Co-Creating Well-Being

Insights Report for Central and Western New York

Health Foundation
for Western & Central New York
Investing in Better Health for People and Communities

Co-Creating
Well-Being

MAPS

ACTIVITY BOOK

ADULT JOURNAL

Got Married

Finances + a vehicle help get my kids to school

Wants to make friends

Cute boys

Help + support from my family makes things possible. [Caregiver]

Family time important

Family

I found out I'm having this

Safety of family member

Kids & family time

Difficult + crabby kids

Estranged from birth family

healthy baby being born

I am pregnant

Birth of great nephew

Reuniting

Celebrations

Table of Contents

Section 1

Introduction and Background
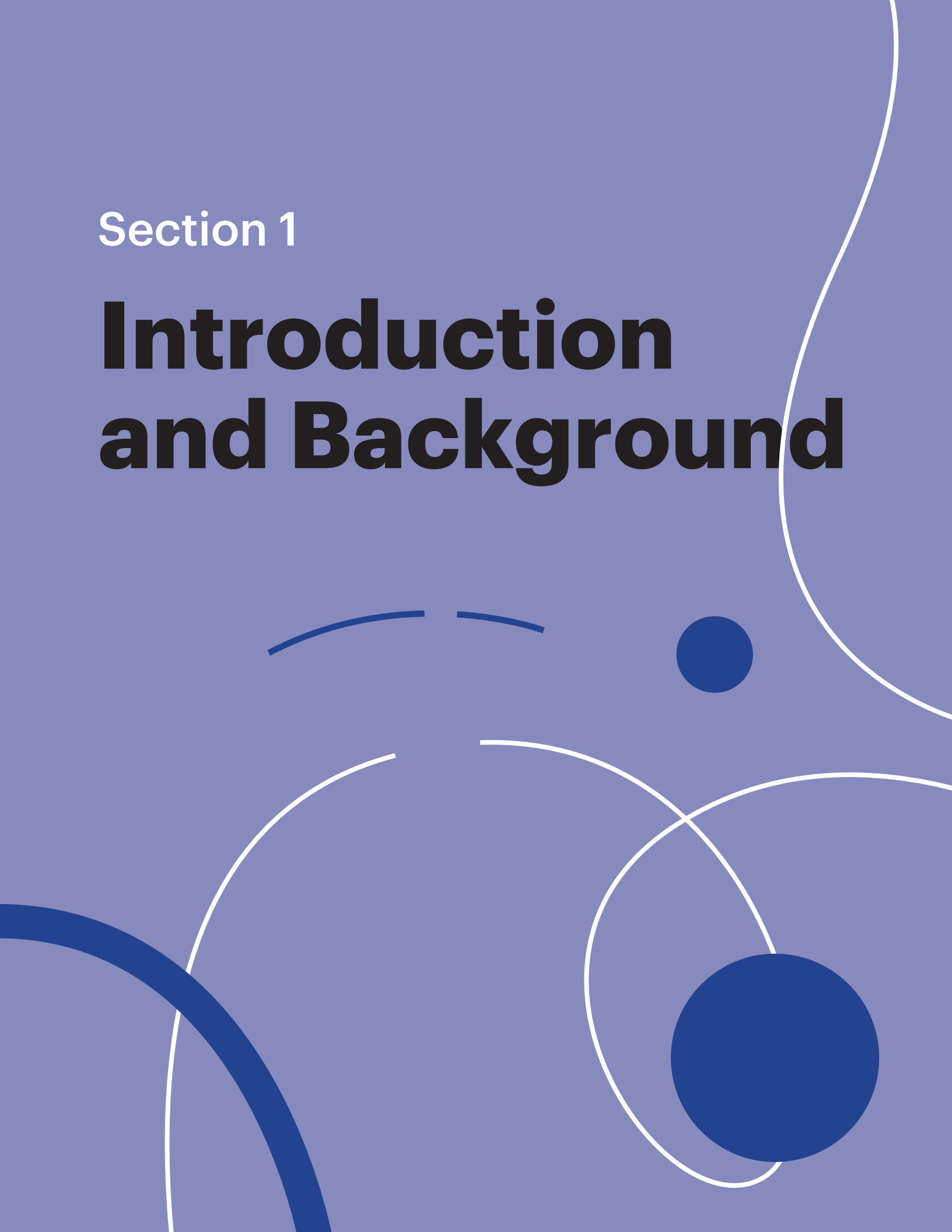
Health Foundation for Western and Central New York

The Health Foundation for Western and Central New York is focused, in part, on assisting families in accessing the care, information, and tools they need so that children are physically, socially, intellectually, and emotionally ready for school. The Health Foundation for Western and Central New York has long acknowledged the potential deleterious effects of circumstances of poverty on families, and in particular on the growth and development of children.

Research shows that, at some point in their lives, nearly half of all people living in the United States will experience a traumatic event. In fact, as many as 90% of children who are in the child welfare system and come from neighborhoods with high crime rates or have parents with unaddressed mental health issues may experience trauma.[1] Further, children may lose a loved one or endure a serious injury, witness or be a victim of a vicious crime, or experience family violence, abuse, or neglect. These vulnerabilities do not only exist in communities impacted by poverty; however, they can be exacerbated by it. The impacts can be both immediate and long-lasting—particularly for young children—and can threaten a child's physical and mental health for the rest of her or his life.

As a funder focused on making sure all young children impacted by poverty are healthy as they enter school, the Health Foundation continues to invest in the development of strong, nurturing community and family environments. This focus led to a scan in 2017 called *Surveying Services and Programs in WNY Engaging Women and Children Who Have Experienced Trauma* that incorporated research and provider interviews. What was learned in the scan led to the 2018 launch of the **Co-Creating Well-Being: Supporting Children and Families Through Trauma Initiative (CCWB)**.

Through CCWB, the Health Foundation for Western and Central New York has partnered with the John R. Oishei Foundation, the Peter and Elizabeth Tower Foundation, the Ralph C. Wilson Jr. Foundation, the Chautauqua Region Community Foundation, as well as government agencies, health and human services organizations, early childhood and clinical providers, and faith-communities.

[1] Benjamin Saunders and Zachary Adams, Epidemiology of Traumatic Experiences of Childhood.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3983688/

It's amazing how people can articulate what their needs and wants are when we ask them, even with simple tools.

– CCWB PARTICIPANT

Why Is This Important Work?

Parents' and children's experiences of traumatic events and toxic stress can create negative birth outcomes, impaired early childhood development, a life-long risk for increased incidence of chronic conditions, maladaptive coping behaviors, lowered educational achievement, and can impede school readiness.

However, we also know that not all individuals who experience trauma are destined to have long-lasting effects. In fact, a conversation that focuses solely on trauma does not acknowledge people's strength and resilience. Exposure to trauma and the response to it (in the form of post-traumatic stress disorder and other comorbidities) contribute to what has been described as a "cycle" of violence and psychiatric vulnerability.[2]

If we are to mitigate the effects of trauma, we must implement a series of strategies centered on universal prevention, targeted interventions/treatments, and adaptations of non-trauma interventions which support the development of protective factors in our children and families and provide a pathway to well-being.

The five key protective factors [3] include:

Parental resilience
Managing stress and functioning well when faced with challenges, adversity, and trauma

Social connections
Positive relationships that provide emotional, informational, instrumental, and spiritual support

Knowledge of parenting and child development
Understanding child development and parenting strategies that support physical, cognitive, language, social, and emotional development

Concrete support in times of need
Access to concrete support and services that address a family's needs and help minimize stress

Social and emotional competence of children
Family and child interactions that help children develop the ability to communicate clearly, recognize and regulate their emotions, and establish and maintain relationships

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[2] Sperlich, M., Seng, J., Rowe, H., Fisher, J., Cuthbert, C., & Taylor, J. "The 'Cycles Breaking' framework: A transdisciplinary, team approach to disrupting intergenerational patterns of maltreatment and psychiatric vulnerability during the childbearing year." (Accepted for 2017 publication at Journal of Obstetric, Gynecologic, & Neonatal Nursing).

[3] "About the Protective Factors Framework." (2018) Center for the Study of Social Policy. https://cssp.org/wp-content/uploads/2018/11/About-Strengthening-Families.pdf

Co-Creating Well-Being Initiative

Co-Creating Well-Being is an initiative of the Health Foundation for Western and Central New York and its partners. It is informed by academic, provider, and community expertise. It focuses on facilitating funding partnerships to expand project reach and is invested in meaningful community partner collaborations.

The goal for the Co-Creating Well-Being Initiative is to support increased skills/technical support for providers as well as better community engagement and inclusion in service design and delivery. It will also expand the availability and type of interventions/programs that address toxic stress, trauma, and well-being. While there are some existing programs and interventions that work hard toward meeting these goals, the reported challenge is that some existing efforts face limited variety/availability, low client uptake, gaps in service, unmet needs, and lack of coordination between services. **There are three integral components to the CCWB Initiative, including human-centered design, trauma-informed care and approaches, and diversity, equity, and inclusion.**

HUMAN-CENTERED DESIGN PROCESS

CCWB takes a human-centered design (HCD) approach to better understand how community and providers can work together to co-design new initiatives, programs and services—a method to solving problems that keeps stakeholders at the heart of the process. There are four core elements to follow that make HCD an especially powerful approach:

Human-centered — the process responds to the actual needs of real people. Starting from the people who are affected, the approach is grounded with the people who are face-to-face with it.

Iterative and incremental — the process helps to minimize the risk of project or program failure because you gradually work up to success, by taking small steps and testing small improvements. The combination of many small improvements can result in new programs and services or will, at the very least, generate improvements across programs and services already in place. We go through the process over and over—it is not a 'one and done' thing.

Collaborative — the approach makes the most of many minds and leverages diversity. It operationalizes collaboration—how to work well with others, particularly those across silos and areas of practice. It helps to structure decision-making and understand where to go next.

Evidence-based — the process is based on what you learn from asking new questions directly of those using a program or service and making some tangible changes in response to what you hear. Empirical evidence is the systematic observation of what is happening 'on the ground'. We develop the evidence needed to make decisions every step of the way. In so doing, we value different kinds of evidence—including trusting people as experts on their own experience.

A TRAUMA-INFORMED APPROACH TO CARE

For many people, trauma can be a difficult, uncertain, and sensitive topic. The principles of a trauma informed care and approach (TIC) do not only apply to the people we serve—they apply to all of us. Even if we are not asking questions explicitly about trauma, it shows up in our day-to-day interactions.

The Substance Abuse and Mental Health Services Administration (SAMHSA) provides six guiding principles to a trauma-informed approach: [4]

Safety — people feel physically and psychologically safe
Trustworthiness and transparency — all decisions made with goal of building/maintaining trust
Peer support — safety, trust, and collaboration come from peers and mutual self-help
Collaboration and mutuality — focus on partnerships and reducing power differences
Empowerment, voice, and choice — recognize and use strengths and experiences as a foundation
Cultural, historical, and gender issues — actively move past stereotypes and biases

> Read more about the principles on SAMHSA's website: **samhsa.gov**

Research shows nearly half of the U.S. population will experience a traumatic event at some point in their lives, such as the loss of a loved one, a serious injury, witnessing a violent crime, domestic/intimate partner violence, abuse or neglect. Recognizing the widespread nature of trauma asks us to acknowledge that trauma is not just an issue for those in the mental health field. Trauma exists wherever people exist—including correctional facilities, addiction support systems, pregnancy and maternity care, health care systems, schools and universities, and even businesses and nonprofit organizations.

When traumatic experiences take place early in life, the implications can be life-long and intergenerational —but they do not have to be. To offset the impact of trauma on children and families, we need to support trauma-informed services and systems in our communities that promote healing and well-being.

Ultimately, a program, organization, system, or person that is trauma-informed **realizes** the widespread impact of trauma and understands potential paths for recovery; **recognizes** the signs and symptoms of trauma in clients, families, staff, and others involved with the system; **responds** by fully integrating knowledge about trauma into policies, procedures, and practices; and seeks to actively **resist re-traumatization**.

CCWB Participant Testimonial

A CCWB participant shared how this Initiative was valuable and different because "it wasn't just a funder meeting or training." Instead, it offered a different experience by making actual work and resources available immediately to help their organization. Through CCWB, their organization received technical assistance, research/evaluation, and program development support that wouldn't otherwise be available. Additionally, the stipend they received for participation made them feel valuable and that the organizational time they were dedicating was appreciated and valued. This leader also mentioned the self-care breaks/opportunities embedded in the sessions were helpful and different from what she had experienced with other funder-driven initiatives.

