



# HORIZONS

THIS ISSUE: I-CREAtE

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# I-CREAtE

INNOVATIONS FOR COMMUNITY RESILIENCE, EQUITY AND ADVOCACY

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I-CREAtE team members Danielle Pinder (research assistant), Rifaa Carter (community researcher), Logan Jackson (community researcher), Dr. Eva Purkey (co-principal investigator), Michele Cole (community researcher), Bruce Knox (project co-ordinator), and Dr. Imaan Bayoumi (co-principal investigator).

# I-CREAtE

## Innovations for Community Resilience, Equity and Advocacy in Kingston and Area

*By Dr. Eva Purkey*

I-CREAtE (Innovations for Community Resilience, Equity and Advocacy in Kingston and Area) is a community-based participatory action research group (CBPAR) that started in January 2020. The group's vision is to create a research hub to meaningfully engage and respond to community needs. This includes exploring, advocating for, and acting on initiatives that enhance family and community resilience and equity.

The research team is made up of four community-based and four university-based researchers, each

with diverse identities and experiences, and guided by a project co-ordinator and a community advisory board (CAB). The CAB comprises representatives from municipal government; public health; school boards; and community agencies for newcomers, Indigenous Peoples, children, vulnerably housed persons, and many more.

While the core team remains consistent, we continue to incorporate additional research assistants, academic and community research partners, and students, who collectively contribute to I-CREAtE's growth and evolution.



I-CREAtE's first project was developed in collaboration between the research team and the CAB. It was funded by the Queen's University Department of Family Medicine and the Office of the Principal at Queen's University, as well as the Social Sciences and Humanities Research Council (SSHRC). Entitled *Engaging Families to Build Healthy Communities*, it explored the experiences of families living with adversity during and since the COVID-19 pandemic to better understand what made it easier or more difficult for families to thrive and to experience resilience in Kingston and the surrounding area. Families were also asked to think about strengths and weaknesses in their communities, imagining things that could improve the resilience of other families like them.

This study focused on families who had already been experiencing hard times or adversity before the pandemic. Some struggled with disability, some with poverty, and some with mental health concerns or substance use. Some families were racialized and had experiences of discrimination, some were new to Kingston or to Canada, and some were members of Indigenous communities. What all the participating families had in common was significant resilience in the face of personal or structural barriers to well-being.

In the first phase of this project, we used different qualitative methods to explore families' experiences and ideas about their own resilience and that of their communities. We used interviews, visual timelines, and photovoice to deepen our understanding of people's stories. We spent hours with each family, trying to get a well-rounded understanding of their experiences. Through this work, the team identified 12 areas that Kingston and the surrounding communities need to work on to enhance the ability of families who experience adversity to thrive. These areas are illustrated on the cover of this issue.

## Priority areas families identified to help build stronger communities

Over the course of the months following this first phase, these findings were shared throughout the community. Photovoice was exhibited in libraries, community centres, and markets, and at community events and academic conferences. The team created videos to share the findings, which were presented

at conferences and in various public venues. Finally, the findings were shared in formal community meetings that were designed to generate ideas about initiatives that could improve these areas of challenge, and that could provide ideas for researchers, community agencies, and communities themselves to work together to enhance the well-being of families with young children. These meetings were hosted by CAB members and other community organizations or leaders who reached out to the team. The recommendations generated in these meetings will be shared with the appropriate stakeholders and will inform the next steps of I-CREAtE's work.

This edition of HORIZONS is

designed to share, in depth, different aspects of this project in order to demonstrate how research can be used to highlight community experiences and needs.

In the first series of articles, readers hear from team members about their experiences of being part of the I-CREAtE team in different capacities and their experience working with a community-based participatory action research group. The second set of articles take deeper dives into some of the areas identified as priorities during this research process. These include an exploration of participants' experiences of substance use and treatment; how participants conceptualized inclusion, or lack thereof; participants' challenges with health- and social-system

**In the first phase of this project, we used different qualitative methods to explore families' experiences and ideas about their own resilience and that of their communities.**



Dr. Eva Purkey and I-CREAt team members gather at a data-analysis meeting.

navigation; and the ways in which arts-based methods can be used to collect, interpret, and share new knowledge in a participatory way. Finally, this edition concludes with articles outlining how I-CREAt has engaged with the community to share the findings of this first study and to consult the community around how to improve the health and well-being of families and children.

Community engagement is a core priority of Queen's University. I-CREAt is one illustration of how partnerships between the university and the community can occur.

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*Dr. Eva Purkey is a co-founder (along with Dr. Imaan Bayoumi) and one of the academic researchers on the I-CREAt team. She is a practising family physician, an educator, and a researcher at Queen's University. Her work focuses on advocacy to improve the health and well-being of people experiencing adversity, as well as on action to change the policies and structures that lead to this adversity. She is honoured to be part of such an amazing team and community.*





Logan Jackson photo: Supplied

# BRIDGING THE GAP

Focus on community voice draws in researcher

*By Logan Jackson*

I am a community researcher on the I-CREAtE team. I also work at Pathways to Education (P2E) Kingston, a program that supports youth in Kingston's North End while they complete high school and transition into adulthood.

When I joined the I-CREAtE team, I was working at P2E providing support to alumni. I later moved into a research role at P2E and I'm now on secondment with our national office to support the design of a new internal management system.

Research is in a lot of what I do, but it wasn't always this way.

Before all of this, I was a youth growing up in social housing while I lived in the community I now serve, Kingston's North End (Rideau Heights). Back then my only interactions with research stemmed from the radio, where radio hosts shared small snippets of research findings (without much context or scope of generalizability, I later learned). The studies shared on the radio spoke to the benefits of a glass of red wine with dinner, how much dark chocolate one should eat,



and how owning a horse might make you live longer (remember, correlation  $\neq$  causation).

