Kingston Community Health Centres
Centres de santé communautaire de Kingston

Journey Mapping Supports for Families of School-Aged Children

An exploration of caregiver experiences accessing health-care and support services for children 4-12 years old with emotional behavioural disorders and/or special needs

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EXECUTIVE SUMMARY

This report presents the findings from a journey mapping engagement aimed at understanding the experiences of caregivers of school-aged children (ages 4-12) with emotional behavioural disorders and/or special needs in accessing health care and support services in Kingston, Frontenac, Lennox and Addington (KFL&A). Through focus groups and interviews with clients of Kingston Community Health Centres (KCHC), the study explored the steps caregivers take to seek care, the barriers they encounter, and the emotional and logistical challenges they face throughout the process.

Through focus groups and one-on-one interviews, seven participants (clients of KCHC) shared their experiences navigating a complex and often disjointed system of care. Additionally, four KCHC family physicians reviewed the participant findings to assess if/how they aligned with their experiences delivering care and provided feedback on potential change ideas to enhance health-care system planning.

The insights gathered through the journey mapping engagement highlight critical gaps in service delivery and emphasize the need for more comprehensive, accessible, and coordinated care. The findings and the recommendations developed through collaboration with clients and providers are intended to inform strategic improvements in service delivery, continuity of care, and accessibility within the health-care system. By addressing key gaps and barriers, a series of proposed change ideas aim to foster better outcomes for children with emotional and behavioural disorders and/or special needs and their families.

The following major themes emerged from engagement findings:

Challenges in Managing Child Behaviour

Caregivers often seek help when their child/children's behaviour becomes unmanageable. They feel overwhelmed and uncertain about how to proceed, leading them to turn to primary care or other health-care providers for support.

Barriers to Accessing Health-Care Services

Caregivers face significant barriers in accessing health care for their children due to transportation challenges, financial strain, and an overall lack of timely care. Providers identified additional barriers, including varying levels of digital literacy, language proficiency, lack of health cards, systemic policies, and resource constraints.

Extensive Wait Times for Specialized Services

Long wait times, often exceeding one year, for mental health and other specialized services critically impact children with emotional behavioural disorders and/or special needs. These delays prevent timely intervention and create significant challenges for caregivers trying to address their children's urgent mental health needs. Providers highlighted the systemic nature of these delays, emphasizing the need for resource and policy improvements.

Complexity in Navigating Government Assistance, Health-Care System, and Community Services

Navigating the health-care system, government assistance programs and community services is overwhelming for caregivers, with many struggling with complex paperwork, unclear guidance, and barriers to accessing necessary resources and support.

Mixed Experiences with Health-Care Providers

Some caregivers reported positive experiences with supportive health-care providers, while others felt dismissed and unheard, leading to a lack of confidence and trust in certain providers and the care their children receive. The findings also uncovered that caregivers and providers sometimes face misaligned expectations, with caregivers seeking immediate solutions for their children with special needs, while providers highlight the complexity of managing such cases and the limitations of the health-care system.

Gaps in Service and Continuity of Care

Participants highlighted the lack of coordination between health-care providers, schools, and community services, leading to inconsistent care, long waits for specialized services, and frustration with ineffective referrals.

Caregiver Burnout and Lack of Support

The emotional toll on caregivers is significant, with many feeling overwhelmed and unsupported due to insufficient resources, in-home support and respite care, contributing to high levels of caregiver burnout. Providers further emphasized the urgent need for accessible respite care and mental health resources to address caregiver burnout, recognizing that caregiver wellbeing is essential for sustaining effective care for children with emotional behavioural disorders and/or special needs.

Insufficient School Support

Caregivers expressed dissatisfaction with the education system's support for their children, citing inadequate resources, resistance to necessary accommodations, and a lack of one-on-one aides to meet their children's special needs.

These themes reflect the primary concerns and experiences that caregivers and providers expressed in focus groups and interviews. They highlight the multifaceted challenges and systemic barriers caregivers face trying to access care and services for their school-aged children, underscoring the urgent need for more comprehensive, coordinated and timely health-care and support systems.

There is an opportunity for the insights captured in this journey map to be utilized as a tool to inform future decision-making, organizational and program development and health system planning in our community and beyond, with the goal of improving health and support systems for these children and their families.

OVERVIEW

The journey mapping process sought to gather insights, perspectives and lived and living experiences of caregivers of school-aged children (ages 4-12) with emotional behavioural disorders and/or special needs* in accessing health-care and support services in KFL&A. The journey mapping explored the steps involved in caregivers accessing care and support for their children, and also captured their concerns, emotions, mindsets and beliefs in relation to this journey. This information is invaluable for identifying strategic opportunities to improve access to and opportunities for care and support services for these children and their families.

Data Collection

To gather qualitative data on the experiences of caregivers accessing care and support for their school-aged dependents, we conducted two focus groups and one one-on-one interview with KCHC clients. The focus groups were one-hour in length and were held in person at KCHC (263 Weller Ave in Kingston, Ontario) in July 2024. The first focus group included four participants, and the second had two, bringing the total number of focus group participants to six. Additionally, a one-hour one-on-one interview was conducted over the phone in August 2024 with a KCHC client. In total, seven participants were involved in this study, all of whom access primary care services at KCHC.

