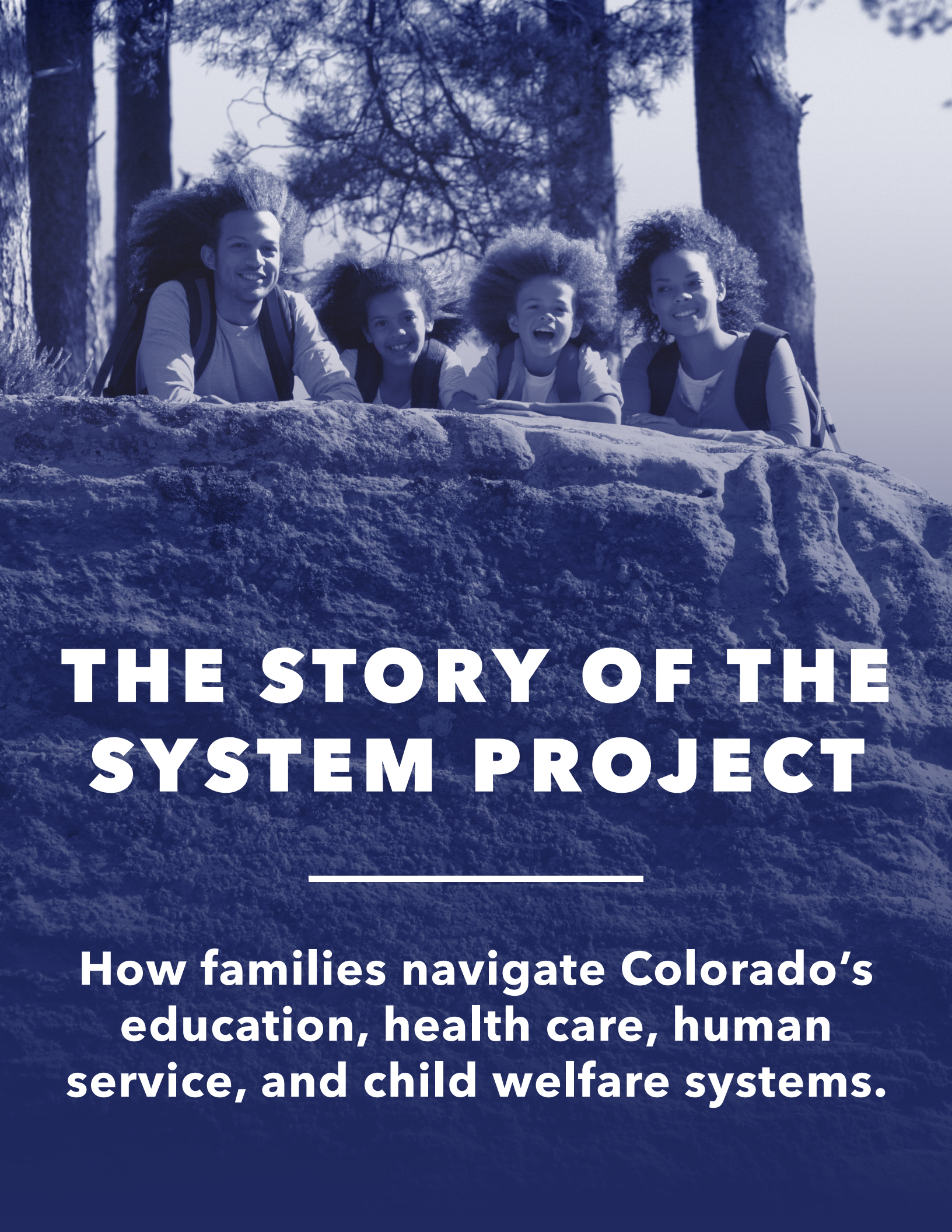




THE STORY OF THE SYSTEM PROJECT

**How families navigate Colorado's
education, health care, human
service, and child welfare systems.**

PROJECT AUTHORS

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PROJECT PARTNERS

**COLORADO PARTNERSHIP FOR
THRIVING FAMILIES**



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"The family is one of nature's masterpieces."

GEORGE SANTAYANA

Spanish-American Philosopher

Overview of Project

In Colorado, families of all social statuses often face the **challenge of navigating a complex web of systems to access essential services and support for their children.** From programs like WIC (Women, Infants, and Children), SNAP (Supplemental Nutrition Assistance Program), TANF (Temporary Assistance for Needy Families), Medicaid, to Child Welfare, and support for children with IEPs (Individualized Education Plan), Read Plans, or developmental disabilities, the journey can be overwhelming. This report delves into the lived experiences of families as they navigate these intricate systems and offers insights into how they can be better supported.