At that same time, I saw problems every day that always seemed pertinent to research but were far less addressed like community violence, food insecurity, and insecure housing, amongst other issues. Were there studies being conducted on understanding poverty in the way the mysteries of dark chocolate had been investigated? Surely these studies existed, yet word never spread to my neighbourhood about them.

I received a Bachelor of Arts Honours in Psychology at Queen's University, and it was through Queen's that I had my first experiences learning about research within an academic setting. It was also in this setting where I discovered that most of those pursuing research didn't have the same focus on community work that I did. In fact, of my 30 or so lab peers in my third-year statistics course, I was one of only two people who weren't working in a lab outside of class. Instead, I dedicated my time outside of class to working directly with my community in afterschool programs, namely P2E.

Once I graduated, I continued on this trend and moved directly into full-time work in the community. I was still left with the feeling that research was disconnected from where I wanted to dedicate my efforts and, more importantly, where I felt those efforts were needed most. Then came along an opportunity to join a research team grounded in community voice, later named I-CREAtE.

I chose to join the core research team of I-CREAtE as a community researcher, however I was initially presented with different levels of involvement for the research project. If I didn't want to be on the core research team, I could have joined as a member on the community advisory board. If I didn't want that, I might have been a participant in a future study. Having the choice to be more than a participant in research was dignifying and I knew that joining in my fullest capacity aligned with my belief in how research can be applied to create change.

After everyone on the research team was acquainted, we started planning our first research project. Each stage of the project presented different opportunities for capacity- and skill-building. The early stages were defined by getting to know our fellow team members, along with deliberations on our research question and what direction we wanted the study to go in. Along with the other community researchers, I learned about structural pieces to academic research like grant writing and the ethics-approval process.

Once we decided on the project design, we moved onto skill-building around conducting interviews and, later, thematic analysis through the NVivo software. I'm certain my high school English teacher would be proud of the number of themes I found in the interview transcripts, however this was to the dismay of my coding partner as my goal to ensure no ideas were overlooked resulted in a summary page that was politely described to me as "maybe a little too much." I tried to be more concise in my coding after that while still respecting the very personal, intimate stories I had the privilege to share.

No longer do I see research as for a select few, out of reach from those who could benefit most. Through I-CREAtE, we can help bridge this gap between research and community, ensuring that community voice informs the research process and that the results are brought back to those who trusted us with their stories.

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*Logan Jackson works as a researcher at Pathways to Education Kingston and grew up in the Rideau Heights community.*





# A KNOWING VOICE:

Recognizing its value  
at the table

*By Catherine Larkin*

I heard about the I-CREAtE advisory board due to my past involvement in community work in rural Frontenac and my continued connection with that community. It was the participatory action-based approach to research that inspired me to engage with the project. I have been a member of the board since December 2020.

I had been aware of participatory action-based research because of my past work in disability rights and my social work studies. I was privileged to be asked by a consumer-survivor group in Toronto to design and implement a participatory action-based research project as part of my Bachelor of Social Work practicum. Additionally, I strongly believe in the values prevalent in disability communities that there should be “nothing about us without us.” The values of Brazilian educator and philosopher Paulo Friere have also guided me over the years. Namely that education, advocacy, and social change are intrinsically tied together.

In addition to my work with people who experience disabilities, I also worked in community services for a number of years in the rural areas of Frontenac, Lennox and Addington. Because of this, I have a strong understanding of both the needs and strengths of the rural communities in this area.

But the voice I bring to the advisory board is not primarily from my prior work or education. Rather, I bring my own voice as someone who lives and accesses services in a rural community. I bring myself as someone who grew up in rural Ontario with adverse childhood experiences including poverty, violence, and two parents with undiagnosed mental health issues. My father, who was diagnosed with shell shock during World War II, likely had ongoing effects from PTSD that affected his functioning, and my mother had clear signs of significant problems with depression and anxiety. Additionally, as outsiders in a small community, I was rejected and isolated as a child due to xenophobic ideas.

The effect of these childhood challenges has resulted in my own mental and physical health challenges. So I bring to the advisory committee my experiences of living with severe depression, anxiety, and PTSD symptoms as well as myalgic encephalomyelitis (aka chronic fatigue



syndrome). I have had to stop working and live on a limited disability income. When the opportunity to join I-CREAtE came along, my life had shrunk from being very busy and actively engaged in providing community services to a place where I was barely able to function or leave my home.

One of the values of a community-based advisory board is that lived experience is important. It's not about education, status, or authority but just being. All lived experience has value and should have a voice and validity in all aspects of research. To have a place to speak that values my voice despite my many current limitations is empowering and validating. This is part of the holistic value of participatory-action research. It's not just about taking data or stories from the community, but giving community members a voice and a space to actively engage in defining what is important in research.

It has not been easy to take on this role. I struggle with intense fatigue, which makes it hard to meet my basic needs let alone take on any additional projects. I also struggle with brain fog, which makes it hard to process information and respond in a timely and meaningful manner. There are many times I have wondered if I could contribute anything meaningful to the board. But every meeting has helped me to gain energy and satisfaction from feeling I do have a valuable role and voice with the group, even from the confines of my bed.

That being said, it's hard to find a good balance on a board with a mix of service providers and community members. It's easy for service provider voices to

dominate in this context. Service providers often speak in a jargon that can be alienating to outsiders. They are practised at having a voice in group meetings and finding ways to get their points across. While I have both education and experience in social services, I have struggled to feel that my voice carries equal weight in the group. I feel that my professional experience and education are dated, and I have struggled to keep up with language and protocols that have changed since I was in the field.

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I have also experienced professionals taking over and speaking with more authority when I've been struggling to make a point. Often, extra care is needed to ensure community voices feel welcomed and valued in these kinds of mixed groups. It's easy to feel intimidated by professionals who may have more education, more confidence in an advisory role, and more practice in speaking with care and precision on difficult topics.