Participants were asked 16 open-ended questions (see Appendix I) designed to explore their experiences and gather in-depth insights into their challenges and needs. Participation in the focus groups and the interview was entirely voluntary, with participants receiving a $25 grocery gift card as a token of appreciation for their time.

Each participant was provided with a consent form, which was read aloud to them, and all participants gave their consent to participate in the study. Participants were informed that they could choose not to answer any questions or withdraw from the study at any time without any impact on their access to services at KCHC or elsewhere, or their children's medical care. They were also given the option to withdraw from the study up until one week after their participation.

The data collected from these focus groups and interviews underwent a thematic analysis to identify common themes and barriers caregivers face in accessing adequate care and support for their dependents. This analysis also included mapping the journey of caregivers from their initial concerns to seeking and receiving support for their children, with the goal of highlighting key pain points and gaps in service delivery.

To further enrich the findings from the journey mapping process, we conducted a one-hour, in-person focus group at KCHC with four KCHC family physicians where they were asked 10 open-ended questions (see Appendix II) to explore if/how the journey map findings from the clients aligned with their experiences delivering care for these needs. Providers were given a summary of the findings from the client journey map to review prior to the focus group.

The purpose of this provider focus group was not only to compare and validate alignment with client-reported experiences but also to gather insights and feedback on potential change ideas that could enhance the system. Providers were encouraged to share perspectives on how best to implement improvements and address specific barriers in care, with a particular focus on strategies to better meet the needs of children with emotional and behavioural disorders and/or special needs, as well as the needs of their caregivers. This engagement allowed for a collaborative assessment of practical steps to improve service delivery, continuity of care, and accessibility within the health-care system.

Participants

Client Journey Mapping Engagement

Age distribution among participants ranged from 28-64 years old, with three participants aged 35-50, three aged 18-34, and one aged 50-64. In terms of gender, six participants identified as female and one as male. One participant self-identified as Indigenous.

The majority of the households have an income of less than $15,000 per year and 100 per cent of participants had household incomes of less than $60,000 per year. All participants live in either K7M, K7P or K7K postal code areas of Kingston.

During this timeframe, all caregivers saw between six and nine different health-care staff, including integrated clinical staff from the Weller Clinic and the Street Health Centre sites of KCHC, including nurse practitioners, physicians, dieticians/nutritionists, nurses, residents, pharmacists, social workers, registered nurses, registered practical nurses, outreach workers, counsellors, practical assistance workers, virtual care registered nurses, THRIVE outreach workers, addiction counsellors, psychiatrists, EarlyON childcare and/or preschool teachers, certified diabetes educators, clinic managers, and medical students.

Client Care Encounters

All seven participants are attached to primary care at KCHC’s Weller Clinic. Collectively, the caregivers have had a total of 424 encounters with the primary health care team in the last three years, which is an average of 20 appointments per year each, with the volume of encounters per person ranging from 22 to 125 encounters in the last three years.

Clinical staff documented a total of 1,315 issues addressed during these visits, including 127 involving children's health and development, 90 related to social and familial issues, 166 for mental health and emotional well-being, 40 concerning administrative and advocacy needs, and 43 related to nutrition / lifestyle.

Children

Of the participants' 12 children, age distribution ranged from six to 14 years old; four female and eight male.

Collectively, the children had 294 encounters with the primary health care team at KCHC's Weller Clinic in the last three years, representing an average of eight visits per year per child, with the number of encounters ranging from zero to 63 per child.

Eighty-three per cent of these children are supported by a team of health-care professionals, ranging from three to 10 different health-care providers, including physicians, registered practical nurses, residents, counsellors, nurse practitioners, dieticians/nutritionists, outreach workers, EarlyON childcare and/or preschool teachers, social workers, nurses, pharmacists, psychiatrists, medical students, community health workers, and occupational therapists.

Clinical staff documented a total of 1,372 issues addressed during these visits, including 303 related to preventative care and routine visits, 176 concerning acute and chronic conditions, 219 involving parenting and familial issues, 249 related to lifestyle and nutritional concerns, 225 for behavioural issues, 36 for developmental and learning issues, 9 for mental health concerns, 90 related to sleep and rest, 23 concerning medication-related issues, and 42 for social and school-related issues.