The Colorado Partnership for Thriving Families' "Family and Caregiver Space" is a group of parents and caregivers working collaboratively across the state of Colorado to engage families in **creating conditions that allow ALL families to thrive.** The Family and Caregiver Space (FCS) is an affinity space of the Colorado Partnership for Thriving Families led by, and for, Lived Experts who have been involved in or otherwise touched by various systems that influence family health and well-being. The goal of the FCS is to lead transformative work alongside and collaboratively with professional allies and lived experts that compose the full Partnership.

Five Lived Experts with personal experience(s) led the initial core team of this project across various Colorado systems, like the child welfare system, substance abuse, Medicaid, WIC, SNAP, IEP, Reading Plans, Immigration, and Developmental Disabilities. The Lived Experts worked collaboratively with Illuminate Colorado to conduct research and produce this report.

"There isn't a stronger connection between people than storytelling."

JIMMY NEIL SMITH

Founder of the International Storytelling Center



The Approach

Participatory Action Research Roots

Participatory action research (PAR) is an **approach to research that prioritizes the value of experiential knowledge**. It enables those directly affected to drive action towards creating emancipatory social change. By engaging in systematic research, we can pave the way for improved understanding and support mechanisms to enhance the lives of families navigating these complex systems (Cornish, et al., 2023).

The term participatory action research (PAR) was coined by Hall (1981) to describe “an integrated activity that combines social investigation, educational work, and action” (p. 7).

Differing But Parallel Interpretations

- Seeking information and ideas to improve organizations with organization members (Whyte, 1989).
- Researchers and the oppressed collaborate for social change (Maquire, 1987).
- Cooperative and experimental inquiry “with and for people rather than on people” (Reason, 1988, p. 1).

PAR As An Approach

- Participants are both subjects and active co-researchers (Argyris & Schön, 1989).
- Participants design, research, present, and discuss action implications for study (Whyte, et al., 1989).
- Due to its design, PAR is highly relevant while ensuring scientific rigor (White et al., 2004). Power sharing, mutual respect for knowledge, both researchers and audience learn, action-oriented (e.g. policy, social initiatives)” (Tandon, 1988).
- Power sharing, mutual respect for knowledge, both researchers and audience learn, action-oriented (e.g. policy, social initiatives)” (Tandon, 1988).

Parallel Studies

“Relationships Matter for Youth ‘Aging Out’ of Care” photovoice PAR research project with narratives about perspectives of three of the youth co-researchers of child welfare policy and practices and their experiences in the PAR project (Doucet et al., 2021).

Inside-Out Prison Exchange Program and Street PAR use college students and incarcerated individuals as co-researchers and focuses on transformational reform of perceptions of crime and justice. Seeks to improve prison environments and better transitions from prison to local communities (Payne and Bryant, 2018).

Engaged 21 women co-researchers who accessed a program for women with substance use in pregnancy. Findings resulted in the development of a transition group for those who accessed services, social support, and stronger peer-to-peer mentorship. Findings disseminated to Dept. of Family practice at Univ. of BC and local maternity providers to improve care for women with substance abuse during pregnancy (Gartner et al., 2018).

Methodology

Participants

The participants in this pilot study fall into two categories. The first set of participants come from the four FCS researchers and their families. The second group are people that the FCS researchers came into contact with via snowballing techniques and the utilization of a recruitment flyer that was shared across the state.

Context

This study took place throughout Colorado. Data gathering occurred between July 2022 through April 2024 during which time the **FCS researchers conducted interviews with each other and 34 other participants.**

Recognizing that **people are more than just statistics**, the FCS researchers interviewed themselves and 34 other participants. During those interviews, participants answered various questions via Likert scales, dichotomous, and open-ended questions. The open-ended questions provided the opportunity to **capture information from storytelling.** The FCS researchers gathered written notes (when they heard or experienced something impactful during data gathering and analysis) while listening to stories from participants. The researchers also collected audio and video when participants gave consent for recording.

The FCS research team took a proactive approach to represent the **multifaceted nature of Colorado's support systems** visually. Aiming to highlight the inherent struggles faced by families, the team created the "Brick Wall" visual, illustrating how families often hit a barrier in accessing services, **hindering their ability to move from surviving to thriving.** Visual mapping is a powerful storytelling tool, emphasizing the numerous barriers within the state's systems that prevent families from achieving optimal well-being and meaningful community engagement.

The Brick Wall became an image that participants used while storytelling to **reference a system and explain their struggles/successes.**



Stories

Theme Findings

Qualitative interviews and participant storytelling were used to understand the **cultural entanglement between all social statuses concerning overall family health and access to Colorado systems and their services.** Collecting families’ experiences and perceptions was vital to learning and shedding light on their real-life experiences as they navigated various statewide systems.

Four open-ended questions were posed to each participant, each question carefully crafted around its respective theme. As the FCS researchers analyzed the data, they identified themes that emerged from the shared stories, showcasing the **varied complexities and nuances** within each account. These visuals are a poignant demonstration of the richness of the gathered information, highlighting families’ **diverse challenges in accessing essential services for their children.**

“When the system kicked in and we received benefits, it was such a relief. When the system works, it is helpful.”