DIVERSITY, EQUITY, AND INCLUSION

As we work to engage individuals, families and communities as active participants in their health and well-being, it is critical to ensure that we obtain feedback from the diversity of people and families we serve across demographics (i.e. race, ethnicity, age, gender, socioeconomic, levels of ability, sexual orientation, etc.) as well as the diversity of thought. Knowing that particular groups have often been excluded from decision-making and equitable distribution of resources—inclusion requires attention and effort to make sure all voices are heard and valued. Equity employs a culturally and community responsive approach to consider and ensure fairness; creating equality of opportunity to participate in a process/project and provide access of information and resources to all. Diversity, equity and inclusion (DEI) must be considered as a package of sorts; and has significant overlap with Trauma-Informed Care.

When approaching our work with a DEI lens, it is important for us to recognize any assumptions and biases we may carry into our work and our interactions with others. Bias, which can be explicit (outwardly expressed) or implicit (unconscious and largely unintentional), is based on our past experiences and colors our perceptions of the world and others around us, both positively and negatively. We need to be deliberate about our thoughts, words and actions and the power they carry to either empower or marginalize others.

Trauma does not include only specific incidents and events that impact individuals and families; but also ongoing and pervasive issues and systems that have created trauma and significant harm to specific groups, neighborhoods and/or communities. Historical trauma considers how systems of oppression such as colonialism, slavery, war and genocide deeply impact individuals and families across generations, and can impact well-being in similar ways to individual, event-based trauma.[5] Community trauma exists in present day, in relation to extreme housing and school segregation based on race and socioeconomics, community-level violence, police brutality, lack of access to education and employment, etc. These types of community trauma create psychological distress in entire communities, and are largely related to concentration of poverty.[6] Historical and community trauma creates cumulative emotional and psychological wounding over the lifespan and across generations, emanating from massive group trauma.[7]

[4] "SAMHSA's Concept of Trauma and Guidance fro a Trauma-Informed Approach
https://store.samhsa.gov/product/SAMHSA-s-Concept-of-Trauma-and-Guidance-for-a-Trauma-Informed-Approach/SMA14-4884.html

[5] Michelle Sotero, University of Nevada Las Vegas Journal of Health Disparities Research and Practice, Vol. 1, No. 1, pp. 93-108, Fall 2006
https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1350062

[6] Prevention Institute https://www.preventioninstitute.org/publications/adverse-community-experiences-and-resilience-framework-addressing-and-preventing

[7] Dr. Maria Yellow Horse Brave Heart https://www.ihs.gov/sites/telebehavioral/themes/responsive2017/display_objects/documents/slides/historicaltrauma/htreturnsacredpath0513.pdf

Trauma-informed care asks us to "realize, recognize, respond, and resist re-traumatization." Diversity, equity and inclusion, and consideration of cultural, historical and gender issues are vital to doing this appropriately. We must realize and recognize that people we serve likely have negative individual, family, community, racial, and/or historical experiences and associations regarding being asked questions by researchers and/or service-providers. To respond and prevent re-traumatization, we can:

Build trust and collaboration through transparency — explain what our research project is, why it is being done, who is collecting data, where data is being collected and sent, and when/how participants will see results.

Embody and reflect diversity and inclusion — utilize researchers/project team members who are of and from the impacted community and/or have shared life experiences whenever possible.

Use an equity lens — consider barriers that the highest-risk/hardest to reach individuals and families face, including translation/interpretation, transportation, family and work conflicts, and compensating participants for their time and expertise. Quality/diversity of participants through intentional efforts is better than a high quantity of participants.

Living Out an Integrated Approach

Efforts were made to apply human centered design, trauma-informed care, and diversity, equity and inclusion when engaging community partners in the learning methodology. With the understanding that community-based and frontline organizations and are often overworked and under-resourced to meet the needs of the families they serve, we utilized a flexible, adaptable approach for engagement—ranging from self-study to multi-day in-person trainings and robust data collection efforts. Stipends were made available to participating organizations to help offset the cost of their participation and in recognition of the knowledge, skill and "co-creation" of this project. Self-care resources and supports were put in place to encourage participants to care for themselves through the learning process and their daily work. Intentional efforts were made to continuously collect feedback on the learning process itself and incorporate that feedback to meet their individual and organizational needs. Lastly, the project leadership and consultant team employed experts in both TIC and DEI to have an eye on continuously integrating these elements with HCD.

"We are not experts in people's lives, they are their own experts.

— CCWB PARTICIPANT

Three Phases of the Co-Creating Well-Being Initiative

CCWB involves three distinct and interconnected phases that build upon one another. It is a multi-year initiative that spans from summer 2018 to winter 2022. The Health Foundation for Western and Central New York recognizes that service providers across central and western New York are working tirelessly to serve children and families—and often to raise their own—which can impact the ability to engage in additional development and learning opportunities.

With this in mind, the CCWB Initiative was structured to allow for the maximum amount of flexibility for providers to engage in ways that align with their capacity and interest. Whether spending ten minutes to read a blog post or three days attending in-person trainings, all engagement—big or small—is one step closer to building the mindset for human-centered design. Through our collective commitment, we are creating transformative change for children, families, caregivers, and providers in central and western New York.

WHERE WE ARE NOW

PHASE ONE

Building Capacity

August 2018 – March 2019

Building Capacity was completed in early 2019. It invited community-based organizations, government agencies, early childhood centers, faith communities, and clinics etc. to participate in one-day workshops focused on trauma-informed care and human-centered design.

PHASE TWO

Engaging Communities

May 2019 – November 2019

Engaging Communities was completed in late 2019. It focused on building organizations' human-centered design skill set in engagement and data interpretation using a lens of trauma-informed care and diversity, equity, and inclusion. The training was offered using a variety of flexible learning modes, including web-based, self-directed learning, and in-person training. In Phase Two, organizations co-created and distributed engagement tools to hear from children, families, caregivers, and providers about community needs.

PHASE THREE

Action Through Grants

January 2020 – December 2022

Action Through Grants implementation will begin in early 2020. This phase aims to increase the type and number of available interventions and programs for children, families, caregivers, and providers experiencing or exposed to trauma and toxic stress in the community to foster healing and well-being.

Phase One included six in-person trainings with **587 unique attendees** representing **182 organizations** across all **16 counties** in central and western New York.

Phase Two included eight in-person trainings and five webinars representing **308 unique attendees** in **138 organizations** across **16 counties** in central and western New York. Through CCWB, **1,353 engagement tools** were collected to inform community needs.

Section 2

Methodology

DEFINE

Describing the problem as they currently understand it

RESEARCH

Doing the homework on the problem space, context & potential solution spaces

IDEATE

Generating possibilities

PROTOTYPE

Making something in order to make it better

TEST

Soliciting feedback to improve or validate what we've discovered or designed

Human-Centered Design Process

Co-Creating Well-Being Approach: Human-Centered Design

At its core, human-centered design (HCD) is an approach to problem-solving that puts the knowledge and needs of people experiencing a problem at the center. The Human-Centered Design Cycle outlines the major modes of working in any project, including Design, Research (Community Engagement), Ideate, Prototype, and Test.

HCD provides a toolkit for deeply understanding people's needs and experiences, generating ideas to meet those needs, and then testing solutions with—and learning from—the people that will use the program or service. Through our work and research around the needs of children, families, caregivers, and providers, we learned that developing and investing in programs and interventions that reach and appropriately meet the needs of this group must be continually evaluated, developed, and expanded upon.

Human-centered design emerged mainly in product system industries from an exploration of theory and practice in a range of disciplines and sciences. Its purpose is to address the human, technological, and strategic innovation needs of our time. For example, in response to a lack of clarity in the emergency room during times of crisis, the leader of the trauma team in a New York City hospital now wears an easy-to-spot orange vest. This has resulted in improved communication and role clarity among trauma team members as it is now clear who is in charge. Further, there are countless examples of human-centered design being used in the technology industry, such as in the creation of Apples' first computer mouse, Spotify, and Fitbit.

However, because of its intentional focus on people's experiences, HCD has been able to shift its focus away from creating artifacts or "things" towards solving complex problems. We now know that it is as useful for improving social challenges, designing interfaces, systems, and services as it is for consumer products. HCD is a process for solving complex problems by putting creativity and empathy to work.

Engagement Methodology
Design Research

Design research provides the practical underpinnings of human-centered design. It is research that starts by engaging people to understand their experiences in order to design—or improve via redesign—services, programs or products. It uses the methods of design itself—such as behavioral observation and iterative prototyping—to gather and synthesize information. Then we reason inductively, using insights that have been observed from real people to arrive at conclusions about things that we haven't observed ourselves (e.g., poverty, trauma, toxic stress). Insights gathered using this method can be communicated visually, with physical objects, or with reports and briefs.

Design research is especially well-suited to developing clarity in complex or changing situations with many and varied stakeholders. Consequently, it is the foundation of user experience design, service design, and community engagement. Design research is how we understand people's needs from their perspective, rather than relying solely on Census figures or county-level statistics to frame a challenge.

With design research and the concept of grounded theory discussed below, we go to the literature **after** collecting data from people. This is different from deductive approaches that go to the literature and pre-select a topic **before** starting the research process.

Interpretation Methodology
Grounded Theory

The types of information we gather determine the types of questions we can answer. Quantitative information—data we can measure or count—can help us work out who is affected by a situation, as well as where, when, and how often. But to uncover what's happening and investigate why it happens, we need to ask open-ended questions and collect qualitative information—descriptive data that are harder to 'sum up'. We need to gather responses without judgment, then review and compare them to discover patterns, trends, and possibilities.

One of our most fruitful methods for interpretation is grounded theory, so-called because it collects data from people experiencing a certain challenge 'on the ground,' and then produces a theory from this 'grounded' data. This is an inductive research method developed for the social sciences by Glaser and Strauss in the 1960s. Instead of designing our questions and topics before engagement, we instead start with engagement and watch as key topics emerge from the observations. The observations around those topics are organized in a way that identifies important patterns or categories.

We used grounded theory for interpreting data during Phase Two because it is an exploratory, descriptive method for developing hypotheses about what's going on. It is a common research method used in the field of nursing, patient care, and for those experiencing trauma and toxic stress. Grounded theory is an approach that helps us turn interviews, observations, and interactions into insights. It enables real people to tell us what themes and insights are important to their well-being

Looking for further information on grounded theory?

Grounded theory creates a bridge between our understanding of how systems and society ought to work, compared to the reality we observe and experience in daily life. **There are eight research practices that are used to enhance rigor in the use of grounded theory:**

- Let participants guide the inquiry process;
- Check the theoretical construction generated against participants' meanings of the phenomenon;
- Use participants' actual words in the theory;
- Articulate the researcher's personal views and insights about the phenomenon explored;
- Specify the criteria built into the researcher's thinking;
- Specify how and why participants in the study were selected;
- Delineate the scope of the research; and
- Describe how the literature relates to each category which emerged in the theory

"Awareness of Dying" (1965) and **"The Discovery of Grounded Theory"** (1967) are landmark books published to highlight and advance the use of grounded theory. Glaser and Strauss attempted the gaps between theory and practice, encouraging other researchers to look at new techniques for conducting research. By starting with a broad subject—dying—instead of a specific hypothesis, Glaser and Strauss they were able to induce on understanding of the awareness of dying in one area of the hospital and build on that understanding by visiting other areas of the hospital. This helped them better understand the impact awareness of dying has on interactions throughout the hospital environment.

"Patient participation: a prerequisite for care" (2017) by Carlsson, Nygren, and Svedberg is a great example of grounded theory used to research patient participation in health care in a pediatric context. For those wanting a more technical and research-oriented description of the method, check out **"Grounded theory research: a design framework for novice researchers"** (2019) by Tie, Birks and Francis.

Phase Two Learning Methodology

Phase Two of CCWB built on Phase One by supporting organizations to continue to expand knowledge and expertise in human-centered design through the following learning opportunities:

Self-Directed and Web-Based Learning

Self-Study Resources include a series of HCD tools and resources such a blog posts and videos to help service providers learn more about the needs of children, families, caregivers, and providers in the community. These resources were available for organizations to access online whenever needed. Additionally, a series of one-hour webinars were posted to the **Co-Creating Well-Being website** and will continue to be available through Phase Three of the project.

Webinar topics included:
• Project Overview and Asking Better Questions
• Trauma Informed Care and Diversity Equity & Inclusion
• Connecting with Children: Activity Book
• Adult Journal and Engagement Guide
• Data Interpretation

All participating organizations also had the option to attend in-person training on human-centered design engagement and data interpretation.

## In-Person Advanced Human-Centered Design Engagement Training

Over summer 2019, six two-day Advanced Human-Centered Design training workshops were delivered across central and western New York. The workshops focused on developing the principles of a design research mindset using the lens of trauma-informed care, historical trauma, and diversity, equity, and inclusion. Participants left with an individualized engagement plan for next steps around data collection to support CCWB and work beyond this Initiative.