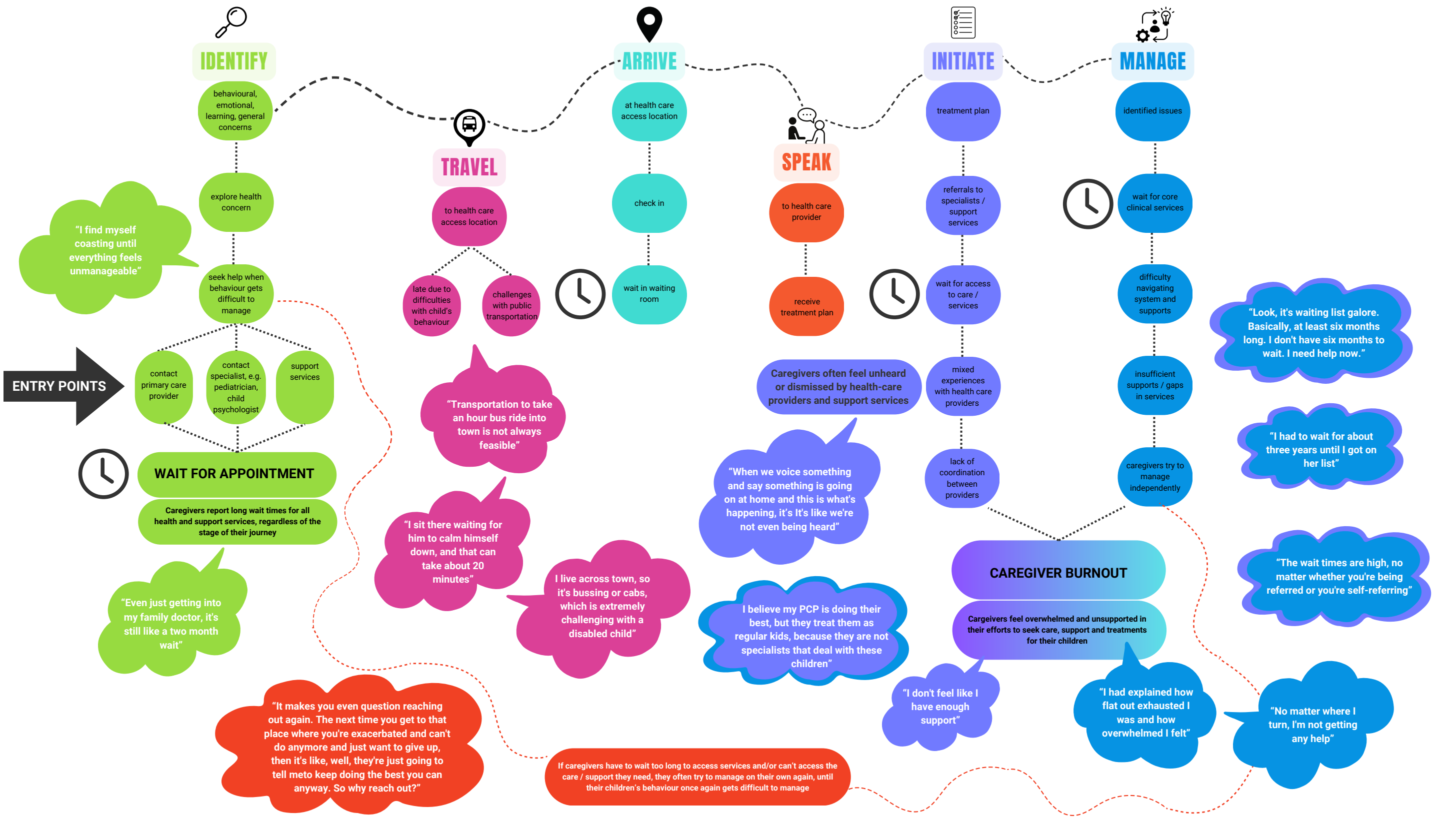
Overall, 81 different staff members, representing 15 different professions and provider types, had appointment encounters with either the caregivers or their children. The data from client care encounters highlights the significant utilization of resources within the KCHC system by these clients, who require intensive, multidisciplinary support to address their complex needs. This level of engagement underscores the value of a comprehensive team-based approach and also illustrates the complexity and resource-intensive nature of care delivery for children with emotional, behavioural disorders and/or special needs, and their caregivers. Furthermore, this data emphasizes the need for streamlined service delivery and efficient care coordination across sectors and the region to optimize outcomes and alleviate strain on the system and health-care providers.

**The Government of Ontario definition of children with special needs (https://www.ontario.ca/page/children-special-needs):*

Children with special needs may have a variety of conditions that may affect their physical, communication, intellectual, emotional, social and/or behavioural development.

Children with special needs may have multiple conditions and/or disabilities that impact their daily activities and functioning. Special needs can include:
- *communication delays and disorders*
- *physical disabilities*
- *neurodevelopmental disabilities*
- *acquired brain injuries*
- *chronic and/or long-term medical conditions*
- *specific diagnoses, such as Cerebral Palsy, Down syndrome, Spina Bifida, Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder (FASD)*