PROJECT PARTICIPANT

What Brought Each Of These Systems Into Your Life?

- 1

Lack of concrete support in times of need
- 2

Fighting for conditions where all children thrive
- 3

Child welfare involvement
- 4

Importance of health insurance

The involvement or door that initially ushered families into these systems is exceedingly narrow, often leaving them **feeling overwhelmed as they seek assistance during times of need.** Families consider health insurance to be a vital component of their survival, prompting them to seek aid within these intricate systems. Many families found themselves thrust into child welfare involvement due to various scenarios, with a prevalent reason being a lack of community

support and the struggle to secure consistent assistance when they needed it most. Moreover, **families expressed their relentless fight for their loved ones’ needs,** particularly highlighting the complexity of accessing services such as therapy, child care, mental health support, food provisions, clothing assistance, disability services, and a myriad of other essential resources.

What Successes Have You Had With The Systems?

- 1

Receiving supports
- 2

Advocacy/Voice/
Community Engagement
- 3

Employment
- 4

Financial assistance

Despite the complexities, some families have found success in navigating various systems. Families report: **being persistent with staff, maintaining clear communication, asking lots of questions, keeping a comprehensive paper trail, and being patient are the tools for success.** Notably, the program WIC has stood out as a beacon of efficiency and compassion.

Each participant painted a positive picture of their encounters with WIC, praising the staff and the seamless enrollment process. Families also shared that once their benefits from Medicaid and SNAP kicked in, **there was a peace in not worrying about the cost of doctor appointments and therapy services.**

What Obstacles Did You Face With The Systems?

- 1

Eligibility issues
- 2

Healthcare issues
- 3

Knowledge and understanding
- 4

Financial issues
- 5

Communication issues
- 6

Employment issues
- 7

Other challenges

Families interviewed faced numerous obstacles in accessing support and services. They encountered difficulties with social workers and court systems. Some families found it **hard to navigate the bureaucracy and procedures involved in seeking assistance, often resulting in delays and frustration.** Many families needed to learn about the available programs and services to help them. This lack of awareness made it difficult for them to utilize available resources. Eligibility and enrollment issues were also significant barriers for these families. Some struggled with meeting the requirements for Medicaid and TANF, making it challenging for them to receive the financial assistance they desperately needed.

Language barriers made it difficult for families to effectively communicate their needs and understand the information provided to them. Cultural disparities and bias were additional challenges that these families faced. **The cultural backgrounds and experiences of the families were not always considered, leading to misunderstandings and miscommunication.** This further hindered their ability to access the support they needed. Unhelpful services were another barrier that these families encountered. Some reported receiving services that were not tailored to their specific needs or were ineffective in addressing their challenges. This left them feeling frustrated and unsupported.

What Is The Overall Impact Of These Systems On Your Life?

- 1

Whole family not considered
- 2

Only helpful when system works
- 3

System not dependable
- 4

Decreased mental health
- 5

Habit-forming - dependency

Acknowledging families’ overwhelming challenges when navigating complex systems to access essential services and support for their children is crucial. **The overall impact of experiences resulting from systemic involvement were negative.** Families reported that they endured mental anguish,

dependent habit forming behaviors, and intervention often lacked a whole family approach. Nevertheless, amidst these challenges, **families expressed appreciation for successfully accessing services and receiving much-needed support.**

Stories (continued)

Findings Summary

The findings highlight the importance of **accessible, equitable, and supportive systems** that meet the diverse needs of families. There is a need for improvements in communication, training, cultural competence, and coordination among different systems to ensure better outcomes for families navigating these services.

1

When services work:

Many participants mentioned the importance of various programs and services, such as Medicaid, SNAP, Child Welfare, and IEP, in meeting their family needs. These services have been beneficial to families regarding healthcare, mental health resources, financial support, and educational support.

"When my family receives their benefits without delay and hiccups, we have a smoother month." – Project Participant

3

Positive impact of services: Participants shared positive experiences and success stories about Women, Infants, and Children (WIC). These services have been instrumental in improving their overall well-being and meeting their basic needs.

"WIC is always easy to navigate. I do not dread my check ins and phone calls with my WIC case manager. I feel like they listen to me about my needs and my children's needs. This is my third time working with WIC. Nothing bad to say about this program. They genuinely want to help and do." – Project Participant

2

Challenges in navigating systems:

Several participants expressed difficulties understanding and navigating these services' application, registration, and renewal processes. Some mentioned language barriers, lack of knowledge, and the complexity of the systems as contributing factors to these challenges. This highlights the need for improved accessibility, clear communication, and support in navigating these systems.