PHOTOS FROM IN-PERSON TRAINING SESSIONS

In-Person Data Interpretation Training

In fall 2019, two-day Data Interpretation training workshops took place in both central and western New York. This training provided a mix of learning about the transcription, analysis, and synthesis process, along with hands-on opportunities for organizations to apply those learnings directly to their data through the CCWB Initiative. The training culminated with a generative card sort— a sensemaking model based in grounded theory— where the themes across all data came together to form interesting insights about life for children, families, caregivers, and providers across central and western New York.
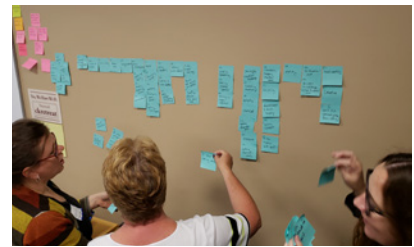
PHOTOS FROM IN-PERSON TRAINING SESSIONS

About the Training Participation

Engagement trainings were held in Buffalo (twice), Ellicottville, Rochester, and Syracuse (twice). The interpretation trainings took place in Buffalo and Syracuse. Across these eight in-person trainings and the five online webinars, 308 unique attendees participated, representing 138 unique organizations across 16 counties in central and western New York.
The self-study resources available on the CCWB website also received over 100 unique visitors each month.

Engagement Tools

Through CCWB, organizations in central and western New York collected stories to better understand life in the community using co-designed qualitative engagement tools. The engagement tools ranged from light touch methods for gathering a quick snapshot of a person's current experience to more in-depth methods where people had the chance to reflect on their day over multiple days. The CCWB team received feedback from community partners at each training and incorporated it continually.

There were five main engagement tools used to inform the CCWB Initiative. These tools were co-designed with the community and local experts in trauma-informed care, historical trauma, and diversity, equity, and inclusion. They included the Postcard, Emoji Wheel, Empathy Map, Activity Book, and Adult Journal.

Light Touch Engagement Tools

Light touch engagement tools offered participants the opportunity to share a quick snapshot of their life at a specific moment in time. Light touch engagement tools used in the CCWB Initiative included the Postcard, Emoji Wheel, and Empathy Map. These tools were also translated into additional languages based on needs identified from communities.

POSTCARD

The Postcard is a tool that provides a quick and easy way for people to share some information about their lived experience. With the exception of a few basic demographic questions, the postcard had just two prompts:

- If you really knew me...
- I consider my biggest challenge to be...

A COMPLETED POSTCARD

EMOJI WHEEL

The Emoji Wheel is a tool easily accessible for young children, families, caregivers, and providers to reflect on their day and emotions together. The caregiver asks what happened in the child's day and helps the child identify which three emojis they are feeling. The caregiver also participates by choosing three emojis and reflecting on their day. The Emoji Wheel helps to gain an understanding of the general state of both the child and caregiver.

A COMPLETED EMOJI WHEEL

EMPATHY MAP

The Empathy Map is a simple, flexible tool to focus a conversation on a person's sensory experience. It can be used to guide a conversation or filled out by a person to reflect on their experience. The Empathy Map is a way to learn more about the perspectives of a range of stakeholders, from young children to adults.


A COMPLETED EMPATHY MAP

In-Depth Engagement Tools

The in-depth engagement tools are much more detailed and designed to promote reflective thought and future thinking over a longer period of time. They also incorporate the education and training compiled for the CCWB Initiative around mindfulness and well-being for children and adults. The two in-depth engagement tools used in the CCWB Initiative were the Activity Book and Adult Journal.

ACTIVITY BOOK

The Activity Book uses the art of play to increase understanding of young children's worldview. It is a fun and engaging way for children of all ages to share experiences about their day over multiple days, as well as learn and process their feelings through focused conversations between a child and caregiver. It also includes mindfulness exercises geared toward children that focus on awareness of breath and being present such as the Emotional Dice Activity and Sunshine Breathing. The Activity Book allows for a deeper level of reflection and can be completed over a two-week period.
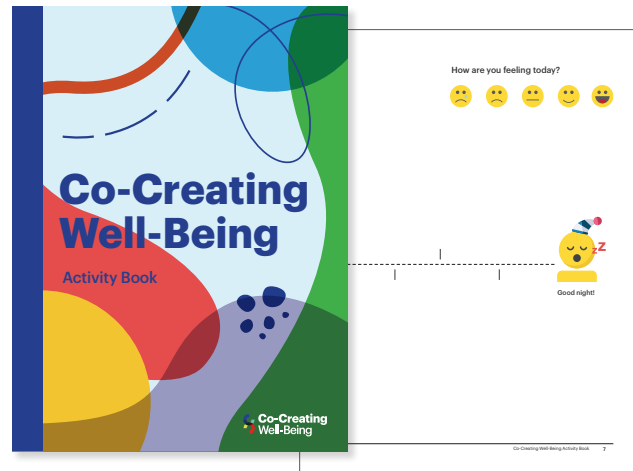
THE ACTIVITY BOOK

ADULT JOURNAL

The Adult Journal asks open-ended reflective questions geared toward adults to reflect upon several days over a two-week period. It also asks questions around specific topic areas such as getting around, hopes and dreams, physical and mental health, getting support from professional services, and words of wisdom. Dispersed throughout the Journal, there are blank pages where people can draw or take notes about their day in a way that makes sense for them. Additionally, this tool includes a series of mindfulness worksheets geared toward adults.
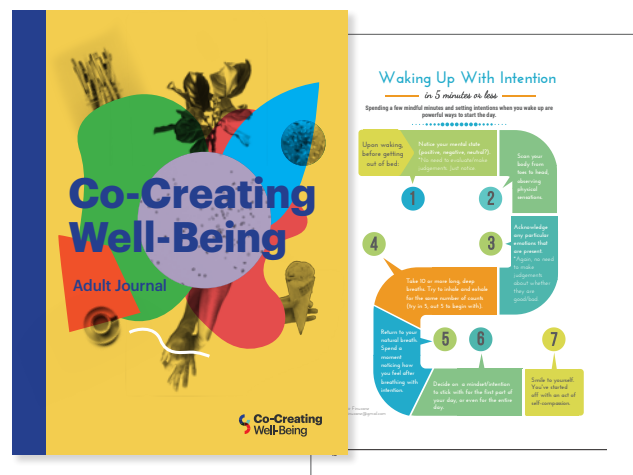
THE ADULT JOURNAL

Copies of the **Engagement Tools** and **Support Materials** can be downloaded from the **Co-Creating Well-Being website**.

Support Materials

In addition to the engagement tools, a number of resources have been made available on the CCWB website, including the Engagement Guide, Feedback Grid, and tips for Starting Solo.

ENGAGEMENT GUIDE

This Engagement Guide walks you through what you'll need to consider as you decide to use the light-touch and in-depth engagement tools. We've simplified it into 4 key steps:

- Build a Foundation
- Develop A Plan
- Iterate
- Practice and Learn
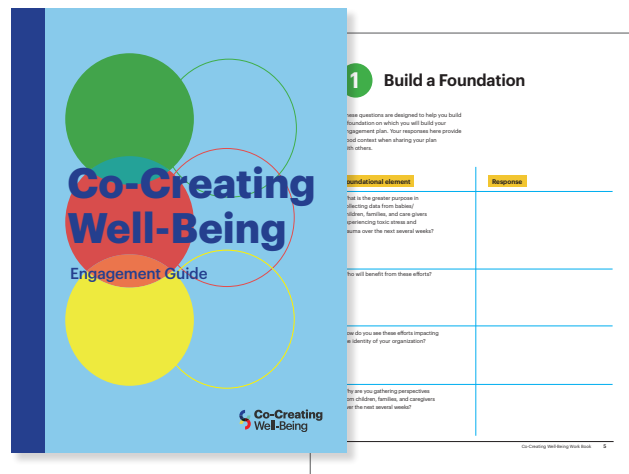
THE ENGAGEMENT GUIDE

Data Collection

Organizations distributed engagement tools in a variety of locations and contexts—as part of one-to-one clinical sessions, support groups, staff meetings, community events, as well as in waiting rooms and other public areas where children, families, caregivers, and providers receive support. All engagement tools were anonymous and completed voluntarily.

In total 1,353 engagement tools were submitted—approximately 70% of the tools were from western and 30% from central New York.

Specific breakdown included:

1,176 postcards	**29** journals
87 empathy maps	**4** activity books
42 emoji wheels	**15** feedback grids

Counties represented included:

Central New York	**Western New York**
Cortland	Allegany
Madison	Cattaraugus
Onondaga	Erie
Oswego	Niagara
	Orleans

It is recognized that there were a number of counties not represented in the data, and it is important to reach out to hear their voices as we move forward.

How to Read This Report

How to Read This Report

This report includes a series of Insights and Themes that emerged through the data in central and western New York. For each Insight, we have included a short description, illustrative quotes, and "How Might We" questions. There are also five Personas included for central and western New York, plus two Personas for children that are relevant to both geographic areas.

Quotes

Quotes represent direct comments made by participants captured through the CCWB engagement tools. They come from a variety of children, families, caregivers, and providers unless explicitly stated otherwise. Read the quotes over multiple times and let them inspire you. They speak directly to people's everyday lived experience.

Personas

Personas are fictionalized accounts of people's lives based on the engagement data. They are part fact, part story-telling. They are general enough to represent a broader community but specific enough to help us imagine a real individual and their needs. These profiles were created to capture the experiences and stories of those participants in the CCWB Initiative.

Personas provide ideas and inspiration for design. They can be used to inform strategic decision-making and to drive action. They can also be used to see overlapping needs across different demographic groups and provide a starting point for how to meet these needs.

Five Personas for each of central and western New York, plus two Personas of children that are relevant across both geographic areas have been created.

"How Might We" Questions

"How Might We" questions help us to get started with developing problem frames. We will use these in conversations with children, families, caregivers, and providers to understand which problems are priorities for them and which problems we didn't hear about through our data collection. Giving people the opportunity to fill in any perceived gaps helps build trust in the engagement process.

As you read through the Insights, think about and record your responses to the following questions:

- What stands out to me?
- What spoken and unspoken challenges are represented in the Insights?
- What strengths are people communicating through these Insights?
- Which solutions to existing challenges are currently working and which are in need of improvement?
- What are some new solutions that don't already exist for these challenges?
- What do I need to take from this to improve what I am doing?
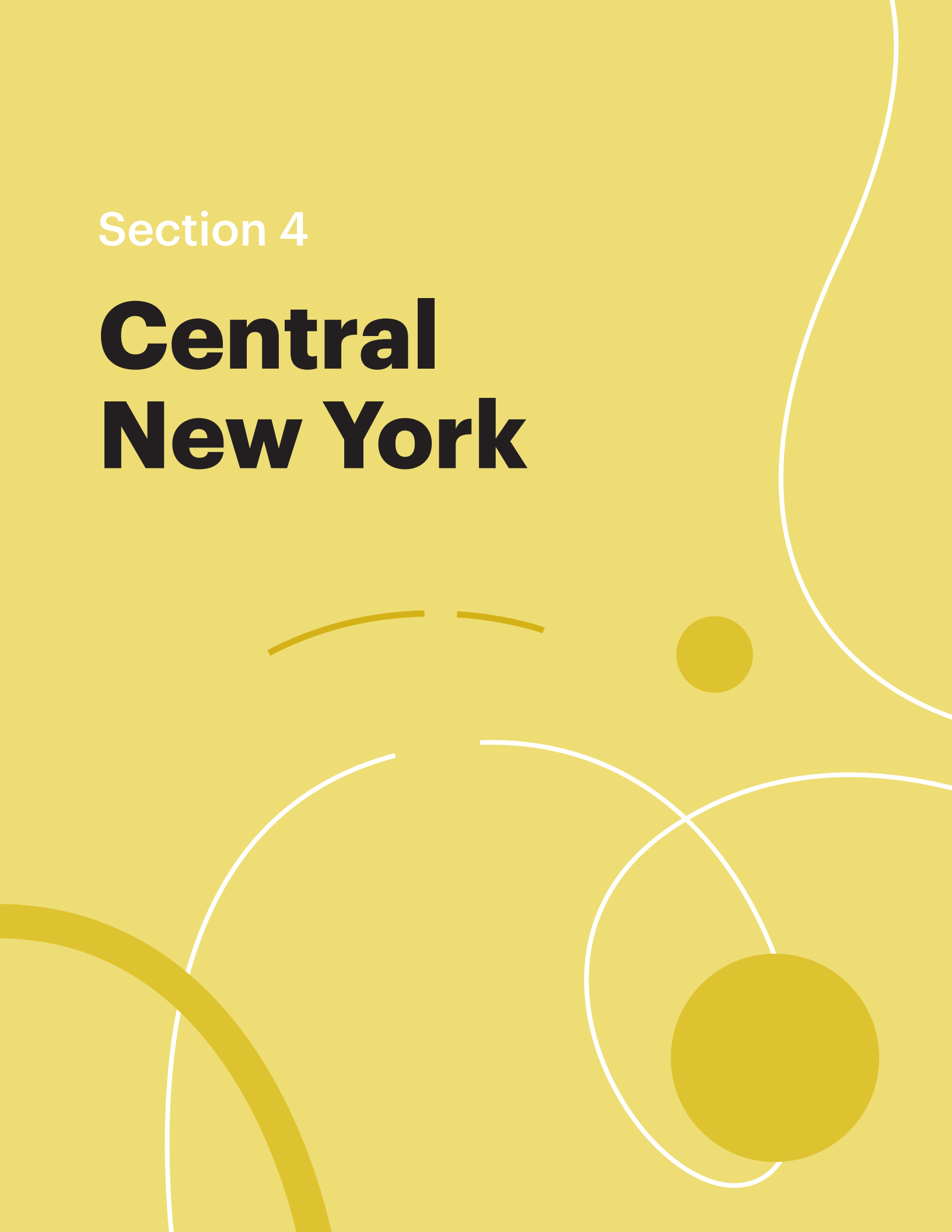- Now that I know these things, how do they square up with what we are doing?