JOURNEY MAP: CAREGIVERS



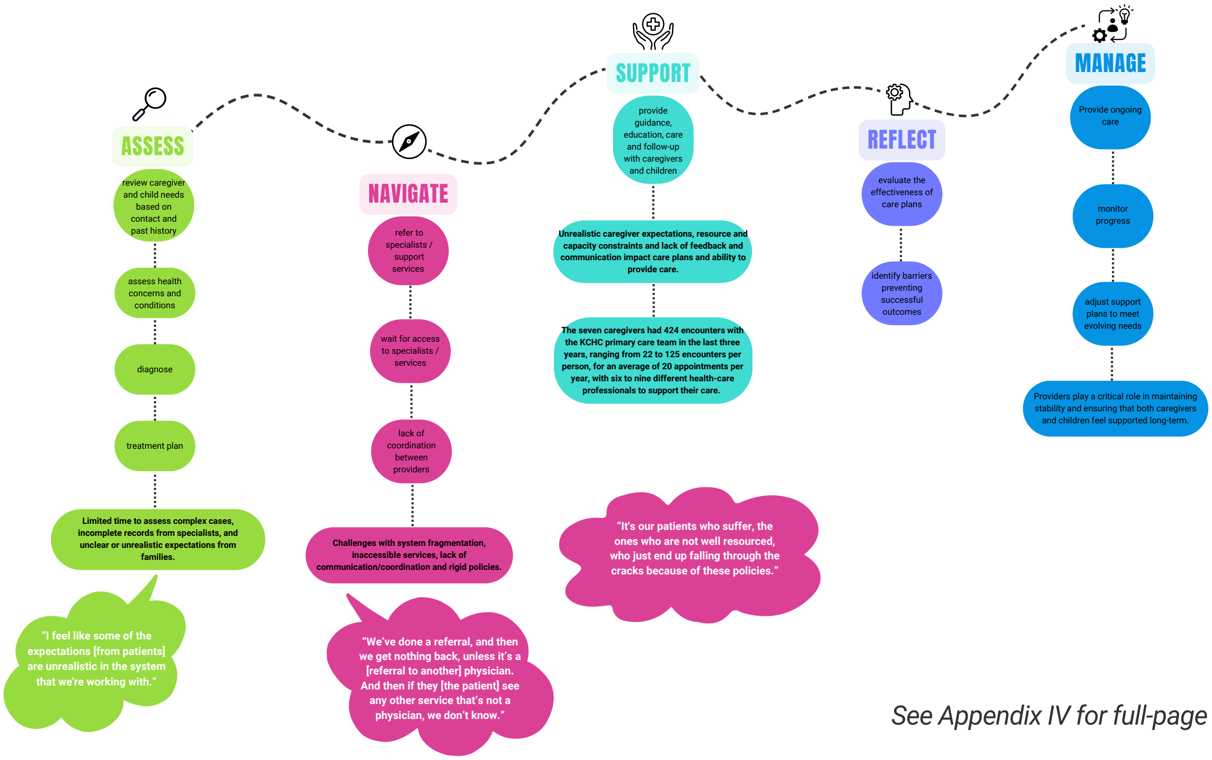
See Appendix III for full-page map

This journey map captures the experiences of caregivers of school-aged children who face significant challenges in managing their children's behavioural, emotional, developmental and educational needs. It outlines the complex and often overwhelming path these caregivers navigate. The journey begins with identifying developmental or behavioural concerns, often prompting caregivers to seek help when the situation becomes unmanageable. Upon reaching out to health-care providers, caregivers frequently encounter difficulties with transportation and navigating the health-care system, including long wait times and barriers to accessing timely care.

The journey is marked by a mix of positive and negative experiences with health-care providers, where some caregivers find support, while others feel dismissed and unheard. Referrals to specialized services are common, but many caregivers face a lack of continuity in care and gaps in services, leaving them feeling unsupported. Parental burnout is prevalent due to insufficient resources and in-home support. Managing ongoing issues is further complicated by long waits for core and specialized services and difficulties filling out paperwork for financial support and government assistance.

Caregivers also face challenges navigating the educational system, where inadequate support and resistance to necessary accommodations further exacerbate their children's challenges. This journey map highlights the urgent need for more coordinated, comprehensive and timely care and systems that can better support both children and their caregivers.

JOURNEY MAP: PROVIDERS



See Appendix IV for full-page map

The provider journey map illustrates the challenges and experiences of KCHC family physicians as they work to deliver care to school-aged children with emotional behavioural disorders and/or special needs and their caregivers. Providers play a central role in guiding families through the health-care system, assessing needs, coordinating referrals, and providing ongoing support. However, their efforts are often hindered by systemic barriers, resource constraints, and misaligned expectations.

The journey begins with providers reviewing child and caregiver needs, assessing health concerns, and developing treatment plans tailored to the family's circumstances. Limited access to complete medical records and poor coordination with external services complicate this process, making it difficult to create comprehensive care strategies. Providers often feel that the expectations of caregivers do not align with the realities of what they can offer within the constraints of the current health-care system.

A portion of the journey involves referring families to specialists or community services. Providers report extensive delays in accessing specialized care and describe the system as fragmented, with minimal feedback loops. This lack of communication leaves them unable to track patient progress or adjust treatment plans accordingly. Despite these challenges, providers continue to offer education, guidance, and follow-up care, aiming to maintain stability for both caregivers and children. Monitoring progress and adjusting care plans to meet evolving needs is a critical but resource-intensive part of their role. However, systemic capacity issues and rigid policies limit their ability to address the complex needs of these families comprehensively. Overall, the provider journey map reveals a pressing need for systemic improvements, including enhanced coordination between providers across the system, timely feedback from external services, and increased resource allocation.