Even though I have many advantages in terms of my education, prior work experience, and level of confidence, I have often questioned the validity of my voice and felt that I have less to offer. I think this is an area where I-CREAtE has room to grow

and develop. I would like to see them strengthen the community voices on the advisory board.

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*Catherine Larkin grew up and currently resides in rural Ontario. She lives with a number of disabilities and accesses services in the rural Frontenac area. Her current accomplishments are to live day to day. She does this with the help of the natural beauty surrounding her, a regular tai chi practice, and playing with Chinese ink painting.*







Roger Romero photo: Supplied

# ACEs AREN'T WILD

Childhood adversity is not a life sentence

By Roger Romero

*“People with an ACE (adverse childhood experience) score of six or more, on average, died 20 years earlier.”*

Those ominous words have been ingrained in my mind ever since I heard Dr. Meredith MacKenzie, a local physician at Street Health Centre (SHC), address an all-staff meeting at the Kingston Community Health Centres (KCHC) where I work. Street Health Centre’s mandate is to deliver health services through a wrap-around care model for people who face barriers accessing mainstream health services. The focus is on

priority populations, including those who are homeless or precariously housed, and those struggling with substance use disorder. Many have been incarcerated, and may be affected by or at risk of acquiring Hepatitis C.

In her presentation, Dr. MacKenzie noted that her daily work revealed the deep connection between toxic stress, childhood trauma, and addiction. She explained that traumatic experiences in childhood can negatively shape brain development, activate prolonged stress responses, and break natural parent-child bonds.

These are some of the leading causes of many of the



ailments she treats. She shared that these adversities are often cyclical, being passed from generation to generation.

I remember being in the room that day and thinking, “Is this presentation about me?” Many of the family challenges, such as neglect, substance use, and poverty, paralleled my personal experience. “Would I die 20 years earlier than the average person?” I wondered.

My journey starts in El Salvador, a beautiful tropical country in Central America. In the early 1980s, the country was plagued by a civil war that displaced more than a million citizens. Most fled the war to access a better life in North America. My father escaped first, to avoid government persecution for his mandatory military service and actions. My mother, brother, and I made the treacherous journey a year later, through Mexico and into the United States, via a network of unconventional travel routes. We were guided by “coyotes” — people who smuggle immigrants across the Mexico-U.S. border for a fee. We were lucky enough to re-connect with my father in the U.S. and were supported by a faith-based network to apply for refugee status in Canada.

Our family settled into our new home in Kingston, where we received generous supports from the community and the government. They took care of all our basic needs. Access to social housing, free education for the children, financial resources, access to primary care, food support, and vocational training for my parents were provided — seemingly, all the things needed to start a new life. As I reflect on our settlement, however, I realize that while deep focus was given to basic needs, no one addressed the trauma we had experienced.

How would these adversities affect our long-term health and social outcomes? As my family transitioned away from supports and into independence, the “real-life” challenges of raising a family — compounded with unaddressed PTSD and mental health challenges — put huge stress on all five of us children. We managed the best we could, but the stark reality was that we siblings had unknowingly absorbed these adversities, which led to varied health and social outcomes.

Dr. MacKenzie’s presentation described the hope that this knowledge can bring. Caring, consistent, and unconditional supportive relationships have the power to buffer the harmful effects of trauma. These kinds of relationships create new neural pathways, deactivate the body’s stress response, and activate the pre-frontal cortex: the part of the brain that gives humans their unique ability to reason, plan for the future, think creatively, and accept nurturing relationships.

As I processed this information, I began to compare my child and adolescent development with that of my siblings. From the time I arrived in Canada, I could recall participating in key community programs, supported by adults, that became interwoven in my life. These adults were not trained mental health professionals but, rather, everyday

people: teachers, coaches, volunteers, and church members.

I now understand that these relationships buffered the adversities I faced and allowed me to embrace challenges such as sports and academics as a learning opportunity rather than something that was stress-inducing. I was able to thrive. Many of these programs implemented non-punitive approaches to slowly foster behavioural change. Due to financial and cultural

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barriers, unfortunately, my siblings did not have equal access to these kinds of supports.

I now have the honour to serve the community where I grew up. I sometimes marvel at the fact that my office in Kingston's North End at KCHC on Weller Avenue was once a derelict bingo hall that my friends and I would break into just for fun. From that same building today, I oversee life-changing services and programs for community youth.

The largest part of my portfolio at KCHC is leading the Kingston Pathways to Education program. Pathways empowers high school students living in Rideau Heights and Inner Harbour neighbourhoods to graduate from high school and successfully transition to post-secondary education or meaningful employment — effectively breaking the generational cycle of poverty through education. Our programs are grounded in trauma-responsive approaches. Pathways provides relational, adversity-healing programs where caring adults build strong relationships with youth. Once established, our staff leverage those relationships, enabling youth to set high expectations and accountability for themselves.

Unfortunately, my childhood story is not unique. Every day families struggle to provide the safe, supportive environments needed for children to thrive. I never blame families, as I know they are doing the best they can with what they have. The reality is that deep, systematic oppression exists in many of the very systems that are meant to heal and restore community.

Will I die 20 years earlier than expected? I-CREAtE is helping the community understand that adversity is not a life sentence. I contribute to the I-CREAtE community board to share this message of hope with our community. What is predictable is also completely preventable. The answer lies in understanding and increasing community resilience.

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*Roger Romero is a first-generation Salvadoran-Canadian. His lived and work experience fuels his passion for equity, advocacy, community-building, and positive social development. He lives north of Kingston with his partner, Melissa, and their two young children.*

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# Understanding the systems navigation journeys of people with adverse childhood experiences

By Ayesha Shakeel

Getting connected with the right health or social service at the right time is not easy in our increasingly complex health and social systems. To access either health or social resources, people must overcome countless hurdles, including those that are personal and those that are a product of the systems around us. Whether it is long wait times to see providers, hard-to-find resources, extensive paperwork, or inaccessible application processes, the health and social systems that surround us are riddled with barriers.<sup>1</sup>

Navigating these barriers to access resources or systems can be even more challenging for select groups of vulnerable, underserved, or underheard people, such as people with adverse childhood experiences (ACEs). Children who grow up in environments that expose them to long-term stressors, or “adverse experiences,” are four to 12 times more likely to face the burden of negative social, medical, and mental health outcomes throughout adulthood.<sup>2,3</sup> For this reason, ensuring their access to the services and resources they need within the health and social systems is a critical first step for them to be able to benefit from these supports.