For more details, download the accompanying **Detailed Research Summary for Central and/or Western New York.**

Section 4

Central New York

Insights and Themes

INSIGHT 1

It can be hard growing up in central New York

Kids, families, caregivers, and even some service providers shared with us the difficulty of everyday life in central New York. From needing more agency and respect, to the stress of figuring out their life, people articulated what impacts them from their past, present, and even thinking about their future. Beyond the effects of past and current trauma, this included the importance of a strong sense of belonging, including feeling worthy, having stable friendships, and having a connection to community.

"Some days are too hard"

"Sometimes it's just getting through the day, but typically it's making sure my room is clean"

"Broken things—a vacuum, barn steps, leaky roof, van, and crazy relatives warring with each other"

"Having the will power to say no"

I need to be reminded that I am important

We heard a lot from people that knew, understood, and were trying their best to use practices in their day-to-day life to improve their well-being. At the same time, people expressed the difficulty of juggling so many things at a time, including supporting others, quality housing, and navigating relationships. Despite the hurt experienced and resulting low self-worth, people expressed gratitude and a willingness to put in the effort to improve their coping skills and self-care routines.

"I am a people pleaser"

"If you think you're small, try sleeping in a room with a mosquito"

"I'm trying hard to be the best person I can be"

"Unlucky in love"

INSIGHT 3

I need you to know that I've lived a long and difficult life

In short day-to-day interactions, it's so rare to have a chance to get to know someone at a deep level. This Insight speaks to the importance of a grounded self-image and the difficulty of being one's true self with others. Trauma, loss, and physical and mental health all impact people in different ways. People want to build on their strengths to make positive changes in their lives, and need genuine empathy and the support of others to help them get there.

" I have deep thoughts
although I am funny
and laugh a lot"

"You'd know I am an orphan
and a helicopter mom"

" You would know how
much pain I go through
on a daily basis"

" I hate drugs
and alcohol"

> **You would know that I am dealing with a lot all the time. And it won't ever change**
>
> – CCWB PARTICIPANT

INSIGHT 4

I am doing all I can to hold it all together
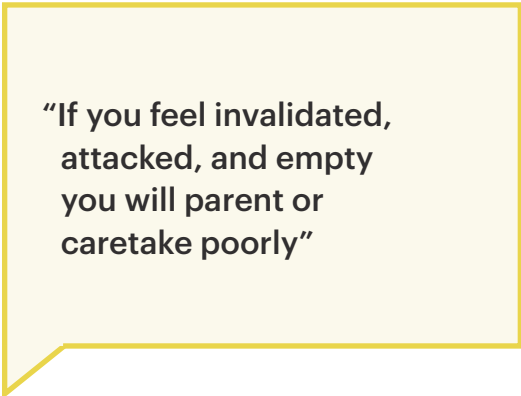
The way people face obstacles standing in the way of improved well-being looks different for those residing in urban and rural areas. People told us they are doing their best with what they have, but that transportation, a lack of resources, and ineffective time management all impact their capacity to hold everything together. Specific examples of things that would help them get through the day better include improved life/work balance, financial literacy skills, and emotional support.

"I can't breathe"

"My smile is held together by a string but still I smile. I am strong"

"I am an organized disorganized disaster"

"I hide my feelings"

Parenting is hard
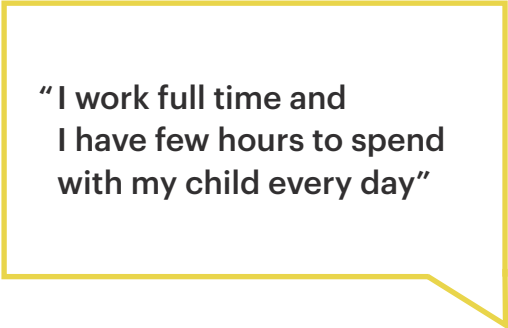
Families and service providers shared with us the stress of caregiving. Supporting kids is hard no matter what your situation. However, perilous family dynamics, competing priorities on their time, and a lack of sufficient resources make the challenging times that much more difficult. People wanted more time to spend on self-care activities that help them recover, like going outdoors, cooking a proper meal, and reading but find it difficult to prioritize when basic needs are not being met.

" I am very friendly and I only wish to be a good father"

"If you feel invalidated, attacked, and empty you will parent or caretake poorly"

" I work full time and I have few hours to spend with my child every day"

" I have seven kids and I need help"

INSIGHT 6

Even though I have uncertainty, I am fine

The feeling of ambiguity or not knowing what is going to happen next takes its toll. People told us that navigating different traditions and beliefs makes it hard to be sure they, or people they know, are doing the right thing. This can surface through worry for loved ones, needing more support to help with emotions and feelings, or discomfort discussing sexual health. Still, many people said despite the difficulty, they know they are doing the best they can.

"I like to smile and never give up"

"I always think everything is going to work out even when things are looking grim"

"Pizza and a beer and a talk with a friend are very helpful"

" I value time to reflect"

This is my life as a refugee in central New York
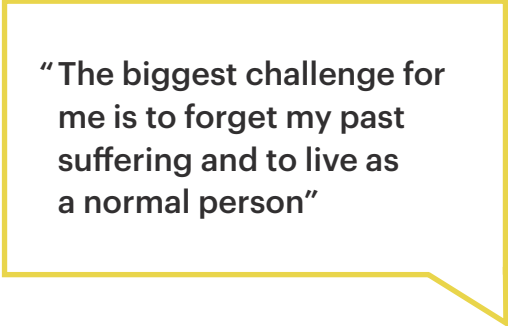
We heard from refugees and similar communities that they find it difficult to stay connected at a distance. By attending community events and connecting virtually, people are trying to increase their sense of safety and belonging. They still need help understanding and managing the impact of stress and anxiety, broader mental health challenges, as well as self-care and coping skills. Adapted or new supports addressing these concerns are also needed considering how difficult it is to get around different communities.

" After a very tough
summer, I need joy
and music for my
soul to heal"

" Optimism is not
always realistic, but it
wards off the worry"

" The biggest challenge for
me is to forget my past
suffering and to live as
a normal person"

" You would be
amazed I really
am a nice caring
person"

INSIGHT 8

I know what I need, but don't have the resources to make it happen

A common theme we heard from children, families, caregivers, and service providers was their inability to put themselves first. As a result of past trauma, people don't know where they fit in the world, are hard on themselves and others, and find it difficult to connect with others on a deeper level. They know that self-care and good coping mechanisms are important, but sometimes lack the resources or energy to follow through—impacting their ability to heal.

"Although I wear a smile on my face, I fight battles on the inside"

"You would probably say I focus too much on other people"

"If something can go right for us for once without anything getting in the way"

"You would be surprised how insecure I really am"

I've experienced trauma, but I want to move on

This Insight highlights the resiliency that exists in our system. People want to move beyond their trauma and reduce its impact on their day-to-day life but need time to process and heal. Working through trauma and building up new, positive practices takes a lot of energy for people and the service providers they engage—from self-reflection to community-building activities. People also need help navigating available resources and supports.

" I love imagination stories and movies because it helps forget past suffering"

" I need a day to process/recover from listening to trauma"

" Doing away with 'if someone hits you, you hit them back'"

My biggest challenge is feeling "safe"

INSIGHT 10

It's hard to do right for myself and others

People want to do the right thing, but past experiences have impacted their ability to trust others and deal with conflict in a healthy way. People are moving forward by telling their story and listening to the stories of others, by fighting back against discrimination, and working through loss in a constructive way. To move in the right direction, people need access to the right education, access to their faith, and access to time and space to relax and feel joy.

"Not set myself on 'fire' while keeping everyone else warm"

"I am a support to others at my job and in my personal life. I feel needed and feel like I am useful to the world"

"I use humor to avoid confrontation and uncomfortable situations"

"I focus too much on other people"

Personas

Archie, 18 months

Preferred pronouns: he/him **Location:** Morrisville, New York

"No, no, no, no, no!"

Archie likes to play toy trucks and dolls with his cousin, but has a difficult time sharing. He loves the word "no" and drinking juice during snack time. Archie does not like napping and he always gets his mom up at 5 am. When his diaper rash is hurting, sometimes he is awake all night crying. He wishes he could tell his mommy just how much it hurts.

Aarya, 26 months

Preferred pronouns: she/her **Location:** Auburn, New York

"I don't like picking up the toys when I am done."

Aarya is very curious and independent. She likes to run up and down the stairs while hollering at the top of her lungs. She always wants to feed herself and doesn't want any help with that. She points to the different characters and animals when being read a book and whispers their name—cat, dog, horse! Aarya recently started dropping things—especially toys—on the floor but does not like picking them up. She finds loud noises and going to the potty to be really scary. Aarya has a lot of strong emotions and has a hard time putting words to them. She loves drawing pictures on paper—sometimes that is a way that she shows what she is feeling on the inside.

NOTE: The first two personas appear in the lists for both central and western New York.

PERSONA 3

Mason, 11 years old

Preferred pronouns: he/him **Location:** Syracuse, New York

"I hate drugs and alcohol."

Mason is in the sixth grade and gets good grades at school—he is tough on himself when he makes mistakes. He loves spending time with his family and younger siblings, baking with his little sister, and playing the trombone. He has been dealing with asthma since he was three years old and it can get in the way when he is practicing the trombone or playing sports. He often feels centered out at school when he can't keep up with the other kids

When Mason's dad comes home from a night of drinking—which has been more often lately—he is sometimes angry and can say really mean things to his mom. Mason is worried that if his dad keeps drinking so much, he might die and leave his mom and siblings alone to take care of themselves. How could he continue to keep his grades up and take care of the family? Mason told his mom that he'll never drink or take drugs because he doesn't want to say mean things.

Alina, 29 years old

Preferred pronouns: she/her   **Location:** Fulton, New York

"I am an orphan and a helicopter mom."

Alina is a single parent of two children, who are twelve and ten. She grew up in Syracuse and moved to Fulton when she was six for her dad's work. At home, she would always speak Spanish with her mother and English with her dad.

Her life changed forever when, at the age of nine, both her parents were hit and killed by a drunk driver when returning home from a quick trip to the grocery store. She remembers how numb she felt when it happened—she couldn't wrap her head around never being able to hug and kiss them again. Alina was lucky to have a wonderful grandmother who raised her but she recently passed away after a battle with pneumonia. Some days she feels positive and others she finds the sorrow for the loss of her parents and grandma to be completely overwhelming.

For as long as she can remember, Alina's whole life has been all about her kids—sometimes she thinks she should back off and give them more space as they aren't babies anymore. She knows that self-care is important and decided to do something about it by getting an education. Since going back to school full-time, she is starting to think ahead to what her future might be like. She has hopes and dreams about helping people as a counselor after she graduates. Sometimes she closes her eyes and gets a kick out of imagining a life where she could dress up in high heels and professional clothes after spending so many years at home raising her kids. She just hopes that a job in the helping profession will pay enough to help her to save up for a new home where she could have a backyard and garden for the kids. Alina loves to be outside, learn new things, and to teach her children about nature. She knows that life is short and wants to make the most of it.