MAJOR THEMES

Theme 1: Challenges in Managing Child Behaviour

Caregivers seek help primarily when their child/children's behaviour becomes unmanageable, both at home and/or in school. They often feel overwhelmed and unsure of how to proceed, prompting them to reach out to primary care providers or other health-care providers for support.

> ***"For the most part, I find myself coasting along, doing what I consider survival parenting, up until [the point] where everything feels unmanageable."***

> ***"He gets kind of in a violent state. So I get a few punches in the face, and it's getting to a point where it's hard on me. It's just getting hard to go out in public in general with him."***

Theme 2: Barriers to Accessing Health-Care Services

Caregivers face significant challenges in attending health-care appointments due to travel time, reliance on public transportation, and difficulties managing their child's behaviour leading up to and during the journey. These barriers often lead to late or missed appointments.

"My oldest, if he doesn't want to go, he says 'No' and he makes it a challenge to leave. He'll keep unbuckling himself. He'll throw himself in the front seat, he's thrown his booster seat at me from the back seat of the car a few times. I haven't even pulled out of the driveway yet. I sit there waiting for him to calm himself down, and that can take about 20 minutes."

"I used to live in the area [of KCHC] which was great, and now I live across town, so it's bussing or cabs, which is extremely challenging with a disabled child."

"Standing at the bus stop and all of a sudden your little one says they have to pee and the bus is coming. You know you're going to be on the bus for the next 40 minutes. You gotta go to take him to the bathroom and come back, and then you miss your appointment. Miss two appointments and you're off the roster. You gotta go back and apply again. Talk about setbacks."

"Transportation to take an hour bus ride into town is not always feasible."

Several caregivers discussed the financial strain associated with accessing specialized care and services not covered by public health insurance, as well as other socioeconomic factors that limit their ability to seek or sustain treatment.

“It's challenging with disabled kids, because there's really not much help out there. You know, you can pay $90,000 a year for proper amounts of therapy. Out of the $25,000 a year they [the government] give you, if you can swing the other $65,000 and most people can't do that. So you're really just left to your own devices and trying to make it work.”

“I can't just have anybody watch her. I need to pay respite specialists $300 an hour because I need two of them on call for her, because she's so much to handle. So it's just really tough.”

“I can't really get a job or anything, because I can't even guarantee that I'll have a full school day.”

Providers highlighted additional barriers for clients in their practice, including varying levels of digital literacy, which often hinder clients' ability to access online health services and communications. They also noted challenges in follow-up communication for clients with limited English proficiency, which can lead to missed information, gaps in care, and difficulties navigating the health-care system. Additionally, providers pointed out that a lack of a health card is a significant barrier to care for some clients. While this may not affect access to care at KCHC, it remains a substantial obstacle for clients seeking services from other providers. These insights add depth to the findings and emphasize the need for tailored support in addressing accessibility and communication barriers within this client population.

It is worth noting that providers also encounter barriers when trying to connect families with the right services and resources due to the complexities of the health-care and social service systems and the limited availability of certain supports. Systemic barriers, such as complicated policies, fragmented communication, and resource constraints, can hinder their ability to provide seamless care.

Theme 3: Extensive Wait Times for Specialized Services

Participants expressed frustration with long wait times for accessing health services, particularly mental health assessments and specialized treatments. The lack of timely care exacerbates the urgency of their needs, which they report often go unmet.

> ***“Even just getting into my family doctor, it's still like a two-month wait. I don't have two months to keep waiting to try and get my child on the proper medication he needs. I can only do so much, and so I don't have time to wait when I need assistance now. Right now.”***

> ***“The wait times are high, no matter whether you're being referred or you're self-referring. I was in a place where I needed help. It had already gone to the point where I felt I couldn't do it anymore, then reached out for help, and then it was another three-month wait past that point of my max.”***

Providers also expressed that policies, like missed appointment protocols that place patients back at the bottom of waitlists, can severely delay access to essential services. Providers report that these types of systemic policies often limit flexibility and contribute to gaps in continuity of care. Capacity and resource constraints add to these challenges, as long waitlists and limited availability for services like mental health support prevent timely access for patients.

> ***“Look, it's waiting list galore. Basically, at least six months long. I don't have six months to wait. I need it [help] now.”***

> ***“It's our patients who suffer, the ones who are not well resourced, who just end up falling through the cracks because of these policies.”***

Theme 4: Complexity in Navigating Government Assistance, Health-Care System and Community Services

Caregivers struggle with the complexity of navigating government assistance programs and completing the necessary paperwork to access funding and resources for their children. This adds to their frustration and stress.

"I have a friend who helps me with all of this. I don't know how to do it."

"I'm not very tech savvy. So I really struggle with different platforms. It can be a little daunting. So I actually don't reach out for support like that anymore on my own. I will call a resource person and ask them to help."

Participants expressed difficulties navigating the health-care system, highlighting a lack of clear guidance, support and ability to access appropriate and necessary services. Even when community services are available, caregivers find them difficult to access due to cost, technology barriers, or insufficient support to navigate these resources effectively.

"I can sometimes find it a bit of a struggle when I'm having to access resources on my own. I used to go through Better Beginnings. I had a support there that I found really helpful. It was like a support worker that would know the resources and know what direction to point me in."