"The system is difficult to navigate; before I received higher education I could not navigate services on my own. Now that I have higher education, I can manage to apply for services on my own and manage my own paperwork." – Project Participant

4

Mixed experiences with Child Welfare:

While some participants mentioned positive experiences with Child Welfare, others expressed frustration and negative experiences. Challenges included biased interviews, delayed processes, and lack of support in addressing family issues. This highlights the need for improved training, accountability, and unbiased practices within the Child Welfare system.

"I found that the welfare system often falls short in providing adequate support." – Project Participant

5

Importance of medical insurance:

All participants emphasized the importance of medical insurance for their families. It provides access to necessary healthcare services and medications, and its availability is crucial in ensuring the well-being of their family members.

"Health insurance is valuable. I find peace in knowing our insurance (Medicaid) is active. I worry less about my family's health."
– Project Participant

8

Limited success with specific services:

Some participants mentioned limited success with certain services, such as IEP, SNAP, and Medicaid. They experienced paperwork burdens, lack of progress, and stigma from others. This indicates the need for improvements in these areas to support families better and ensure the effectiveness of these services.

"There is no such thing as a waiting list – it is about a relationship and who you know."
– Project Participant

6

Disparities and cultural challenges:

Some participants mentioned cultural disparities and challenges people of color face in accessing and navigating the systems. This highlights the need for addressing cultural competence, eliminating biases, and ensuring equitable access to services for all individuals.

"No one asked them what they needed – the system made decisions for them instead of taking into consideration my family's cultural needs as a black family living in white America."
– Project Participant

9

Families often become reliant on the benefits these systems provide:

It's vital that families have access to knowledge and training resources to acquire the skills needed to transcend beyond utilizing services and instead become self-reliant. The system should extend beyond offering immediate benefits during challenging times; equipping families with the tools to establish a stable foundation is vital for their progression toward a state of thriving. By empowering families with the resources to graduate from merely receiving benefits to proactively building a sustainable future, we pave the way for long-term success and independence.

"My family has become dependent on our benefits. I cannot afford for my children to not have coverage, and without benefits, we cannot afford to eat every month. I feel like a failure sometimes."
– Project Participant

7

Emotional and financial burden:

Navigating these systems can be emotionally draining, frustrating, and financially challenging for many participants. The stress of registration, renewal processes, and lack of support adds to the burden on families already facing difficult circumstances.

"Some months I live in constant worry and stress. I never know when my families' services will be cut off. Some months we receive a letter saying we have no services and some months we are okay."
– Project Participant

"Storytelling is among the oldest forms of communication. Storytelling is the commonality of all human beings, in all places, in all times."