PERSONA 5

Abdul, 43 years old

Preferred pronouns: he/him **Location:** Syracuse, New York

"My smile is held together by a string but still I smile."

Abdul is married with two daughters and a son under the age of seven. He obtained a U.S. Visa in 2017 because there were threats to his life for speaking out in Somalia. He brought his kids with him to the U.S. because he wanted to ensure he could get them into school as soon as possible, but his wife is still back home waiting for the proper Immigration Visa.

Abdul has a strong Somali accent and doesn't look like many people in Syracuse. It is not uncommon for him to hear racist or anti-immigrant comments when he is out at the grocery store, shopping mall, or restaurant. This makes him feel unwanted and unsafe—he fears for the world that his children will grow up in if these harmful attitudes don't change.

When he is honest with himself, he can admit that he is so lonely—the hardest part is living in the U.S. without his wife after being together nearly every day for the past 20 years. Between his two jobs, they try to connect a couple times per week using Skype, but it is just not the same as being able to hold her next to him.

Abdul loves playing video games with his kids, but he also tries to limit their screen time as this is a big change from their life back home. Abdul is a strong person who has been through a lot, and he tries to teach his children the importance of strength and resilience, even during the toughest times.

After all his monthly expenses are covered and the children have what they need, there isn't a lot of money left to go around. He tries to make sure he puts away a few dollars each month so he can enjoy a grande chai latte at Starbucks. He looks forward to pulling up a chair by the window and watching the world go by.

Lo, 15 years old

Preferred pronouns: they/them **Location:** Oswego, New York

"Sometimes it's just getting through the day, but typically it's about making sure my room is clean."

Lo is 15 years old and is an only child. They feel like they do not fit traditional gender norms, and identify as bi-sexual. A few months ago, Lo went to a party with some friends from school and hooked up with someone there. They were taking birth control, but had missed several pills and didn't think it was a big deal. They didn't have any condoms on them because they always felt uncomfortable going to the pharmacy to buy them. Two months later, Lo found out they were pregnant and expecting their first child.

Lo lives at home and feels really lucky to have supportive parents who accept them as they are—even their disastrously untidy bedroom! Lo loves spending time with their family and cooking for them whenever they can. They also like making their own clothes and feel like the way we look and express ourselves on the outside says a lot about how we feel on the inside too.

In a few months, Lo will give birth to their baby boy. Soon after, they would like to go back to school so they can create a future for themselves. They have always found high school to be a struggle because they learn differently than the way things are taught. Lo is hopeful that things will be different this time around because they will be enrolling in an alternative school with other adults who learn in a similar way.

PERSONA 5

Valentina, 57 years old

Preferred pronouns: she/her   **Location:** Oneida, New York

"I have deep thoughts although I am funny and laugh a lot."

Valentina has been working with children with disabilities for over 15 years. She began directly serving children, then moved into a supervisor and most recently, a program director role. It has been a dream for her to serve her community in this way, but it doesn't come without a toll. Over the years, she has witnessed a series of funding cuts to her program—and many other similar programs—first hand. Her heart goes out to all the kids who are, and will continue to be affected by the cuts—the kids who won't be able to access the much-needed services essential to their ability to thrive in life.

Although she tries to speak out about the impacts of these changes in her leadership role, she feels like it is falling on deaf ears. She strides into work as a hopeful leader with a smile on her face everyday, but lately she has been feeling the resentment building within her. She's not so sure she can work in this field much longer into the future if she does not see changes at all levels.

Valentina recently got divorced and has been pouring attention into her two children in high school to take her mind off that relationship and the troubles at work. Lately, she has focused on teaching them Italian so they stay connected to their family roots. She feels like she is at an impasse in her life, but is trying to see this as an opportunity for change. In the meantime, when the stress becomes all too much, she puts on "It's a Wonderful Life." She's seen it a thousand times, but each time she watches it, she notices new things and that brings her joy.

"How Might We" Questions

1. It can be hard growing up in central New York

HMW help people worry less about being successful in the future and support them to be successful in the moment?

HMW create programs and services that respect kids' agency in a supportive and educational way?

HMW help kids who are worried about their future to have fun, learn, and enjoy being a kid?

HMW teach and educate kids in fun and creative ways?

HMW support people who struggle to make or maintain healthy friendships?

2. I need to be reminded that I am important

HMW help alleviate some of the stressors that are always on the minds of children, families, and service providers in CNY?

HMW support people in growing their resilience to personal stress and struggles?

HMW help parents and guardians learn and grow together with their children?

HMW promote positive, healthy coping mechanisms for kids and their families?

HMW increase quality affordable housing options?

3. I need you to know that I've lived a long and difficult life

HMW support people to be their authentic selves in their family lives, friendships, and workplaces?

HMW help people find time for positive self-reflection in their day-to-day life?

HMW help people make the positive changes that they realize are important but struggle to make?

HMW create safe spaces where people can heal?

4. I am doing all I can to hold it all together

HMW support our staff/volunteers to access mental healthcare?

HMW create a culture that puts well-being first in CNY?

HMW support people to improve their time management skills?

HMW increase financial literacy for people in CNY?

HMW find new and innovative resources for organizations to increase funds?

5. Parenting is hard

HMW help parents be the best parents they can be?

HMW encourage good boundaries for parents between family, personal, and work responsibilities?

HMW create opportunities for cheap or free fun for families in CNY?

HMW help families celebrate the highs of life and rally together during the lows?

HMW support our staff and fend off burnout before it's even on the horizon?

6. Even though I have uncertainty, I am fine

HMW help those who are doing fine getting by to fully excel in their lives?

HMW provide services and care that are more accepting of cultures outside of the dominant Western European and American culture?

HMW support people in finding time for joy and self-care in their busy lives?

HMW make everyone in CNY hopeful about their future?

HMW better understand what "being trauma-informed" means to people from other cultures that we serve?

7. This is my life as a refugee in central New York

HMW connect newcomers in CNY to community events and groups?

HMW make it easier for refugees and newcomers to get around CNY?

HMW help facilitate new friendships and connect those who feel isolated in CNY?

HMW provide culturally appropriate mental health and well-being supports for refugees and newcomers to CNY?

HMW support long-distance relationships and healing that may be necessary despite great distances?

8. I know what I need but don't have the resources to make it happen

HMW support people of CNY in their creative endeavors?

HMW help people to access the resources they need for positive well-being?

HMW help people find the support mechanisms that work for them—and what to do when they fail?

HMW create a sense of belonging for all people in CNY?

9. I've experienced trauma, but I want to move on

HMW reduce the number of times people have to explain their challenges or reasons for seeking care?

HMW help people navigate support services and resources?

HMW support those who have been abused in the way that works best for them?

HMW promote a culture of personal reflection?

10. It's hard to do right for myself and others

HMW support families through grief and major loss?

HMW let people know it is beneficial to take time for themselves?

HMW help people deal with conflict in a healthy way?

HMW promote a culture of storytelling and listening?

As you read through the Insights, think about and record your responses to the following questions:

- What stands out to me?
- What spoken and unspoken challenges are represented in the Insights?
- What strengths are people communicating through these Insights?
- Which solutions to existing challenges are currently working and which are in need of improvement?
- What are some new solutions that don't already exist for these challenges?
- What do I need to take from this to improve what I am doing?
- Now that I know these things, how do they square up with what we are doing?

Western New York

Insights and Themes

Using self-awareness to take ownership and action around mental health

We heard a lot about the impact of mental health on children, family, caregivers, and providers. Past trauma, professional challenges, and other significant mental health challenges impact how people see themselves, interact with people around them, and take control—or don't take control—of situations happening to them. People also shared with us the need to take ownership of, and action on, these challenges as well as the practices, resources, and supports that may help them to accomplish this.

"My heart causes me to illuminate like the morning sun"

"People tell me I'm strong, but I secretly feel weak and exhausted"

"I've been there—I was a troubled youth myself"

" My purpose in life is working with children and youth"

Connectedness to opportunities for self-expression can be hindered by people's stereotype of me

Strong connections start from a place of deep empathy and understanding. It is this authenticity and radical self-honesty that enables people to engage in creative activities, physical fitness, and team sports. People recognized the importance of access to the outdoors, the arts, and sports and recreation in terms of their ability to participate and ultimately improve their well-being. We heard that this is particularly true for students who are having trouble engaging in traditional classroom settings.

"I like to dance"

"I need to find ways to stay motivated to exercise and stay healthy over the winter months"

"I love to make someone else smile from the inside out"

"Anything is possible"

INSIGHT 3

Finding my healthy place

This Insight dives deep into the everyday challenges we all face—to different extents—in our journey to strong well-being. From the pace of society today to the complexity of single parenting, so many things impact a family's ability to improve their health. Specific issues related to mental and physical health are made more difficult due to a lack of financial resources. Future growth is important and a lot of people are focused on their day-to-day realities.

"Life isn't perfect and I struggle to find meaning some days"

"My mental health affects me a lot, sometimes makes me want to give up"

"Body aches and pain, not having my own apartment, and the loss of my baby"

"Optimism is key to success"

Even though I have a lot of inner pain and anxiety, I try to be a beacon of light to others—usually with a smile on my face

– CCWB PARTICIPANT

INSIGHT 4

Voicing my needs is important to make my life more balanced

People told us they are looking for more balance in their lives. Whether it is between life and school/work, the needs of different family members, or managing finances, balance is critical across all areas of life. People are looking for help prioritizing time, money, and most importantly, themselves. They want to get better at advocating for their needs to ensure they have the best possible chance at succeeding at school or work.

"I'm too nice"

"I learn all this by starting with myself"

"Sometimes wish I could walk away from my responsibilities with no consequences"

"Help"

Systems problems and solutions

So many of the themes we heard are deeply interconnected. This Insight speaks to the need to understand problems and solutions while considering the broader systems context. People shared the systemic barriers they face to meeting their basic needs, improving their sense of belonging, and capitalizing on opportunities for growth. Programs that are designed by and for middle class citizens—with no attempt to coordinate, collaborate, or communicate with others—often overlook the needs of families who are marginalized.

"Working and advocating for students whose parents can't"

"Teaching kids who become violent when things do not go their way"

"My biggest challenge is being a black male"

" My biggest challenge is having a successful life"

INSIGHT 6

Meeting basic human needs and advancing social interactions

It's important to remember all of the strengths and personal growth people shared through the engagement phase. People told us they and are proud of what they have accomplished, felt good about who they are today, and associate themselves with positive self-identifiers. However, a lot of people also shared that they wish others saw them as they see themselves. They felt reducing power dynamics would go a long way to feeling a strong sense of belonging.

"I'm a single mom and wish my family was whole"

"I am a man that statistics say should not have survived their youth. I am a survivor who firmly believes in paying it forward"

"Stop judging me and actually help me"

"We need to hear voices of refugees and immigrant folks"

Adversity in the journey to well-being

While every experience is unique, there were common challenges shared by children, families, caregivers, and providers. People struggle to meet their goals, stay engaged in school/work, and take care of themselves. Many people communicated that they are doing the best they can, leaning on spirituality, rest and relaxation, as well as routines to get them through the challenging times. When all else is up in the air, people look to their values and the values of those around them to find the strength to keep moving forward.