One of the key culprits behind the challenges people face in accessing and remaining connected to relevant services is their ability to navigate the complex systems

in which they exist.<sup>4</sup> This is why understanding the challenges that people with ACEs face when navigating and interacting with health and social systems is an important predictor of their access and use of services. For this reason, we explored the facilitators and barriers of navigating health and social systems for people with ACEs in the Kingston, Frontenac, Lennox and Addington (KFLA) region.

In the community-based participatory research (CBPR) study *Engaging Families to Build Healthy Communities*, this was a key challenge that families experienced and shared with the research team. By speaking with community members about their experiences and perspectives, we learned that personal factors such as the resources one has access to and their cultural identity, as well as the innate structure of systems, are important in determining a person’s ability to navigate the health and social service spaces.

In terms of personal resources that are important in helping people with ACEs navigate systems, technology and community networks play a big role. To access many resources and services, prior steps that require digital literacy and tech access are commonly required.



Maria Sherwood, community services worker at Queen’s Family Health Team, helps patients with system navigation.



For example, a device such as a laptop and reliable WiFi connection are needed to book appointments virtually or submit online applications for services. Having these resources, and knowing how to operate them, is required for navigating systems to reach the desired service or resource. Strong community connections are also a great help with finding out about available and relevant services through word-of-mouth, and receiving referrals from others.

At the same time, accessibility needs to be prioritized in the design of health and social systems. Currently, people with ACEs express not knowing where to look for resources, how to find them, or whom to ask. This indicates that improved promotion of resources should be prioritized so that services can be better reached and utilized. At the same time, this sheds light on the need to establish the role of navigators within the health and social systems. As professionals working within these systems, these individuals would be responsible for helping community members get connected to the right services at the right time.

While considering approaches to improve access to systems for people with ACEs, it is vital to not undermine the importance of culture and its role in making resources more attractive and effective. Indigenous Peoples, immigrants, and other communities who identify strongly with specific cultural values are often seeking resources that are culturally safe. Respecting different communities' worldviews and providing options that align with their cultural or religious values is an integral step in making those resources effective for them. This can take many forms, but one possible initiative may include the creation of roles for designated Indigenous systems navigators who are able to connect and advocate for Indigenous community members throughout the health and social services spectrum.

The process of systems navigation can appear as a labyrinth to people with ACEs. For researchers, policy makers, and systems leaders, it is important to understand the barriers in the systems-navigation process and an appreciation for the factors that facilitate them. Next steps include creating policies and practices that implement some of our findings to improve the accessibility of the health and social systems for people with ACEs in the KFL&A area.

*Ayesha Shakeel is an MD student at Queen's University and an MSc. candidate in Health Systems Leadership at the University of Toronto. She is a research assistant on the I-CREAtE team and is passionate about health systems design, community-based approaches to research, and knowledge translation. Her previous work includes research on community-led communication for development initiatives in geographically isolated areas with the Reach Alliance at the Munk School of Global Affairs & Public Policy.*

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## How KFL&A families navigate substance use within their community and family unit

By Ryan Truong

As part of the analysis of the I-CREAtE study *Engaging Families to Build Healthy Communities*, we investigated the experiences of families facing adversity and substance use in the context of family and community resilience. Families shared the impact of substance use on their family and communities and then identified solutions based on their lived experience. This article summarizes our key findings.

### Background

In 2012, Statistics Canada reported that 21.6 per cent of Canadians would meet the requirement for diagnosis with substance use disorder.<sup>1</sup> Numerous studies have also revealed that the number of substance use-related deaths has increased since the beginning of the COVID-19 pandemic, a statistic that continues to trend upwards. Within KFL&A, we saw an increase from 13 deaths per year in 2016 to 42 deaths per year in 2020



due to overdose.<sup>2</sup> Nationally, the Canadian Centre on Substance Use and Addiction estimated that substance use disorders cost Canadians \$49 billion in health care, criminal justice, and productivity loss in 2020.<sup>3</sup> These costs were most greatly incurred due to alcohol, followed by tobacco, opioids, and other illicit drugs.<sup>3</sup>

At the level of the family, substance use disorder causes social isolation, financial and relationship problems, and family instability. Children from families with substance users are more likely to struggle with substance use themselves.<sup>4</sup> They suffer from poor interpersonal connection and isolation throughout life and have an overall worse quality of life, including mental health challenges and chronic health conditions.

### **Community-based participatory action research**

Traditionally, research has focused on highlighting the shortcomings of a group. When many think of research, we assume it involves experiments, comparing different groups, and determining problems. We are driven to find and then (sometimes) solve problems.

However, the traditional research approach has historically been harmful to oppressed peoples. For example, the Canadian Residential School Nutrition Trials and the American Tuskegee Syphilis Trials have left some Indigenous and Black people distrusting of research and academia.

Understanding the importance of communities leading the research process, the I-CREAtE team utilizes community-based participatory action research (CBPAR). This framework involves the community in all phases of research including the design of projects and meaningfully engaging the community around their concerns and needs. Most importantly, it centres on the

strength of people's lived experience as expertise. In this case, CBPAR allowed us to address power dynamics while exploring the resilience of families navigating substance use and recovery.

Through our analysis, we found that parents find motivation for recovery from substance use because of their children. We learned that navigating recovery as a family presented unique challenges, including how

families maintain relationships while in recovery. Learning directly from families who experienced substance use disorders also allowed the research team to explore experiences of community safety and trust.