Providers also observe that many patients face significant challenges in navigating government assistance programs, the health-care system, and community services. They noted that these systems often assume a high level of literacy and organizational skills, which many clients struggle with. Complex forms, confusing digital platforms, and inadequate support for completing necessary steps create barriers that leave patients feeling overwhelmed and stuck.

Additionally, providers identified that fragmented communication between various services adds to the difficulty, with clients often unaware of next steps or left unsupported in following through with referrals. For newcomers or individuals with language barriers, these issues are amplified, leading to missed opportunities for care and assistance. Providers emphasized the need for more practical support, such as system navigators or resource assistants, to help patients complete applications, access services, and navigate health-care and social service systems more effectively.

"It's a very difficult system for patients to navigate. A lot of our patients don't have the capacity to navigate it themselves."

Theme 5: Mixed Experiences with Health-Care Providers

Some participants reported positive experiences with health-care providers, particularly primary care providers and Family Health Educators at KCHC, and indicated that they provide a supportive and non-judgmental space for them to share their concerns.

"My doctor here [at KCHC] is amazing."

"When I was dealing with [my family doctor at KCHC] 100% I really get the feeling like she totally does her best for my kids. It's been really positive."

"My one specialist who knows all about disabled kids and everything happening that she has to offer is completely different from what my family doctor brings to the table."

"The only thing is, they [KCHC providers] aren't aware of this stuff in the area. I believe [my primary care provider] is doing their best, but I don't believe that they are informed of everything that the community has to offer, and they are not educated only on disabled children, so they treat them as regular kids, because they are not specialists that deal with these children."

Conversely, many caregivers reported feeling unheard or dismissed by health-care providers and support services, leading to frustration and a need to advocate strongly for their children's needs. This has also led to a lack of confidence and trust in these providers and/or services.

"I think we're trying our best to advocate for our children, because they can't really speak up for themselves most times, like it's our job as their parents to be their voice in those appointments. And when we're trying to speak and tell them [health-care practitioners] what we see and be their voice, we're being shut down. But when we voice something and say something is going on at home, this is what's happening. It's like we're not even being heard."

"I brought it up, about my kid's violence, how he started hitting me. I'm like, 'Hey, look, he's doing this.' And then she's like, 'Oh, he's just a kid. That's what kids his age do. He's a boy.'"

"I'm told 'He's a kid. That's what kids do. He's a boy. Boys play rough. Boys do all this.' I'm like, okay, but it's getting to be a challenge at home, like I'm fighting with him constantly. He's not listening. He's off doing his own thing, always running away. He has no self awareness of what's going on around him when he gets in these moods. I'm trying to explain this to her, like it's becoming a danger for him, a danger for his brother, and it's progressing, but I'm always told the same thing, 'We'll check back in in a few weeks.'"

One area of misalignment between caregivers and providers centres on expectations regarding the support and outcomes health-care providers can realistically deliver for children with emotional behavioural disorders and/or special needs. While caregivers often approach appointments with hopes for immediate solutions or definitive answers to complex issues, providers explain that these expectations can sometimes be unrealistic. Providers note that families may expect them to have all the answers or to quickly resolve behavioural and developmental challenges, leading to frustration when progress is slower or solutions are more complex than anticipated.

Providers express a sense of empathy for these expectations but feel that the health-care system's capabilities are sometimes misunderstood, particularly when it comes to managing intricate cases without specialized resources.

"I feel like some of the expectations [from patients] are unrealistic in the system that we're working with."

Theme 6: Gaps in Service and Continuity of Care

Caregivers expressed concern over the lack of coordination and communication between health-care providers, schools, and community services. Many participants highlighted the inconsistency in care, with frequent changes in health-care providers or staff, which disrupts ongoing treatment plans and makes it difficult to build trusting relationships.

The analysis also revealed that there is inadequate access to specialized services and gaps in services for children with behavioural emotional disorders and/or special needs. Frustration was often expressed regarding referrals to specialized services, where caregivers felt the services did not meet their children's needs adequately.

"Out here [in Kingston], for the amount of services you have out here, for mental health for children, it's more teeth pulling, trying to get your kids in and getting service than it is anywhere else [in the region]."

"No, they don't offer the kind of support we need. So we just have to deal with it on our own until we can see a specialist."

"No matter where you get the help from, there's always gaps, either gaps in service or gaps in meeting yours and your child's needs."

Providers also experience challenges stemming from the lack of integration and communication across service providers, schools, and community organizations, which significantly complicates care coordination. Without clear communication channels, providers struggle to receive timely updates from specialists and other services, which disrupts the continuity of care and limits opportunities for cohesive support. This disconnect often means that families experience fragmented care, with providers unable to monitor or adjust treatment plans effectively, contributing to frustration among both caregivers and primary care providers.

> ***"We've done a referral, and then we get nothing back, unless it's a [referral to another] physician. And then if they [the patient] see any other service that's not a physician, we don't know."***

Theme 7: Caregiver Burnout and Lack of Support

The emotional toll on families navigating these challenges was a recurring theme. Caregivers reported feeling overwhelmed, burnt out, and unsupported in their role as caregivers and in their struggle to obtain proper treatments and supports for their children, especially those caregivers with their own mental health challenges or neurodivergent conditions. The lack of respite care and caregiver support services exacerbates this issue.