"My biggest challenge is saving for the future"

"Desire for improved quality of life"

"You would be surprised by my struggles"

"Confident about my future"
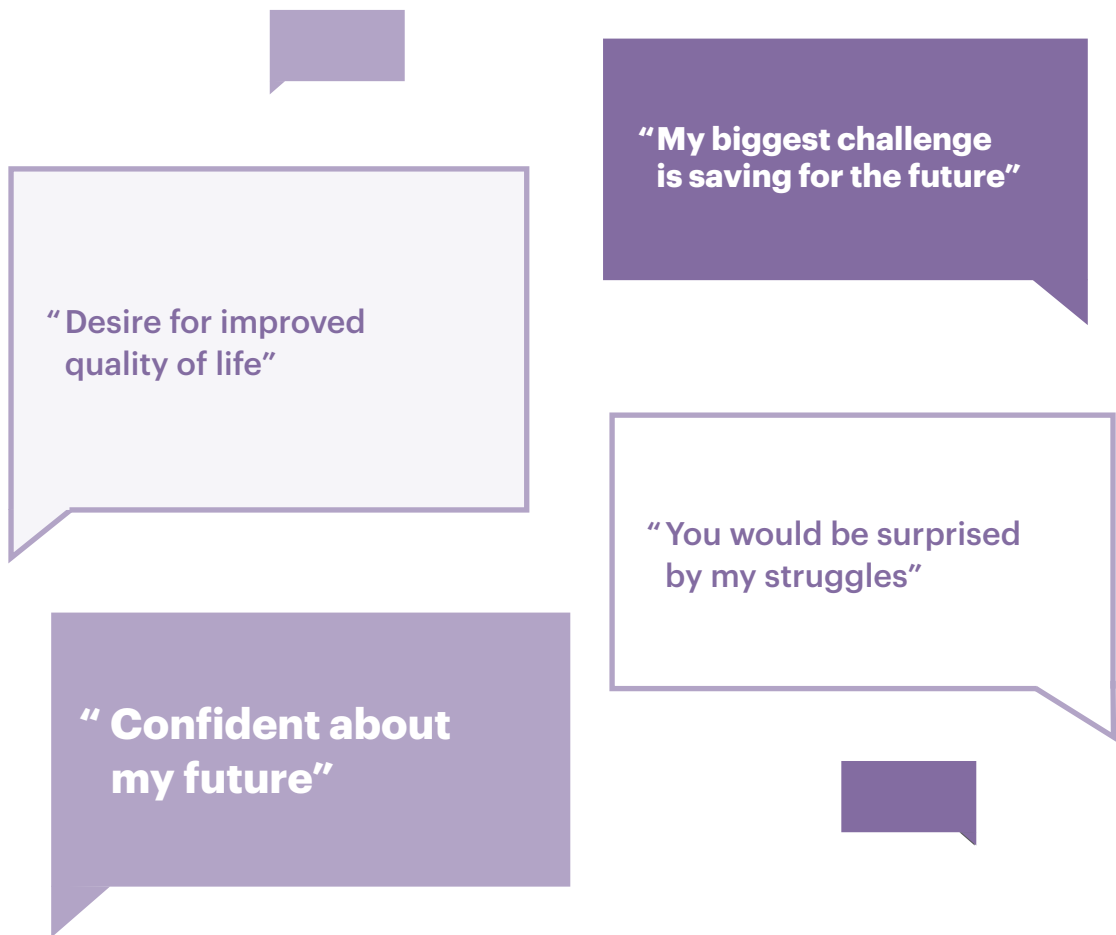
INSIGHT 8

Personal, professional, and relationship wellness

People shared with us how they juggle personal, professional, and relationship challenges in their day-to-day life. People communicated that they face challenges managing emotions, finding time to relax, and dealing with substances. While school/work is important to them, they often face barriers like having the right skills, dealing with challenging content or people, and maintaining a healthy lifestyle at home. This includes engaging in positive self-care activities like spending time alone, with family, or with animals.

"I am accepting situations and adapting"

"As a caregiver, I also need mental breaks and support in return"

"I want the best for my clients. I feel lucky to work with the people I work with"

" Life is hard but it is also good"

Personas

PERSONA 1

Archie, 18 months

Preferred pronouns: he/him **Location:** Batavia, New York

"No, no, no, no, no!"

Archie likes to play toy trucks and dolls with his cousin, but has a difficult time sharing. He loves the word "no" and drinking juice during snack time. Archie does not like napping and he always gets his mom up at 5 am. When his diaper rash is hurting, sometimes he is awake all night crying. He wishes he could tell his mommy just how much it hurts.

PERSONA 2

Aarya, 26 months

Preferred pronouns: she/her **Location:** Jamestown, New York

"I don't like picking up the toys when I am done."

Aarya is very curious and independent. She likes to run up and down the stairs while hollering at the top of her lungs. She always wants to feed herself and doesn't want any help with that. She points to the different characters and animals when being read a book and whispers their name—cat, dog, horse! Aarya recently started dropping things—especially toys—on the floor but does not like picking them up. She finds loud noises and going to the potty to be really scary. Aarya has a lot of strong emotions and has a hard time putting words to them. She loves drawing pictures on paper—sometimes that is a way that she shows what she is feeling on the inside.

NOTE: The first two peronas appear in the lists for both central and western New York.

PERSONA 3

Sato, almost 7 years old

Preferred pronouns: she/her **Location:** Buffalo, New York

"Every night before bedtime I give love to everyone in the house."

Sato lives with both her parents in a three-bedroom apartment and is the youngest sibling of six. She is an open heart and a kind soul—she loves giving love.

Both of Sato's parents work a lot to make enough for the family. She wishes that she got more attention, especially given how much time goes into her brothers' football games and sister's band recitals. There is often chaos in her house when all eight family members are together. However, Sato knows that she has a better chance of being heard by her parents over her siblings if she speaks to them in Japanese. She has picked up the language more easily than her siblings, and her parents are proud of her for this.

Sato enjoys helping out around the house and doing chores because it makes her feel like a grown up. She loves to eat with her family, but doesn't like when her parents make her eat zucchini or broccoli—she thinks they taste gross and slimy.

Sato is very active and gets bored easily—her favorite activities are dancing, soccer, and swimming. She also gets really excited for birthday parties in her family— and there are lots of them—because she can make a big mess and doesn't have to help clean up afterward! At school, she finds it hard to sit still in her desk and is bullied by some of the older kids because she looks different. Math is the subject she finds the hardest.

Ashley, 17 years old

Preferred pronouns: she/her **Location:** Belmont, New York

"Stop judging me and actually help me."

Ashley is 17 years old and a single mother of two children under the age of three. She had her first child at the age of 14 when she met a boy in the ninth grade. Her kids have changed her life and given her purpose in a new way.

Ashley enjoys playing with her kids—building the tallest Lego structure possible is a really fun game. Although she has a difficult relationship with her mother, she enjoys spending time with her younger brother who just started the sixth grade. Sometimes the two of them let loose by dancing around in her apartment like no one is watching and singing their favorite songs.

She knows that her kids need a good routine to be happy, so she tries to provide consistency in their lives by making sure they wake up, eat, and go to bed at the same time every day. She goes to school during the day and works the evening shift at the local diner—her income depends heavily on her tips. She needs to sleep more, but it is not possible between school, work and taking care of the kids.

Currently, she lives in an apartment in an old duplex house. She is grateful to have housing, but wishes that she could raise her kids in a safer area where she felt comfortable leaving them with neighbors. She also found out that there is lead paint and worries about the impact on her kids' development. One day, she would love to have her own home with a fenced-in yard so the kids could have space to play outside. She dreams of having a cat to keep her family company but knows that she can't afford it right now.

Ashley is a survivor of sexual assault. Group therapy, along with yoga and meditation have been helpful to cope day-to-day. She tries to be optimistic, but it has been a struggle. She lives in a rural community in Allegany County and is connected to a number of services—her biggest challenge is making it to appointments on time and getting food stamps because she has trouble finding rides from friends and family. She sees the look on people's faces and knows that people judge her when she walks down the street with her two children, and she wishes that they knew that she is proud of how far she has come.

PERSONA 5

Sean, 32 years old

Preferred pronouns: he/him **Location:** Buffalo, New York

"Getting kids together outside of school is nice."

Sean is a single father of three young children. His ex-wife had issues with alcohol and the relationship broke down as a result. They have been separated for five years. The kids live with Sean full-time, and they see their mom on some holidays. They would like to see her more often but visits need to be supervised because of her struggles.

Sean works in a factory and is often asked to work different shifts. This schedule makes it difficult to be home for his kids at consistent times during the week, but he feels fortunate to have his parents living three houses down. They help out when they can to care for the children, which helps keep the daycare bills low. He has trouble keeping up with the costs of car repairs because it keeps breaking down on him.

Sean loves to play with his kids—whether it is playing outside, making music or reading comic books or novels with them. He tries to make homemade meals whenever he can, but it is only possible when he works the day shift. After his wife left, he created a weekly pizza night tradition with the kids to give them something exciting to look forward to each week. Most times he orders from the local pizzeria, but if money is really tight, he'll pick up a frozen pizza from the grocery store—the point of the tradition is to spend time together as a family.

He struggles being a black male in a predominantly white community and the stereotypes that are imposed upon simply because of the way he looks. Layered upon this is the toxic masculinity he faces that restricts his ability to freely express his emotions in favor of being seen as 'macho.'

Sean is his own worst critic and also has a complex relationship with alcohol. He drinks beer and liquor to take the edge off, but finds it can spark a lot of negative thinking because it makes him think about his ex-wife—How could she choose alcohol over the kids? He is determined to not let his issues with alcohol get in the way and continue to be there for the kids, but recognizes that this will take a lot of hard work and dedication on his part.

Chloe, 28 years old

Preferred pronouns: she/her **Location:** Niagara Falls, New York

"I am a very strong person and I never let it get in the way of caring for anyone."

Chloe has always loved kids, and was sure from a young age that she wanted to work in a profession that would make a difference for them. Fresh out of college, she got a job as a direct service provider at an agency serving young children. Although the job is not an easy one, she wouldn't have it any other way. She feels unconditionally devoted to her role and the kids she serves.

Recently her life changed as she found out that she is expecting her first child. She was excited and relieved after going through two miscarriages. Chloe does a lot of research and feels strongly about the importance of breastfeeding and good nutrition. She brings this lens to her work and will continue to bring it into her own family—particularly with the addition of a new family member. In general, Chloe is very principled and has strong beliefs that guide her decision-making. However, she knows that everyone comes from a different background and she tries hard not to judge others.

Her simple pleasures are coffee—for both the taste and caffeine—and going for long hikes in the Gorge with her dog. She also loves to see people smile and laugh and creatively express themselves through music and painting. She tries to see the glass as half full and to be as positive and caring as she can to others.

PERSONA 7

Adelina, 51 years old

Preferred pronouns: she/her **Location:** Tonawanda, New York

"Although I come off as tough and mean, I am very sensitive."

Adelina is a manager of programs serving young families at a small community organization in Buffalo. She is also a mother of two grown children and recently became a grandmother. She is also a caretaker to both her parents. She lives with her wife and speaks three languages—English, Spanish, and Italian. Her mom is from Italy and her dad from El Salvador. In her spare time, she loves learning about geology, going out to concerts, and eating out with friends.

Adelina has a passion for her job, and watching kids grow. However, she struggles to get more help for families living on a low income—the funding cuts and income guidelines have been getting worse over the years. This is a stress that weighs heavily on her both inside and outside of work. To add to this, the organization often seems unsettled because of the constant staff turnover—the reality is that it is impossible to pay her dedicated staff what they deserve on the funding she is receiving. Staff often stay only for a short period of time before they move on to private institutions where they can do similar work while making more money.

Adelina has experienced homophobia from staff, parents, and board members—this is an on-going challenge that she faces. She wonders why who she loves matters so much to others—she is excellent at her job caring for families and has never heard a complaint. She has to put up a tough front that these comments don't impact her, but the truth is that they hurt her deeply.

"How Might We" Questions

1. Using self-awareness to take ownership and action around mental health

HMW promote easy ways parents can incorporate well-being practices into their daily lives?

HMW provide better mental health support to kids, parents, guardians, and providers?

HMW promote self-care to those who always put others first?

HMW provide more individualized care?

2. Connectedness to opportunities for self-expression can be hindered by people's stereotype of me

HMW promote the right outlet for the right kid at the right time?

HMW create opportunities for kids to be well-rounded and find joy in a variety of activities?

HMW promote the healthy goal-setting aspects of competition?

HMW help kids and their families get to and from recreation and leisure activities?

3. Finding my healthy place

HMW support kids and families who are just barely getting by?

HMW support teachers who are working with students who have multiple consistent stressors?

HMW better support parents who have a chronic mental health issue or challenge?

HMW make sure those around us aren't going hungry?

HMW educate families to have better financial literacy?

4. Voicing my needs is important to make my life more balanced

HMW create better life/work balance within our organization?

HMW help people feel more in control of their finances?

HMW better support people who are going back to school?

HMW promote a healthy life/work balance in WNY?

HMW better support people who are pregnant in WNY?

5. Systems problems and solutions

HMW break down the barriers that are preventing people in WNY from meeting their basic needs?

HMW collaborate and coordinate a collective impact project to ensure all people in WNY have the resources they need to be successful?

HMW work against oppressive systems that unfairly target people in our community—including ourselves in some cases?

HMW reduce barriers to transportation and getting around for people in WNY?

HMW create a system of belonging for people in WNY?

6. Meeting basic human needs and advancing social interactions

HMW promote positive social-emotional skills in young children?

HMW better support children and youth in school and their educational pursuits?

HMW better relate with young children?

HMW help parents better relate to their children?

HMW make the school system more welcoming to a diverse range of students?

HMW empower all of our kids as a community?

HMW support secure attachment among children and their caregivers?

7. Adversity in the journey to well-being

HMW help families create a routine that works for them?

HMW help people and families that plateau or struggle on their way to well-being?

HMW support people in using healthy coping mechanisms when they face adversity?

HMW help people maintain their values in the face of adversity?