RIVES COLLINS

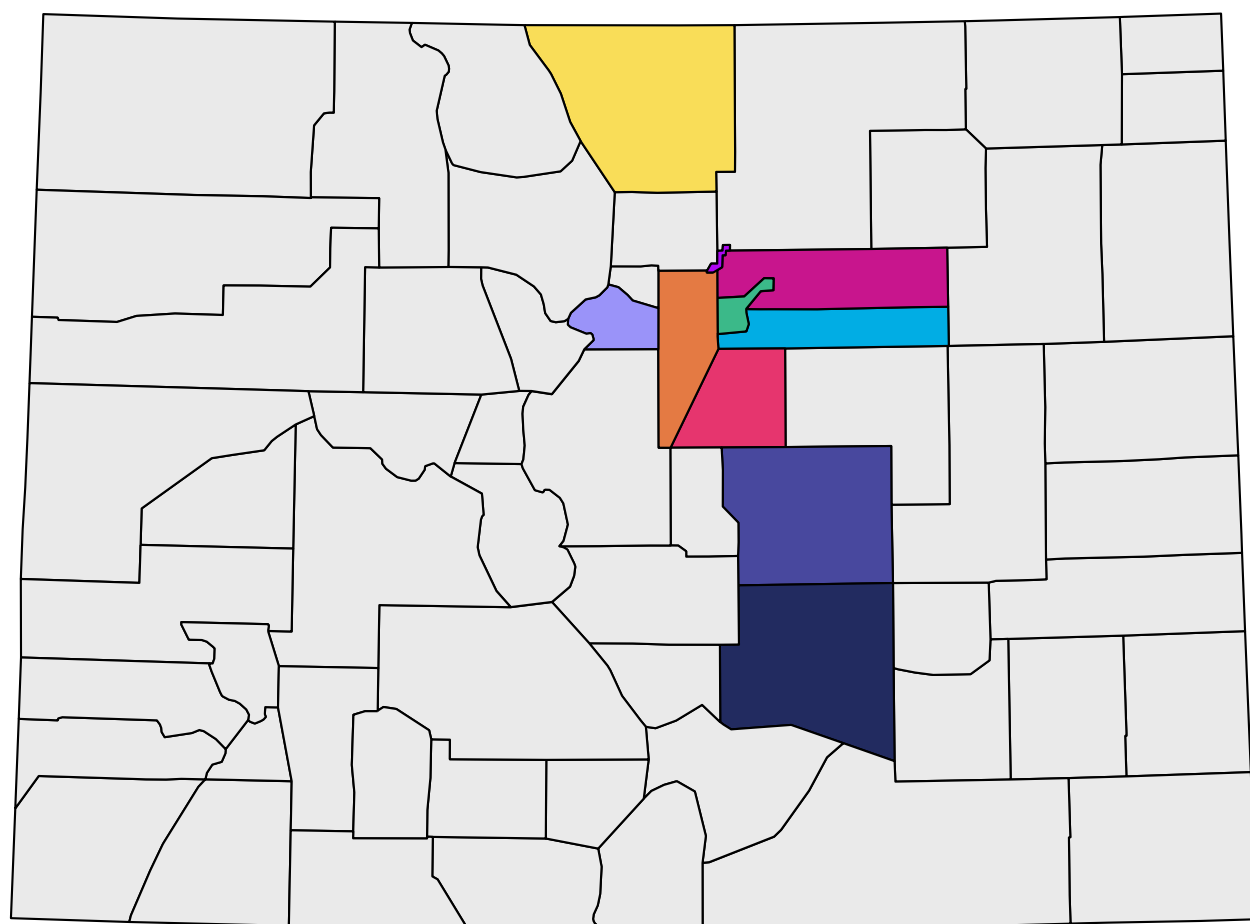
Author, Storyteller, and Professor

Demographics Data

The study included two categories of participants: the FCS researchers and the individuals connected to the system through the co-researchers. The research team interviewed participants around the state. **Of the 50 interviews scheduled, 37 were conducted.**

It is vital to highlight that 100% of participants agreed that health insurance was paramount to their health and their families.

Participant Demographics



16% Denver

16% Adams

14% Arapahoe

11% El Paso

11% Pueblo

11% Jefferson

8% Douglas

5% Larimer

5% Broomfield

3% Clear Creek

78%

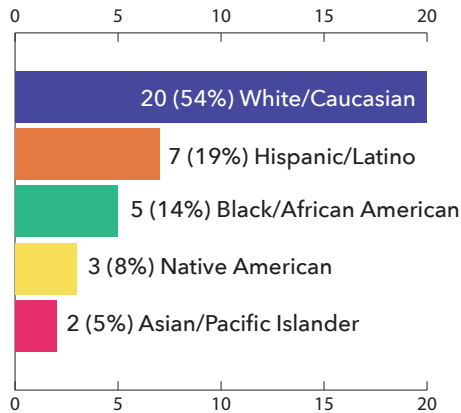
were female participants

22%

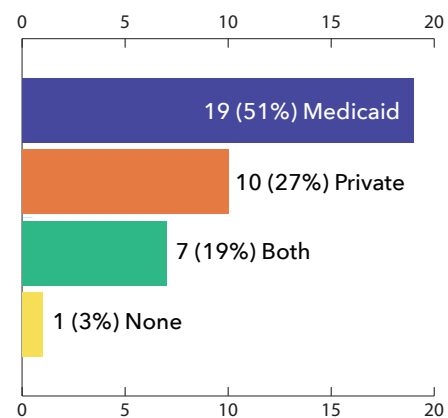
were immigrants

3.27

average number of children
per household



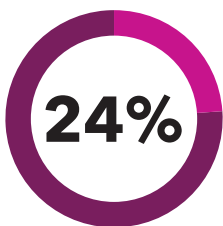
Ethnicity



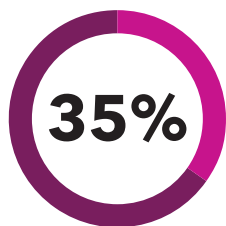
Health Insurance

System Interactions

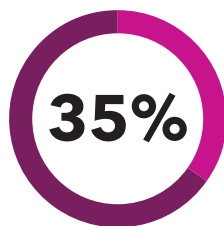
Our interview protocol asked participants which systems they have interacted with from a list that we provided. The systems provided were: **Medicaid, CHP+ (Child Health Plan Plus), Food Stamps, WIC, TANF, FSR (Family Support Registry), Child Welfare, IEP's, Read Plans, and Developmental Disability systems.**



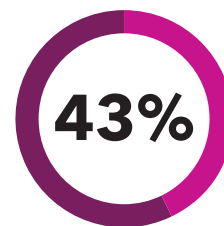
involved with
CHP+



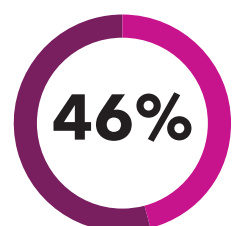
engaged with
TANF



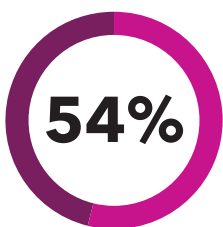
interacted with
Read Plans



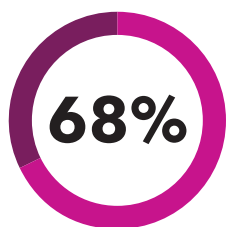
engaged with the
Family Support
Registry