**We learned that navigating recovery as a family presented unique challenges, including how families maintain relationships while in recovery.**

### **KEY FINDINGS**

#### **Children as a driver for change**

Parents in recovery felt that their motivation to remain substance-free was grounded in protecting and caring for their children. Several families noted that their children were a source of hope. Parents in recovery reported that a commitment to remaining substance-free was a commitment to the well-being and future of their children and families.

#### **Overcoming unique challenges in recovery**

A barrier for those in recovery was the lack of family and peer support services, including support with childcare while accessing recovery services. For example, one family described having to leave their children with taxi drivers while accessing methadone. Another family feared that their child overhearing their support group would normalize substance use. In both cases, parents had cut ties with their family members and friends who were still using substances, thereby limiting their ability to get childcare for their children when accessing the services they required.

The commitment to protect their recovery and family resulted in isolation and a challenged sense of belonging with family, friends, and the broader community. Some families also had difficulties with maintaining relationships with individuals who have never struggled with substance use disorder. This challenged parents' recovery as they felt under-supported and judged. Those in recovery also struggled with maintaining connections with old friends as they felt these individuals could compromise their recovery.

## Community safety and trust

In addition, some parents (including parents who have and have not used substances) were worried about the physical dangers attributed to substance use and the materials users left behind, such as needles. The perceived presence of drug activity caused distrust among families, resulting in avoidance of local spaces such as parks for fear of harm. The negative perceptions among families have perpetuated distrust and stigma. Many families wanted to be part of a supportive community yet expressed discomfort and barriers to forming connections with the neighbourhood and broader community.

## Lived-experience solutions

Families described a spectrum of perspectives and solutions for substance use and poor perceived community safety. Some families were very empathetic and understanding towards people who use substances, as they felt that this was a result of current socio-economic challenges and lack of affordable housing and mental health support. Suggested solutions for these challenges were for more employment agencies, a basic income guarantee, and disposal bins for drug paraphernalia in community spaces.

## Key takeaways

Through consultation with the community, the community research team, and a review of existing literature, this study showcases how relationships, support, and community play a paramount role in facilitating the well-being of families in recovery. To address gaps in services and support for families, efforts including family-friendly services, childcare, and building a sense of safety and cohesion within communities are needed.

**The commitment to protect their recovery and family resulted in isolation and a challenged sense of belonging with family, friends, and the broader community.**

*Ryan Truong is a research assistant with the I-CREAtE research team and a second-year medical student at Queen's University. He developed and piloted the Queen's Health Sciences Outreach & Summer Program for equity-deserving high school students in KFL&A, is engaged in the Weeneebayko Area Health Authority high school outreach program, and is continually involved in community youth programming.*

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# SOCIAL INCLUSION

Economic, social,  
and political



By Riffaa Carter and Dr. Eva Purkey

Social inclusion, the idea of making all people in a society feel valued and important,<sup>1</sup> is a complicated concept. For some, it means the process by which efforts are made to ensure equal opportunity for people to achieve their full potential.<sup>2</sup> For others, it is a more descriptive understanding of the ways in which society's parts fit together and share values.<sup>3</sup> Ideas around values (and feeling valued), participation, and opportunity are often features of definitions of inclusion.

In *Engaging Families to Build Healthy Communities*, the first project of I-CREAtE (Innovations for Community Resilience, Equity and Advocacy in Kingston and Area), many study participants shared challenges related to social inclusion. As a result, our team felt it was important to think about what these stories teach us about ways our own communities here in Kingston, Frontenac, Lennox and Addington (KFL&A) are involved

in improving people's social inclusion, or in creating spaces from which people are excluded.

There are many ways of understanding inclusion. One framework, from the United Nations Department of Economic and Social Affairs (DESA), outlines three components of inclusion: economic inclusion, political inclusion, and social inclusion.<sup>3</sup> These components overlap, and each one has in itself many different pieces, but this framework presents an interesting way to think about the ways in which people are included, or not included, in their society.

**Economic Inclusion.** The first concept in the DESA framework that families in our study illustrated is economic inclusion. This component of inclusion involves people's ability to participate in the labour market, gain employment, earn a living wage that allows for an adequate standard of living, and access structures that are involved in or enhance the economy such as housing, health care, and education.

Families in our study often struggled with economic inclusion. Many did not make a living wage, either due to low paid work or inadequate social assistance. Some were barred from the labour market due to a criminal record or could not find work that was compatible with their physical or mental health conditions. Others struggled to find work due to language barriers or discrimination on the basis of race or accent. Some engaged in work that seemed to be a last resort, with one participant telling us that they engaged in sex work to be able to afford to eat. Many did not have adequate housing. Some had lived with their children in shelters, while for others housing was substandard or unsafe, with rodents and bug infestations. Families turned to neighbours, engaging in bartering or sharing of goods no longer needed, which helped with economic inclusion. Nevertheless, material deprivation was a concern for almost everyone in our study. Participants were able to identify the unfairness of not being able to engage in the economy in a meaningful way, and the disadvantage this placed on them and their children.

**Families turned to neighbours, engaging in bartering or sharing of goods no longer needed, which helped with economic inclusion.**

**Social Inclusion.** The second concept in the DESA framework is social inclusion. This involves what is perhaps the most commonly thought-of form of inclusion: the inclusion of newcomers, of ethnic, cultural, and religious minorities into the life of a community. It considers constructs such as spatial exclusion — the exclusion of some groups from certain public spaces (gated communities, design of parks and public spaces, etc.). It also considers the segregation of communities (the ghettoization of newcomers, unhoused people, and people living in poverty). Social inclusion involves interpersonal relationships but also structures — which structures are built in which communities, who has access to different spaces, is the public infrastructure (buses, parking, accessible services, etc.) accessible to all.