8. Personal, professional, and relationship wellness

HMW design solutions that integrate personal, professional, and relationship needs?

HMW help those that work with kids balance the energy it takes with the impact they can have?

HMW take more time to celebrate our accomplishments and help others do the same?

HMW improve self-care activities that people, couples, and families can do together?

**HMW** ensure people have the skills they need to do the job at hand?

As you read through the Insights, think about and record your responses to the following questions:

- What stands out to me?
- What spoken and unspoken challenges are represented in the Insights?
- What strengths are people communicating through these Insights?
- Which solutions to existing challenges are currently working and which are in need of improvement?
- What are some new solutions that don't already exist for these challenges?
- What do I need to take from this to improve what I am doing?
- Now that I know these things, how do they square up with what we are doing?

Reflection and Next Steps
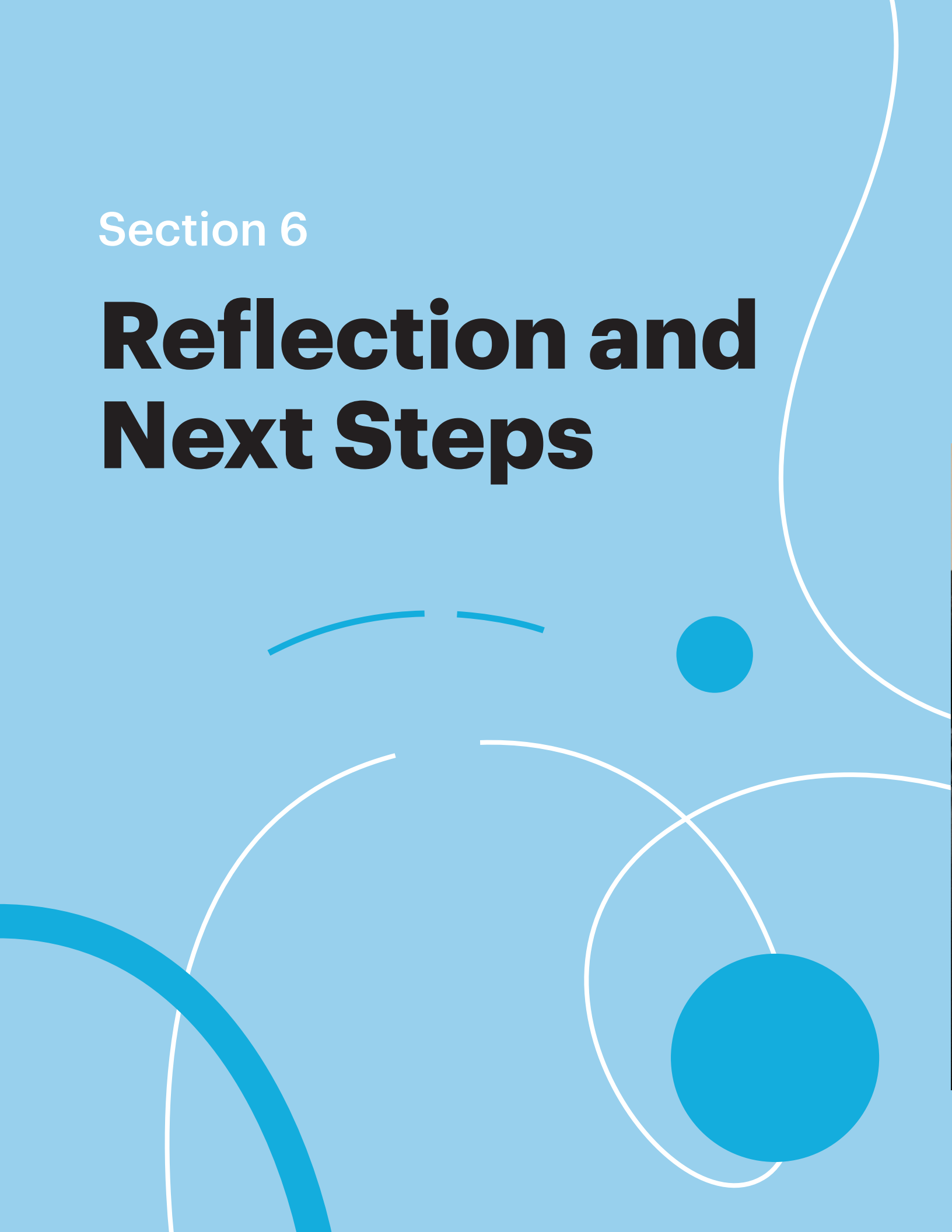
Reflections on the Process from Service Providers

CCWB training opportunities not only helped participants/providers to learn new skills and processes related to human-centered design, but also had a transformative impact in a deeper sense. Reflective conversations with providers surfaced deep learning and powerful insights gleaned through the CCWB Initiative to date. These learnings are highlighted below.
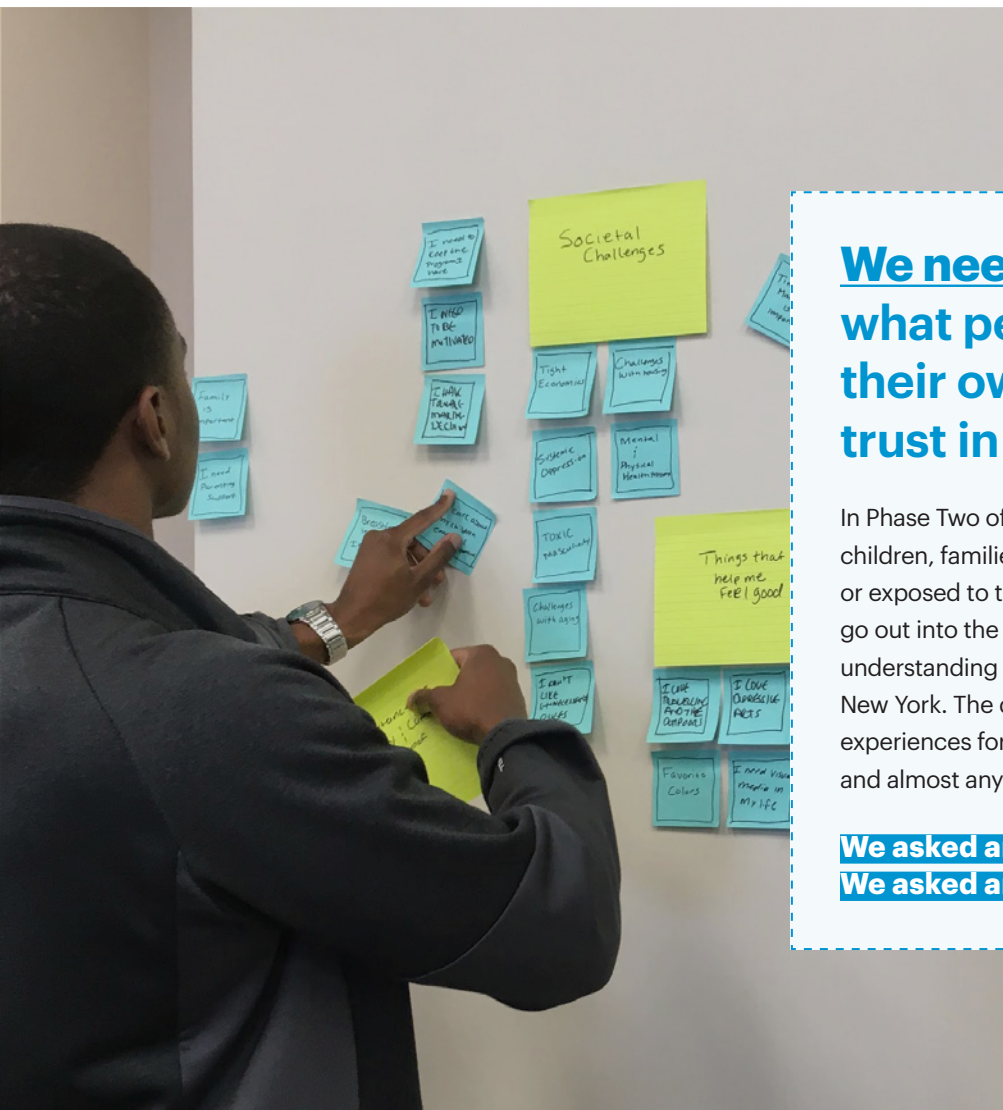
We need to listen to what people want in their own words and trust in their expertise

In Phase Two of CCWB, organizations that work with children, families, caregivers, and providers experiencing or exposed to trauma and toxic stress were asked to go out into the community with the goal of better understanding what life is like across central and western New York. The data collected speaks to the diversity of experiences for children, families, caregivers, providers, and almost anyone that is involved in the system.

We asked and we listened.
We asked and people responded.

"It is amazing how people can articulate what their needs and wants are when we ask them, even with simple tools."

The most popular engagement tool used in Phase Two was the CCWB Postcard. With the exception of a few basic demographic questions, the postcard had just two prompts:

If you really knew me...
I consider my biggest challenge to be...

These two simple prompts are responsible for the majority of the Findings, Themes, and Insights that we uncovered through our engagement efforts. As caregivers and service providers, we sometimes focus too much on the questions that need answering to complete the task at hand. Alternatively, when we went out with these simple engagement tools, the community responded with overwhelming clarity of their needs and desires beyond more narrowly-focused service experiences.

"You think you know what someone needs, but you don't know until you ask them. This is the reality of life. People are telling us what they need."
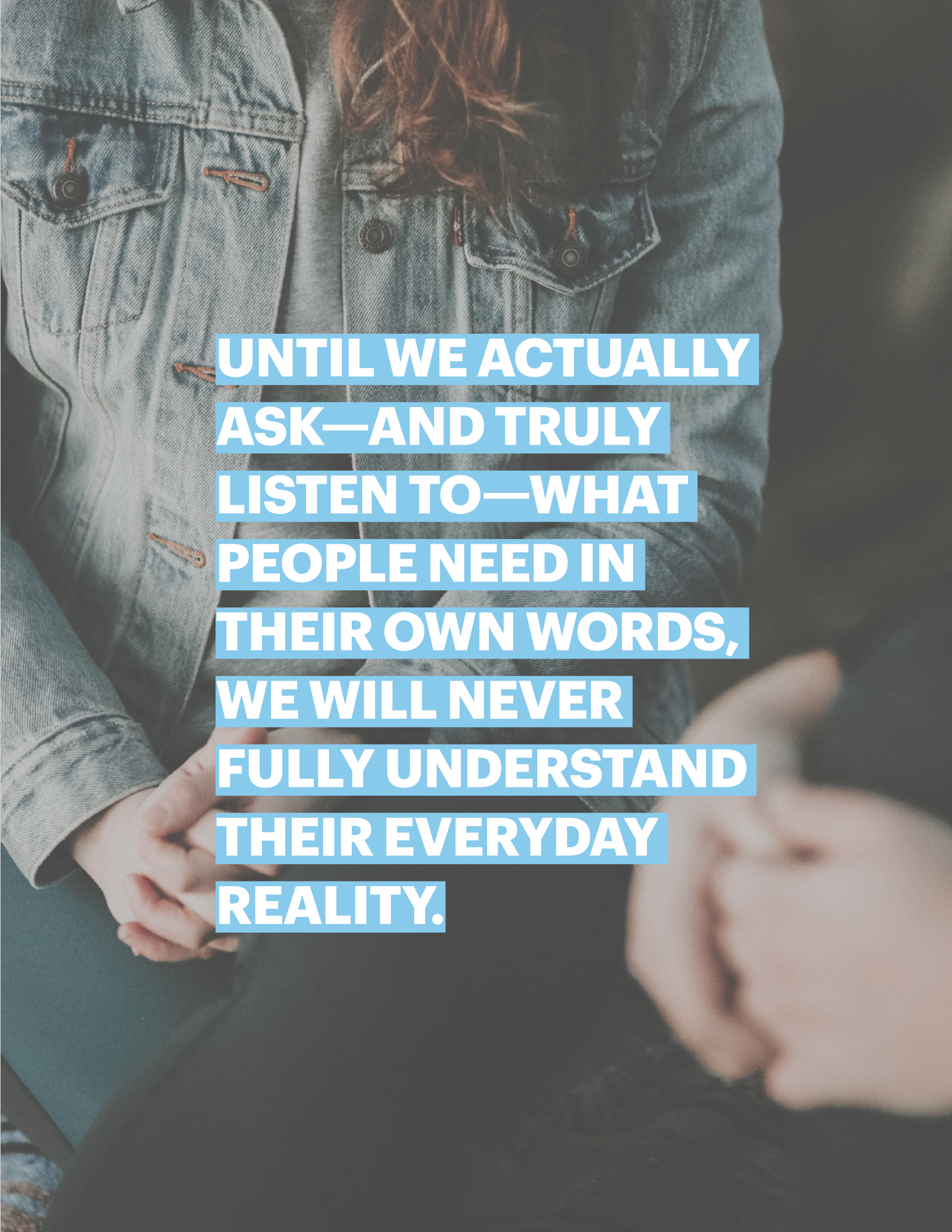
Through the use of the engagement tools available in Phase Two, we changed the nature of conversations organizations have with the community. Many policies, processes, and approaches we use in our work don't leave space for understanding the individuals we serve as a whole person. We are often asked to make quick judgement calls based on little information.