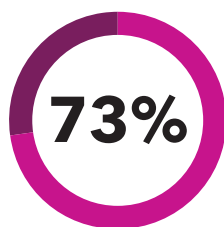
interacted with
Developmental
Disabilities
systems



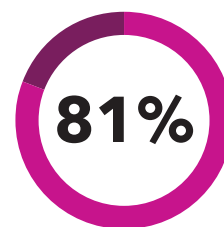
involved with
WIC



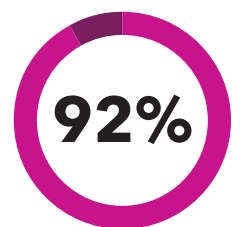
interacted with
the IEP System



engaged with
the Child Welfare
System



engaged with
Food Stamps or
SNAP



involved with
Medicaid



Project Learnings

Trauma-Informed Practices

One of the key aspects that the research team quickly understood was the importance of Trauma-Informed Practices. Having read a book about Trauma Stewardship and completing a Trauma-Informed Training, the team recognized the **impact of trauma on individuals accessing these services**. It is crucial to provide trauma-informed support not only to those receiving services but also to those conducting interviews, who may also be affected by the trauma shared through oral storytelling.

In Person vs. Virtual

Initially, the research team aimed to conduct the project primarily in person. However, during the pilot project, the realization of accessing families across the state proved to be a barrier. We value the in person interactions; however, driving across the state to capture stories was not a valid option for the research team. The study was modified to collect virtual stories only. This adaptation allowed for a more **flexible and inclusive approach to engaging with the community**, and accessing families where they reside in the comforts of their spaces proved to be valuable. We were able to capture candid interactions between the researchers and respondents.

Creating a Resource Document

A suggestion put forth by the research team is the creation of a comprehensive document outlining free to low-cost mental health services available to individuals participating in the project. This resource document aims to provide support and guidance to those who may require additional mental health services while engaging with the System Project. By offering resources for mental health support, the research team hopes to **promote holistic well-being and ensure individuals feel supported** throughout their interactions with the project. This resource document was not created. However, if funding is available in future projects, this document would be vital and helpful.

Scheduling

The pilot project highlighted the challenges faced in scheduling interviews with individuals who have experienced trauma. Recognizing that revisiting traumatic events can be emotionally taxing, the research team learned the importance of allowing individuals the time and space they need. Flexibility in scheduling and understanding the need for potentially rescheduling appointments are essential in fostering trust and ensuring a positive experience for all involved. Before interviews began, we **highlighted to participants that they have the right to stop the interview at any point**.

“No one knows what they are doing and no one has an answer.”

PROJECT PARTICIPANT

Recommendations

The FCS researchers identified these six recommendations

1

Improve communication and clarity within the systems to ensure families understand the processes and procedures.

Enhancing communication channels and providing clear and concise information about the processes and procedures of the systems will help families navigate them more effectively. Creating channels of communication between governmental systems is vital for families to navigate successfully between services. This can include developing user-friendly guides, providing regular updates, providing a resource book of information that outlines to families a road map of what they need to do next and how to accomplish it, creating more jobs for caseworkers, and ensuring families can access knowledgeable staff to address their questions and concerns.

2

Foster a supportive and empathetic approach within the systems, including Family Support and Resource Centers (FSR), to address concerns and provide assistance with empathy.

Creating supportive and empathetic approaches within the systems can enhance the overall experience for families. This can involve training staff members to be empathetic, providing resources and support groups for families, and actively seeking family feedback to improve services.

3

Build a solid foundation of support within the systems to ensure that families receive the quality care they need to support their lifestyle and well-being.

A strong foundation during a family's first touchpoint with a system will ensure that families receive the quality care and assistance they need to support their lifestyle and well-being. This can involve creating comprehensive support networks, providing ongoing training and resources for professionals working within the systems, and fostering a collaborative and holistic approach to addressing the needs of families.

4

Funding on the local level, to community based organizations, supports families with their everyday needs. Community supports help to provide the basic needs of families.

Providing essential items and resources for families in need of support is crucial, especially in rural counties where access to services may be limited. By increasing funding and support for community organizations, families can access the food and tangible items they need to thrive. Additionally, community support can reduce the need for families to interact with systems like child welfare repeatedly, helping to create more stable and secure environments for children.

5

Through our interviews, we heard over and over again that **kinship providers are constantly fighting for the same rights as foster parents.** This is inequitable and doesn't allow all caregivers to thrive.

Foster and kinship parents are crucial, we know that they require a different level of support and care for the children in their care. By increasing funding and support for organizations that cater to Foster and Kinship families, families can access the resources they need to provide a safe and nurturing environment for children in their care. Collaboration is vital to ensuring that foster and kinship parents can access the necessary support and resources. Families can receive comprehensive and coordinated care that meets their unique needs by fostering partnerships between nonprofit organizations and government agencies. We also learned that support groups are a crucial part of gaining knowledge and community for these caregivers.