Participants in our study focused on four components of social inclusion: **community safety**, newcomer inclusion, community connections, and community

design. Many spoke of community safety, which was a broad concept for families involving everything from the perceived risks related to needles and drug paraphernalia in parks to the experience of having racial slurs yelled at them or their children in public spaces. Families talked about how feeling like a neighbourhood was unsafe had a big impact on their well-being and sense of belonging and connection within their community.

Families also talked about challenges to **newcomer inclusion**. Despite many programs for newcomers, participants described overt racism and lack of opportunity or connections due to their newcomer status (and this was true both for people who had just arrived in Canada as well as those coming from other Canadian communities). Families talked about the fundamental importance of **feeling connected** to other members of their community, of mentorship, and of having spaces they could go where they felt “seen” within their communities.

These important concepts led participants to talk about **community design** — parks and greenspaces were important spaces for people to come together, to meet informally, to create relationships, and to be seen. Transportation systems were important for children and youth, as well as for families who did not have a vehicle. Libraries and other public institutions were identified as spaces where communities could come together to enhance inclusion. People were explicit about the importance of having these spaces accessible, safe, and embedded in many different communities and neighbourhoods to enhance inclusion. They also talked about how some communities had fewer services and were perceived as more “ghettoized” or “tough” places to be. These communities had fewer resources and sub-optimal engagement with authorities (services, police, etc.), which, depending on the respondent, could mean either over-policing or inadequate response to emergencies.



**Political Inclusion.** The final concept in the DESA framework is political inclusion. This can be divided into many parts, including everything from the right to vote at the federal, provincial, or municipal level to the right to participate more broadly in civic life through community groups, organizations, and things like protests or demonstrations. Our study participants did not talk about federal or provincial politics, but they did talk about civic engagement. One participant talked about coming to city council meetings, recognizing that even they, as a person living in poverty, could be invited to consultation processes to provide input and opinion. More frequently, though, participants talked about participating in volunteer, grassroots, or community-based organizations, many of which had developed organically in response to increased community need during the pandemic. Meal programs started to provide food for people who were unhoused. Participants felt positive about being able to give back, particularly those who had needed support in the past, themselves. Participants talked about being involved in faith-based institutions that provided care for community members, and how volunteering for different organizations brought them outside of their own concerns and gave them a broader view of what was going on in the community and world around them. This form of civic participation or political inclusion, for those to whom it applied, was universally a positive experience.

Seeing the experiences of families living in adversity through the lens of inclusion provides many ideas about how our community can change and adapt to enhance people's experiences of inclusion. This is particularly true for those who may find themselves on the margins socially, politically, or economically and thus struggle with finding ways to participate in meaningful ways.

As the I-CREAt team moves into the second phase of our project where we are engaging with the community throughout KFL&A to share our study's findings and

to hear people's ideas about what could make their community better, we are reminded again and again about how much people want to participate and how many ideas are out there if only we create spaces for people to be heard and to participate in effecting change. We believe that creating a community in which everyone has the opportunity for inclusion, in the broadest sense, is a way to move forward to improve the lives of all people in our communities. Inclusion is a determinant of health. By including everyone, we will improve the lives of many who struggle, and it is our belief that we will enrich the lives of all.

**Participants felt positive about being able to give back, particularly those who had needed support in the past, themselves.**

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Community researcher Riffa Carter makes notes about a family's data during a data-analysis meeting.

## Reconsidering the research process and how researchers influence it

By Meghan K. Ford

Before starting a research project, it is important to create a research plan to determine the project goals and how data (information) will be collected and analyzed. For researchers, it can be tempting to choose familiar methods for gathering data (e.g., a questionnaire for quantitative research, interviews for qualitative research) and to bring together a research team solely based on academic qualifications or interests. However, traditional research methods and teams may not be enough, or appropriate, to fully address certain research topics or questions — particularly when considering under-represented groups.

“Participatory methods” involve the collaboration of researchers with individuals with lived experience (e.g., community members, newcomers, Indigenous Elders) in some or all aspects of the project (e.g., conceptualization, data collection, analysis, and reporting). Arts-based research is one type of participatory method that utilizes art to collect, interpret, and share new knowledge. Adopting participatory methods such as arts-based research techniques has the potential to capture authentic data and enrich the experience for individuals with

lived experience. These approaches are capable of transforming individuals from “participants” to “collaborators” in the research process.

There is a need for researchers to critically consider the methods they use and how they can undertake research in culturally safe ways. This means creating an environment where there is mutual respect, openness, and a willingness to listen with a shared understanding and acknowledgment of each other’s identities.

Sometimes culturally safe research is compromised, not due to lack of awareness of the participants’ culture but because of unequal power relationships, marginalization, researcher biases, unexamined privileges, and institutional racism. Culturally safe research refers to acknowledging the barriers that naturally arise in research, such as awareness of differences and power imbalances. Research projects that adopt culturally safe practices aim to recognize and consider the impact of the researcher’s bias on participants, collaborator perspectives on research activities, and team values. Researchers need to consciously consider cultural safety throughout the research process.



Arts-based research methods challenge dominant, colonial research frameworks by using research practices that are more person-focused, collaborative, and creative. Arts-based research offers an innovative way to produce data through the shared creation of various forms of art (e.g., written, visual, verbal, performance) as the predominant ways of understanding and exploring the research topic. For example, graphic timelines are developed from important life events participants identify. Timelines are positioned in chronological order, with visual emphasis on the importance or meaning attached to each event.

The construction of timelines is one technique for participants to reflect on their lived experience and create a collaborative interview environment. Timelines can increase the depth of participant sharing and aid in relationship-building by shifting the power dynamic between the interviewer and interviewee — putting the power in the hands of the interviewee to express their own story.

Arts-based research methods are participatory in nature by inviting individuals with lived experience to collaborate because the researcher recognizes the value of their input.