Until we actually ask—and actually listen to—what people need in their own words, we will never fully understand their everyday reality.

"The depth of these insights could never have been reached through more traditional research methodologies."

As we move forward into Phase Three and begin taking action through grants, we cannot lose sight of the importance of engaging the community using a human-centered design approach. While quantitative approaches and traditional research methodologies are incredibly important in ensuring we are effectively delivering quality services, Phase Two enabled organizations to get to a deeper level of insights.

The open-ended questions used in the CCWB engagement tools allowed us to deeply hear what is important to participants, and therefore enable unexpected Insights to arise. People are living complex lives, and interaction with services is only one small part of it—well-being and resilience cannot be overlooked.

UNTIL WE ACTUALLY ASK—AND TRULY LISTEN TO—WHAT PEOPLE NEED IN THEIR OWN WORDS, WE WILL NEVER FULLY UNDERSTAND THEIR EVERYDAY REALITY.

We need to better understand all sides of a person because we are all complex

As organizations engaged the community through thousands of conversations, it became clear that we were not just learning about people's issues with current services. The engagement tools gave us a multi-dimensional view into the lives of people across central and western New York. We heard about the positive, negative, and complex interconnected aspects of the lives of people, from children to families, direct support workers to management.

The Insights that emerged do not speak to any one individual's experience yet, reading through each Insight, we can't help but have a specific person come to mind.

"It's important to put a face to the story."

When asking so many people about their experience, it can be difficult to hold onto the nuance that exists between their stories. One of the approaches we use in human-centered design to ensure every story has a face is Personas. To understand how Personas impact our process, check out the Personas included in this report. Notice that these Personas describe complex individuals. We don't pick one dimension like "dealing with present trauma" or "dealing with vicarious trauma". The face we put to these stories are a shortcut to remember and design for the diversity of experiences we heard, but they are not intended to oversimplify people's life situations.

Each Insight represents a different story we heard through Phase Two. While it's not specific to any one person we talked to, it is representative of people from across central and western New York.

"This is life, and aligns with people no matter what their socio-economic status is. These are societal issues, positive and negative. We are dealing with these issues as people."

These Insights are meant to remind us and reconnect us with the people in our community. Yes, this means better understanding the people we serve as providers and leaders in this system. It also means better understanding each other, our peers and colleagues. When we start from a place of empathy—doing our best to understand one another's perspective—we make decisions differently. People working in these types of organizations did not get into this line of work without good reason.

Trauma doesn't just impact people of low socioeconomic status, and low socioeconomic status doesn't just impact the people we serve—it impacts everyone across central and western New York. However, we know that poverty plays a role in increasing risk and limiting resources.

"Helps to change perspective as service providers because often people come to see us when they need help, but they were able to be positive with the Postcards."

People don't access the programs and services our organizations offer when everything is going well. They typically engage—or engage in a deeper way—when they need help. Because of the approach we took through Phase Two, we learned about different aspects of people's lives than you might with more traditional research methods. The simple engagement tools were able to draw out many of the positive aspects of people's lives.

If we want to incorporate more trauma-sensitive and strengths-based programs and services, we need to ensure we aren't just asking about people about the things that are not going right in their life.

"People are positive and resilient. This should be reflected in the report. No matter how hard things are, they still have joy."

The view presented through the Insights represents a snapshot in time. While sometimes we overemphasize the negative aspects of people's experiences, it's essential to remember people's resilience and everything in their lives that create joy.

If reading through these Insights, we feel hopeless, it's critical we acknowledge the strength and optimism that exists in our community. Further, we need to listen deeply to how people describe their own situation and understand that it is their own personal journey to define.

We need to be positive language ambassadors because it shapes everyday reality

CCWB asked organizations to use a human-centered design approach to improving trauma-informed programs and services in a way that acknowledged or even advanced diversity, equity, and inclusion. During Phase One, we brought in new language related to trauma-informed care and human-centered design. In Phase Two, we expanded on this language by learning about historical trauma, diversity, equity, and inclusion in our work.

The words we use are important. In this report, we intentionally do not use descriptive language that "others" people such as client, consumer, or service recipient.

"The words poverty and trauma are missing; but that is not how people define themselves. Service providers often use language to describe people that doesn't connect to their actual experience."

One of the first things we noticed after completing the Insights Framework is that words like trauma, toxic stress, and poverty don't actually appear anywhere in our Themes and Insights. While a bit of a surprise, the most likely reason for this is fairly intuitive.

People with experience in this system don't use words like poverty or trauma to describe their story. This may not be true in the future. For example, terms like "mental health—while once were uncommon—are now mainstream. However, at this time, trauma is not a word people use consistently to tell their stories.

"We are not experts in people's lives, they are their own experts. We don't use the same words that people themselves use to describe their situation."

We were reminded of the importance of collecting, understanding, and valuing different forms of evidence. Because people are experts in their own lives, engaging communities through this Initiative helped us deepen our understanding of people's experiences in the language used to tell their stories. Through the Advanced Engagement training sessions in Phase Two, we redefined what serves as evidence and evidence-based interventions for our organizations.

Approaches like human-centered design actively collect evidence throughout the process by questioning and testing the assumptions we have about problems and solutions.

"It is surprising how much the kids could articulate as clearly as they could."

When co-developing the engagement tools we used, children, families and providers gave feedback which was incorporated into new versions of each tool. At the same time, we made deliberate decisions to ensure we didn't over-simplify the language, giving kids the opportunity to safely step outside their comfort zone.

Even though we understand kids' capacity, the data collected genuinely surprised some of us. Their ability to articulate their needs so clearly demonstrated an understanding of their experiences and reminds us that children in fact, always absorb what happens to them. We were witness to the maturity and wisdom we don't get to see often enough in our day-to-day work with kids. Even seemingly silly responses gave us a window into their lives.

"We used to ask people 'what is wrong with you?' and now we ask them 'what happened to you?'"

The language we used in Phase Two evolved from our first "prototype" training session in Rochester (as a midway point for western and central New York partners) to our final Interpretation Training in Buffalo. Recognizing that many of these concepts exist on a spectrum, we built out and clarified terms like "trauma-informed care" into phrases like "building a trauma-informed culture".

We also discussed the fact that we used to ask people what was wrong with them, while we now know to ask what happened to them. We also learned about historical trauma as a concept to understand that what we are addressing has a long history behind us and it will also have a long-standing impact into the future. These shifts are a great example of the change in attitude, culture, and system that we are looking for in CCWB. The importance of language may begin on an individual level, but its impact and influence also extend to larger systems that impact healthy children, families, and broader communities.

We need to work within an interconnected system where clarity of communication is key

"Many organizations are seeing similar challenges in the community, but we often use different wording that means the same thing."

Language doesn't just have an impact on communication between people in the community and the organizations that serve them, it also affects communication between service providers. Using different words to describe the same thing is confusing and impacts our ability to coordinate services, collaborate on new programs and services, and galvanize energy and efforts behind systems change.

As we look to create collective impact and improve the experiences of people accessing services across central and western New York, we need a common starting point. Through common language and processes, we can ensure we are journeying together.

"The Insights reflect the social determinants of health."

In reflecting on the completed Insights Framework, we noticed that the Insights we developed reflect a complex and interconnected set of issues that impact healthy children, families, and communities. Social determinants of health include things like socioeconomic status, work conditions, environment, behaviors, supports, services, education, genetics, gender, culture, and race. Often in our work, we only have time to dive deeper into a couple of these areas. Through community engagement, we heard about how each of these aspects impacts people's day-to-day lives. It's important to consider these social determinants because they provide insight into where health inequities exist in the system.

"There are major systemic issues happening in our communities that need to be addressed, such as racism and historical trauma—this can feel daunting."

Seeing the Insights Framework come together can feel overwhelming, as it represents powerful experiences of people from across central and western New York. Systemic racism and historical trauma are both good examples of significant systems-level issues that have an impact on people's everyday lives. Culture, gender, and racism are all social determinants that contribute to health inequities. These structural issues impact each and every Insight, and how we work together to improve the lives of children, families, and providers across the system.

"

So many of the challenges in the community are interconnected—we need to be able to see the big picture and not try to address these larger issues in isolation.

– CCWB PARTICIPANT

"

Next Steps: Leveraging Insights, Themes and Personas to Create Systems Change

To respond to these Insights and Personas, we will take a three-step approach:

1 **Make sure the people we collected data from see themselves in the Insights and Themes**

❑ To tackle this, we are going to use the Personas. We typically don't ask people directly whether or not they associate with one of the Personas. Instead, we ask if a Persona reminds them of someone they know. We want to know how resonant these Personas are, what people feel is missing, and how we can refine these tools to use going forward.

❑ Once people are familiar with the Personas, we want to engage them to help us develop a problem frame.

2 **Engage stakeholders to help us define a specific problem to work on**

Problem framing—how we define a specific problem to work on— is a very important aspect of human-centered design. A problem frame that is too broad can prevent us from developing specific and meaningful solutions. A problem frame that is too narrow can constrain our creativity and prevent us from thinking of truly new solutions.

❑ To get us started with developing problem frames, refer to the **"How Might We"** questions. They can be a launching point to have a conversation with stakeholders and learn about what may still be missing.

3

Co-design new solutions with stakeholders to improve the lives of children, families, caregivers, and providers

❑ Practice trauma-informed care and diversity, equity and inclusion

❑ This is the part of the process when we generate new ideas. To co-design solutions to problem frames that we have identified, we will invite children, families, caregivers, and providers into the process.

Here are some guidelines for the discussion when leading an ideation session:

Always start solo. You will get more and better ideas if you give people the opportunity to write their own ideas down before asking them to share with the group.

Defer judgement. Come back later to converge on the best solution, leave time early in the process to come up with new and different ideas.

Seek quantity, not quality. It's always a good idea to start with a lot of ideas. It turns out your first few ideas are rarely your best.

Question assumptions. Encourage people to break the rules, challenge assumptions we have about both the problem and potential solutions.

Go over the top. We need different ideas to get us outside of our comfort zone. We may not implement the idea but it can lead us in surprisingly useful directions.

Stir. Debate ideas for clarity, combine & extend ideas, and use ideas as stepping stones. Discussion of the ideas can act as a building block to get you to places that you would never get to on your own.

Take notes & follow through. Share the information broadly so we can continue to learn from new perspectives and validate our work.

4 Consider Community, Cultural, Historical and Systems Context

The Insights and Personas present opportunities to better understand and respond to the needs of our community. We cannot look at any of these Insights in insolation. Each individual change we make needs to align and contribute to the overall systems change. Oftentimes, individual traumas and the path to resiliency requires service providers and policy makers to tackle issues such as poverty, racism, community violence, and structural inequities across the social determinants of health (housing, food access, education, and employment, etc.)

It is critical to empower individuals we serve to have agency in their own lives, families and communitie, and for us as providers to act as allies whenever possible. We are all learning in this process to create a more just, equitable, healthy, and sustainable region and world. We know that improving programs and services is part of the solution, but we must focus more time, energy and resources on prevention of trauma.

We need service providers to help us consider how we might do more of this in the next phase of our work by helping us respond to the following questions:

☐ **How might we** increase access to opportunity and mitigate the trauma through well-resourced early childhood education and schools, living-wage employment, job training and placement for formerly incarcerated community members?

☐ **How might we** add value to the socio-cultural context of those we serve considering assets and building relationships and resiliency in communities disproportionately impacted by trauma and disparities?

☐ **How might we** support investment in the and built environment to create a grounded space for healing and sense of safety, place, and self-worth? This may include quality and affordable housing for all, re-pairing crumbling roads and sidewalks, and community-driven projects related to public art, green spaces, and playgrounds.

This report is a starting point.

The Insights and Personas present opportunities to better understand and respond to the needs of our community. We cannot look at any of these Insights in isolation. Each individual change we make needs to align and contribute to the overall systems change.

By responding to the Insights in this report and co-designing solutions with children, families, caregivers, and other providers, the work currently underway and what we take on through Phase Three will create the impact and outcomes needed to evolve our system for the better.

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