6

Language Justice is one of those items that should be included in every budget. Every family has the right to understand and absorb the information given to them in all settings.

The ability to access services in the language of a family's heart is paramount for the success of that family while interacting with Colorado systems. Language justice ensures that individuals and families have equal access to services and resources regardless of their language proficiency. This promotes inclusion, effective communication, access to services, empowerment, and cultural preservation.

As families navigate the intricate systems in Colorado, it is crucial to **prioritize transparency, empathy, knowledge sharing, and collaboration** to ensure they receive the support they need. By implementing the recommendations outlined above, we can create a more seamless and supportive experience for families seeking assistance for their children.

"When I found out I was pregnant with my first child, that's when 'family' started to mean something to me. Growing up in foster care, that was not a thing. It gave me a different perspective on what 'family' means."

PROJECT PARTICIPANT

Conclusion

The Story of the System Project examined the **cultural entanglement between all social statuses concerning overall family health and access to Colorado systems and their services.** The study delved into the profound impact of personal experiences on families as they maneuver through various support systems in Colorado. These systems include WIC, SNAP, TANF, Medicaid, Child Welfare, and also extend to families raising children with IEPs, Read Plans, or other developmental disabilities. Through this exploration, we aimed to understand how these experiences influence the pathways and outcomes for families seeking assistance and support. The intricate interplay between personal narratives and the complexities of these systems sheds light on the challenges and triumphs faced by families in need.

Lived experts are in the right place to complete this work.

Our team comprises individuals experiencing systems alongside the families who participated, and we are not affiliated with any of the systems families utilize for services in Colorado. **This unique position allowed us to establish trust and build community with the participants.** Following the conclusion of the study, several participants chose to continue to collaborate with the FCS researchers within the Colorado Partnership for Thriving Families. **Building relationships creates doors for transparency; honest conversations are born from transparency and trust, leading to proactive conversations about how systems can adjust to better serve the families they touch.**

Highlights

- Lived Experts co-created and led the Story of the System Project. The researchers co-created with professional allies from Illuminate Colorado. Illuminate helped to create connections between the researchers and consultants that provided the training(s) needed in order to **conduct research and lead a project of this magnitude.**
- [Foster Source](#) was mentioned as an exemplary organization, having been praised by numerous participants for its invaluable assistance to **foster and kinship families with essential resources.**
- Interestingly, amidst the challenges, **WIC shines as the only system that families found accessible without imposing barriers to their services,** emphasizing the importance of streamlining support mechanisms for families in need.
- This [resource book](#) was created by one of our participants. It is fact checked on a yearly basis to assess if the **resources are actively available to families.**

Authors/Researchers

Heather Hanson



Heather Hanson (she/her) is a Puerto Rican mom of three, a wife, an Applied Anthropologist specializing in Structural Violence, and a passionate Librarian with a deep commitment to systemic change. For over a decade, she has championed the involvement of lived experiences in creating an inclusive society for thriving children and families. Heather is actively engaged in the Colorado Partnership for Thriving Families, the Reimagining Child Welfare Project, and the Story of the Systems Project, holding roles such as co-founder, co-chair, leader, committee member, researcher, and activist. Her leadership emphasizes amplifying lived experiences and advocating for family inclusion in systemic transformations. Heather seeks to foster co-creation, equity, empathy, and knowledge exchange between families and professionals to enhance collaboration and community support. Her vision is to promote family-engaged systems that integrate lived expertise to drive positive change and holistic support for all families.