Traditional research frameworks exclude such voices in the research process. Engaging the voice of people with lived experience in the research process increases the awareness of underrecognized perspectives. However, it is important to acknowledge that no research method, participatory or other, is culturally safe in and of itself without critical reflection of the researcher's influence on the study. This process of critical reflection is called reflexivity — the questioning of how education, income, ability, gender, ethnicity, assumptions, beliefs, interests, and experiences influence the research process. Critically reflecting on how researchers influence a research project is an ongoing process. It prompts researchers to continually shift and (re)think their understanding of the research process and how they influence it. Ultimately, reflexivity encourages researchers to embrace discomfort and to be flexible when designing projects.

When considering how to engage in reflexive practices throughout the research process, there is no “one size fits all” approach. Reflexive engagement means asking questions and engaging in critical discussions from the very start of the research journey. Bias exists in topics and early stages of the research process, even if all efforts have been made to remove objectivity. Asking broad questions such as “why am I studying one population and not another,” “why am I using this method for data collection,” and “am I the one who should answer these questions” may

help ensure research is culturally safe. Researchers must challenge the unequal power dynamics displayed between researchers and participants by ensuring they collaborate with community experts and individuals with lived experience throughout the entire project. Establishing a team that comprises not only academics but community members and/or leaders contributes to building trusting research relationships within communities. This can also assist in better recruitment and data-collection strategies and uptake of research findings, and ultimately ensure research is grounded and meaningful to individuals with lived experience.

**Arts-based research is one type of participatory method that utilizes art to collect, interpret, and share new knowledge.**

There is a need for ongoing, meaningful discussions before, during, and after the research process to identify and address preconceived ideas about research methods. Arts-based research techniques are one way to promote reflection, raise awareness of issues being investigated, empower collaborators by recognizing their knowledge and expertise, and support more equitable relations between researchers and participants. To achieve ethical research, scholars must carefully consider the methods used, dive into the uncomfortable, and conduct research in culturally safe ways.

*Meghan K. Ford, BA, MSc, is completing her PhD in Clinical Psychology at Queen's University. She strives to encapsulate the voices of collaborators throughout the research process through utilizing participatory methodologies and methods.*

# PHOTOVOICE

Lived experiences shared through inclusive voices

By Yvonne Tan and Danielle Pinder

Developed in the 1990s by Caroline C. Wang and Mary Ann Burris, photovoice is a research methodology that combines visual storytelling with community engagement to amplify marginalized voices and catalyze social change. At its core, photovoice invites participants, often from equity-seeking communities, to capture images to document, reflect upon, and communicate their lived experiences.

The goals of photovoice are (1) to enable people to record and reflect their community's strengths and concerns, (2) to promote critical dialogue and knowledge about important issues through large- and small-group discussion of photographs, and (3) to reach policymakers. In other words, the process not only serves as a means of self-expression, but also facilitates social change by bringing attention to issues that may otherwise go unnoticed. By allowing individuals to represent their own realities, photovoice can help bridge the gap between academia and diverse communities, fostering a more inclusive and equitable approach to research. Additionally, by giving a platform to those whose voices are often unheard, photovoice can be used to shape policy in ways that foster inclusive and empathetic communities.

Researchers have adopted photovoice to explore the needs of different populations, such as people with physical and intellectual disabilities, people who use substances, and people experiencing homelessness. Our study used photovoice to identify factors contributing to family and community resilience from the perspective of families who self-identified as having a history of adversity and being resilient during the COVID-19 pandemic.

Five main themes emerged from our study:



Kingston Community Health Centres was among a variety of settings at which the photovoice exhibit was displayed.

## Theme 1: Social Support Networks

Many participants were able to find people similar to them, allowing for a sense of belonging, connection, and support. Families also noted that fostering bonds through the exchange of resources not only helped address immediate needs, but also nurtured a sense of shared responsibility.

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*"I would say most important is the friendship from the mature students. And we resonate (with one another's) struggles. The struggles of balancing study and family life, especially time with our children." (Family 043)*

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## Theme 2: Factors Fostering Children's Development

Public spaces for play were noted to foster social interactions, as well as provide a way for families to spend time together. Learning opportunities were also highlighted as providing children with personal and intellectual development. Families noted that fostering



children's autonomy was a fundamental aspect of their healthy development.

*"We just need to ... provide these stories to our children so that we are giving them the tools and resources in an age-appropriate way for them to learn about things that are going to shape the world." (Family 007)*

### Theme 3: Access and Connection to Nature

Many noted that time spent in nature proved healing for both their physical and mental health. Families also noted that the outdoors allowed for geographically and financially accessible leisure activities.

*"Exposure in nature is good for everybody ... it's so accessible to everybody. It's free. It's easy to get to." (Family 009)*

### Theme 4: Having a Space of One's Own

Families shared how ownership and autonomy over their homes greatly contributed to their resilience. Others noted that having their own space within their homes was essential for their mental well-being.

*"It was a huge strength for myself and my family that we managed to keep our home and thrive in it ... You can be resilient without a home but, me personally, I needed the home to be resilient." (Family 003)*

### Theme 5: Access to Social Services and Community Resources

Families highlighted the importance of resources such as libraries, Indigenous community resources, services tailored toward women and children, and substance use services as catalysts for their resilience.

*"The methadone program in and of itself has been an enormous driving force in my life changing for the better. I'm grateful that it's there ... When you reach, there's a hand there, that's huge resilience." (Family 047)*



To share our findings, we showcased the exhibit in various settings across the Kingston, Frontenac, Lennox & Addington region. The photovoice exhibit was featured at the local farmer's markets, community health centre, public library, and other frequented community locations. The community's response to the exhibit was overwhelmingly positive. Observers actively engaged with the showcased stories and photographs, prompting reflections on their own resilience. Many community members resonated with the featured stories, expressing that they had encountered similar adversities.