"I don't feel like I have enough support because I feel like I don't have anyone to talk to about my child, and I'm so focused on trying to get the help my child needs that I will push myself aside to ensure that he has everything he needs."

"I had explained how flat out exhausted I was and how overwhelmed I felt, and she suggested we didn't start any kind of intensive in-home or therapy at all until I was stable enough and ready to start all of this, because in order to take on these services I needed to be in a place where I was able to take on more but essentially, what I said to her after that was, if I'm waiting to be stable enough to receive the help, I'm never going to receive the help."

"I definitely think there's more supports needed out there for parents. If they were out there, I know I would utilize them. My husband would. It's so hard because so much of your attention goes to your disabled child every day, like making time for your other kids and then yourself, and then for your partner is, like, impossible."

"I'm dealing with his tantrum, and I have my own stuff that I'm dealing with also, and I'm trying to maintain myself and handle my son's mental health at the same time, which is challenging."

"Definitely more supports needed for parents, but till then, we'll just keep on trucking along."

Providers acknowledge the critical need for more comprehensive support and resources to help caregivers manage their own burnout. They recognize that the intense demands placed on caregivers, particularly those who have limited respite care or support networks, can lead to significant mental, emotional and physical exhaustion. Providers observe that without these supports, caregivers often neglect their own wellbeing to focus on their children's needs, creating a cycle of burnout. They advocate for accessible respite options and mental health resources specifically for caregivers, understanding that strengthening caregiver resilience is essential for sustained family and child support.

Theme 8: Insufficient School Support

Caregivers expressed dissatisfaction with the support provided by schools, citing a lack of one-on-one aides, resistance from school administrators to provide necessary accommodations, and inadequate resources to address children's special needs.

"Well, he wants to go to school, but they won't let him."

"He has an EA when he's in school, but only for half days."

"They're all short staffed. The schools are all suffering. My daughter is qualified for two EAs, but half the time they have to pull one of her EAs because they need extra support somewhere else in the school, so she's not having her two people that she needs."

"[My child] is so far behind in his afternoon classes cause he's only allowed to go to school half days most of the time."

Providers also identified gaps in school support, emphasizing challenges such as insufficient access to psychoeducational assessments and limited availability of occupational therapy services within schools. They highlighted the scarcity of resources, such as educational assistants (EAs), and noted the increasing difficulty for teachers to manage classrooms, particularly when dealing with students exhibiting complex behavioural needs. This lack of support often places additional strain on both families and educators.

"He's losing out on education because there is not enough support."

CHANGE IDEAS

The following change ideas emerged from a comprehensive analysis of the journey map findings and through collaboration between KCHC administrative staff, Family Health Educators, clinic managers, and primary care providers. This collaborative approach ensured that the proposed solutions reflect the diverse expertise of health-care teams and the lived experiences of families. They focus on improving the experiences of caregivers, families, and children by addressing key gaps in access, support, and coordination within existing systems.

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1 **Simplify access to resources for caregivers.**
Develop a centralized navigation system and/or resource hub (online platform or mobile application) to consolidate, simplify, and streamline access to health-care services, respite services, government funding applications, and community resources and programs. Offer workshops for caregivers who need assistance with understanding and accessing financial aid, government assistance, or completing paperwork.

2 **Develop a community-based Quick Response Program.**
Create a program to support youth (ages 4 and older) by providing short-term stability, support, and assessment services. The program would work in tandem with caregivers, equipping them with tools and resources to navigate the broader health-care system while their child receives immediate support.

3 **Provide practical assistance to families.**
Expand access to practical assistance for families, with a specific focus on providing tailored support for parents with low literacy skills or intellectual disabilities. This initiative could include parenting support programs; case management for low-literacy caregivers; accessible communication tools; and onsite assistance services at health-care centres, schools, and community hubs where families can receive one-on-one help with forms, funding applications, and other bureaucratic processes.

4 **Develop flexible and comprehensive parenting programs.**
Create and implement flexible, accessible drop-in and hybrid (in-person and online) parenting programs, with integrated supports like childcare, meals, and transportation, focusing on key topics like child behavioural management, parenting strategies, sleep hygiene, healthy routines, dealing with screen use, coping strategies, and caregiver wellness, to support caregivers, help reduce burnout, and address challenges in managing child behaviour.

5 **Expand access to behavioural health services:**
Implement mobile health clinics and/or virtual care services for families with transportation barriers, providing behavioural health check-ups and consultations from home. Partner with community organizations to provide transportation vouchers or subsidized services for families needing in-person visits.

6 Advocate for policy revisions.

Help reduce barriers to care by advocating for revisions to hospital and clinic policies, such as strict missed appointment penalties, to improve flexibility and equity in care.

7 Gather caregiver insights to drive improvement.

Establish a caregiver feedback loop to incorporate family experiences into the continuous improvement of care delivery.