Fikile Ryder

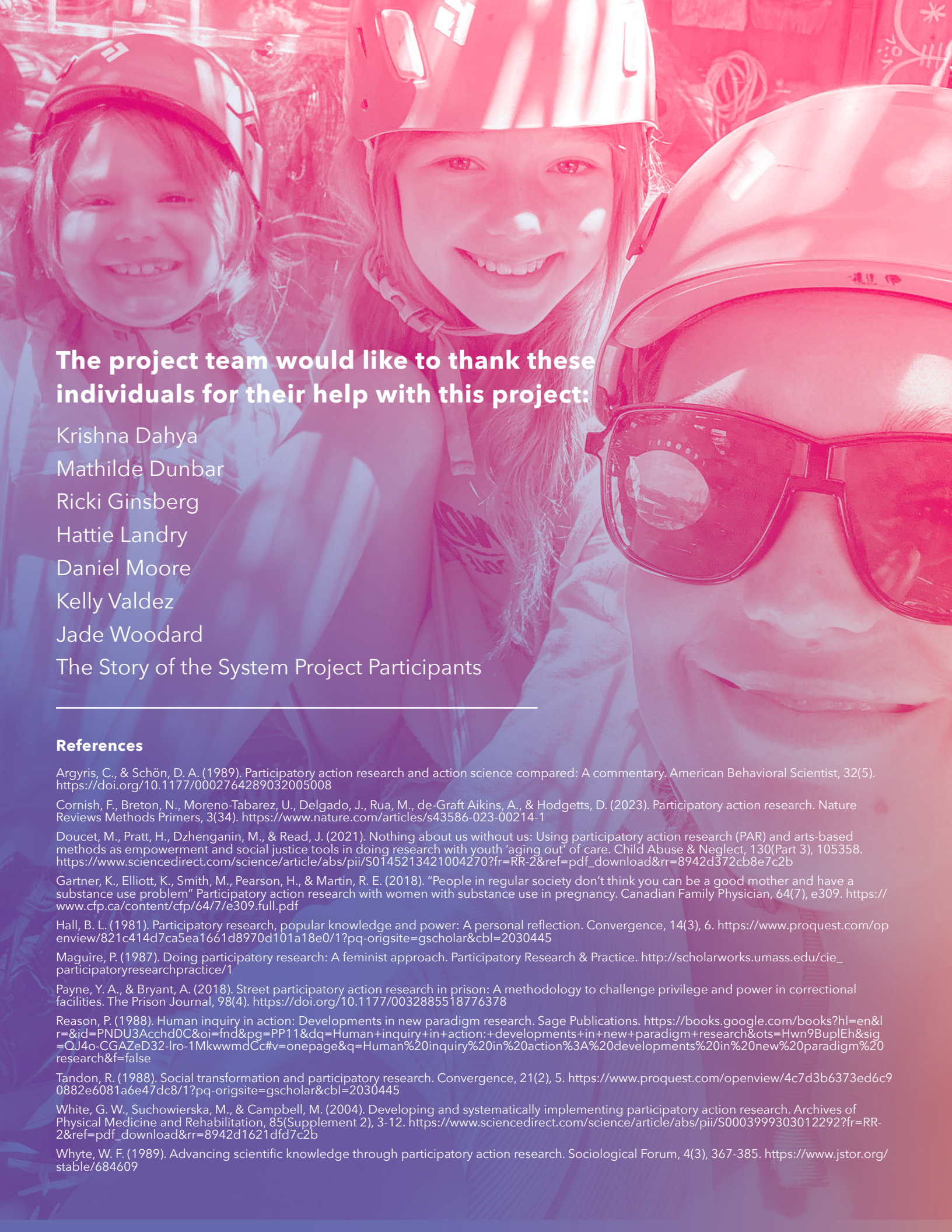


Fikile Ryder (she/her) is a lived experience expert who brings a unique perspective as an immigrant and a dedicated advocate for immigrant families in the community. As a mom of two boys and a supportive wife to a disabled veteran, Fikile understands the challenges and barriers that underserved and overlooked immigrant communities face. In her role with the Colorado Partnership for Thriving Families since June 2020, Fikile serves as a valuable representative, ensuring that the voices and needs of immigrant and refugee families are heard and prioritized. She is a co-creator of the Family and Caregiver Space, providing a safe and inclusive platform for families to share their experiences and support one another. Fikile's contributions as the Co-Chair for the Partnership Policy Workgroup demonstrate her commitment to effecting change on a systemic level. Through her leadership, she actively advocates for policies and practices that promote equity and fairness for Colorado communities. Her dedication to the cause extends beyond her involvement in the Partnership. Her ultimate goal is to create a community where underserved immigrants can access services without fear and experience the support they deserve.

Kaylie Weese



Kaylie Weese (she/her) is a retired military spouse, mom of 4 kids living in Adams County. Kaylie had her fourth child in 2018 and with the little community support that she was aware of, felt like she was alone and didn't exist outside of her children. It was at this time she discovered the Early Childhood Partnership of Adams County and the work of a Community Lived Experience Expert. Her involvement with ECPAC grew from Family Partner to Vice Chair 2 to Vice Chair as her passion and love grew for Community Engagement. Through this work, Kaylie was then hired by the Early Childhood Partnership of Thriving Families as their Family Engagement and Leadership Coordinator to head their family engagement work. Also around May of 2020, Kaylie began working with the Colorado Partnership for Thriving Families as a Family and Caregiver Space member, as well as a participant in many of their other spaces. In 2024, Kaylie was elected as a partnership Co-chair and a Financial Well-Being Space co-chair. Kaylie is also an active advocate for all children, as she is the PTSA President at her children's elementary school, Vice President at their middle school, and District Accountability Committee Articulation Area Representative for the Pomona area where her kids go to school. Kaylie believes that engagement in schools and community are one of the best ways to support families in an immediate fashion.



The project team would like to thank these individuals for their help with this project:

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Hattie Landry
Daniel Moore
Kelly Valdez
Jade Woodard

The Story of the System Project Participants

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