Additionally, many appreciated the exhibit's accessibility, acknowledging that much research tends to be confined to the academic realm. By sharing photovoice across these diverse community spaces, we aimed to establish a genuine connection with the community.

Overall, photovoice has allowed us to ensure that our findings are firmly grounded in and responsive



In this photovoice image, one family highlighted the importance of learning and providing children with opportunities for personal and intellectual development using age-appropriate books to learn about the social world around them.

to the community's needs. The photovoice method allows research to transcend the confines of traditional academic settings and foster a more inclusive and meaningful exchange of knowledge. By putting the narrative in the hands of participants who become the storytellers of their own experiences, photovoice empowers voices that may have been traditionally marginalized. This inclusive storytelling not only informs program and policymakers but also resonates with the broader community.

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*Danielle Pinder is a research assistant with I-CREAtE. She received both her BSCh in Life Sciences and Master of Public Health from Queen's University.*

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Stakeholder organizations chose assertions for discussion based on 12 priority areas families identified to help build stronger communities.



# COMMUNITY MEETINGS

## Participatory knowledge mobilization

By Bruce Knox and Danielle Pinder

In the beginning of this edition, we introduced that the findings from I-CREAtE's first project, *Engaging Families to Build Healthy Communities*, were shared in community meetings. These meetings were designed as a platform for generating ideas that could enhance family and community well-being. As a community-based participatory action project, they served as the knowledge-sharing phase of this initiative. Thus, they enabled us to relay insights gathered from participating families back to community members, service providers, and community organizations. We actively engaged these groups in discussions, asking them, "How do we solve this, and what do we do next?"

### Planning the meetings — Who and how?

As was done during the data-collection phase of the project, the knowledge-sharing phase aimed to reach as diverse an audience as possible. It was crucial to carefully consider who we were sharing the results with and, in the same breath, whose voice we were soliciting ideas from. Community-based participatory action research projects are community-led; thus, we

worked with I-CREAtE's community advisory board (CAB) to reach a diverse audience of community members and service providers who played a pivotal role in the idea-generation component of this project. The recommendations and next steps will revolve around centering their valuable ideas.

The I-CREAtE team purposefully worked with stakeholders on the CAB and community partners through other networks at Queen's University to organize these community meetings. Each stakeholder was responsible for identifying the most important groups to engage, including the people they serve or work with, and recruiting them to attend the meeting. Organizations the I-CREAtE team met with during this phase included the Seniors Association Kingston Region; Kingston Community Health Centres; Trellis HIV and Community Care; Adverse Childhood Experiences & Resilience Coalition (ARC) of Kingston, Frontenac, Lennox & Addington (Community Foundation for Kingston & Area); the City of Kingston; Limestone District School Board; KEYS Job Centre; Pathways to Education; and members of the Kingston Indigenous community.

While stakeholder organizations were responsible for bringing people out to the community meetings, the I-CREAtE team designed and facilitated them. Prior to

each meeting, the stakeholder organizations were asked to choose three assertions they would like to focus on. Each assertion represents a priority topic participating families identified during the project's data-collection phase. The I-CREAtE team then crafted each meeting around the chosen assertions, ensuring the format was attuned to each audience's particular needs. Each meeting began with the I-CREAtE team introducing the research project, and explaining how information was collected and how the resulting assertions were identified. This was to help community members conceptualize the research participants' experiences and the factors that contributed to their resilience and well-being. Once the project had been introduced, the I-CREAtE team presented the three assertions for discussion. To do so, the team presented fictional case examples and quotes from participant interviews that illustrated each assertion.

### **Sharing research data — Meaningful communication using participatory methods**

Once each of the three assertions were introduced, the I-CREAtE team presented three questions, one for each assertion. The questions were framed to generate a discussion about the assertion and ideas about ways to improve family and community resilience and well-being.

The approach to this process differed based on the audience. For some, a group discussion proved most effective for generating feedback, as community members wished to hear and build upon each other's ideas. In other meetings, a World Café activity was used, in which participants were involved in small-group discussions, moving periodically around the room to expand upon each other's ideas in response to the questions posed. Additionally, some meetings used activities in which community members jotted down their ideas on Post-it Notes and placed them under the relevant question.

Each activity had its strengths and weaknesses. Group conversations allowed community members to potentially build community cohesion around topics and allowed for all to contribute, regardless of literacy level. However, they proved challenging for everyone to meaningfully contribute and often resulted in discussions veering off-topic. Likewise,

World Café activities enabled deeper conversations in smaller groups, allowing all participants to actively contribute. These activities also allowed participants to converse with a diverse set of individuals, allowing for the evolution of ideas. However, additional time was required during meetings to regroup to discuss what was shared during smaller groups. Likewise, Post-it Note activities allowed participants to anonymously provide suggestions, helping people feel more comfortable contributing. However, these activities did not account for varying literacy levels and language barriers.

### **Transformative power in research — What lies ahead**

Overall, every community meeting followed a unique process tailored to the specific needs of the participating community members. The flexibility the I-CREAtE team maintained during these meetings resulted in the successful collection of feedback from the community and numerous ideas. Ultimately, this community-based participatory process puts the power back into the hands of the community and, through this component of the project, the I-CREAtE team has proven that community members are not only willing but eager to actively contribute to shaping their own communities.

Through the winter and spring, the I-CREAtE team will work to bring the community's ideas gathered during this knowledge-sharing process into a list of recommendations for appropriate stakeholders. To do so, the I-CREAtE team will compile and categorize ideas by theme. These recommendations will then be brought back to the community as an "action plan" that can be used in conjunction with I-CREAtE's existing community report to inform programs, policies, decision-making and, ultimately, the future of I-CREAtE's work.

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*Bruce Knox is I-CREAtE's project co-ordinator, a role he has held since January 2021. On top of this role, Bruce also works in EDIIA and community engagement for Queen's Family Medicine. Outside of work Bruce spends his time growing food in Stone Mills and walking in the forest.*

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