8 Enhance provider training for trauma-informed care.

Offer training programs for health-care providers to emphasize listening, collaboration, and trauma-informed care practices.

9 Expand Family Health Educator programs

To provide early interventions for families, focusing on building core life skills, improving parenting strategies, and addressing the effects of Adverse Childhood Events (ACEs). This expansion should include increased collaboration with health care and community partners, such as schools and the Limestone District School Board and Algonquin and Lakeshore Catholic District School Board, to better support complex family needs.

10 Ensure seamless coordination across sectors:

Develop a care coordination platform to connect health-care providers, schools, and community services to streamline communication, improve care management across different sectors, and help support school-based identification of needs with expedited pediatric consultations and social prescribing.

11 Expand respite and mental health support for caregivers.

Enhance support for caregivers by increasing the availability of in-home respite care services and creating more opportunities for caregivers to access counselling, peer support groups, and mental health resources. This initiative should also include embedding more mental health specialists within primary care centres to provide immediate, integrated mental health support for caregivers.

12 Collaborate with schools to support special needs.

Encourage co-design between families, schools, and health-care providers to create education and health plans for children with complex needs. This collaborative approach empowers families to take an active role in care, addressing medical needs, fostering community connections, and supporting holistic well-being through social prescribing.

13 Increase access to free school-readiness programs.

Expand the availability of free school-readiness spaces for preschoolers with special needs to better equip them for the transition to school environments. These programs should focus on fostering social, emotional, and cognitive skills while providing tailored support to meet the unique needs of these children. By addressing developmental gaps early, this initiative aims to improve long-term educational and social outcomes.

CONCLUSION & NEXT STEPS

The journey mapping report highlights significant gaps in care and support for school-aged children with emotional behavioural disorders and/or special needs. These findings underscore the urgent need for innovative solutions and stronger collaboration among local and regional care providers. Addressing these gaps will require efforts to reduce wait times, improve access to care, and enhance continuity of care through better coordination between health-care providers, schools, and community services. Expanding support and respite care services for caregivers is also crucial to improving overall outcomes.

Findings from *Engaging Families to Build Healthy Communities*, the first report from I-CREAte (Innovations for Community Resilience, Equity, and Advocacy research team at Queen's University Centre for Studies in Primary Care), further reinforce these conclusions. In particular, findings six through ten emphasize critical themes such as the importance of family-specific supports, challenges related to navigating the health system, and the impact of material deprivation on community resilience. These findings validate the need for initiatives like a centralized resource hub and expanded behavioural health services to improve accessibility and streamline care for families.

Additionally, I-CREAte's report underscores the importance of holistic, family-centred approaches. This aligns with the change ideas for flexible parenting programs and peer-supported caregiver groups. Both reports highlight the necessity of integrated, community-based supports that address the social determinants of health and foster trust, connection, and resilience.

There are numerous opportunities to incorporate the insights and perspectives gathered from the journey mapping engagement into future organizational and program planning at KCHC, as well as into broader program models, funding proposals, and health system strategies. By building on the shared themes identified in both reports, we can strengthen partnerships and drive meaningful improvements, creating a more responsive and equitable system of care that meets the diverse needs of families in the region.

APPENDIX I

Caregiver Focus Group & Interview Questions

PRE: Access
Identify behavioural / learning / developmental / general concerns

1. What prompted you to look for help for your child/children? Difficulties at school? Difficulties at home?
2. What leads you to make an appointment with a health-care provider? What kind of provider did you see first, if not a provider at KCHC?
3. Do you experience any challenges in making an appointment? If so, what are they?
4. How do you travel to the appointments? Do you experience any challenges in getting to or finding time to attend the appointment?

DURING: Healthcare providers

1. What was your experience when you talked to your primary care provider or Family Health Educator about your child's challenges?
2. Do you feel like your feelings, fears, ideas, and expectations about your child were being addressed?
3. How would you describe the decision-making portion of your encounter? Are you involved in the decision-making? If there are medications or specific treatments offered, do you feel you have enough information and support to decide?
4. Do you feel like you are clear on what the next steps are for you to take/what is going to happen next after the visit? Are the instructions and information that you are provided with at the conclusion of your visit clear?

Accessing Support Services

1. Were you referred to a community agency or a specialist for support? If so, which ones, and how was your experience with them?
    a. Mental health? Behavioural therapy? Developmental assessment? Parenting programs?
2. Were you referred to receive any in-home support for your child? If yes, what kind of support? How was/is this experience?

POST: Manage identified issues

1. What are the biggest challenges you face as a parent of a school-aged child?
2. Can you describe any specific behaviours your child exhibits at home that are difficult to manage? What steps do you take to manage these behaviours while you wait for services?
3. What happens while you wait for specialized services? I.e. Do you receive communications updates? Do you seek other support while you wait for specialized services? Do you contact your PCP (if available)?
4. What happens when you try to access support services for your child on your own?
5. Have you had to fill out paperwork/applications for financial aid? What are the barriers to getting this done? What supports have you received?

Closing Question

1. Is there anything else you'd like to share about your experiences or needs as a parent of a school-aged child who struggles with school adjustment issues?

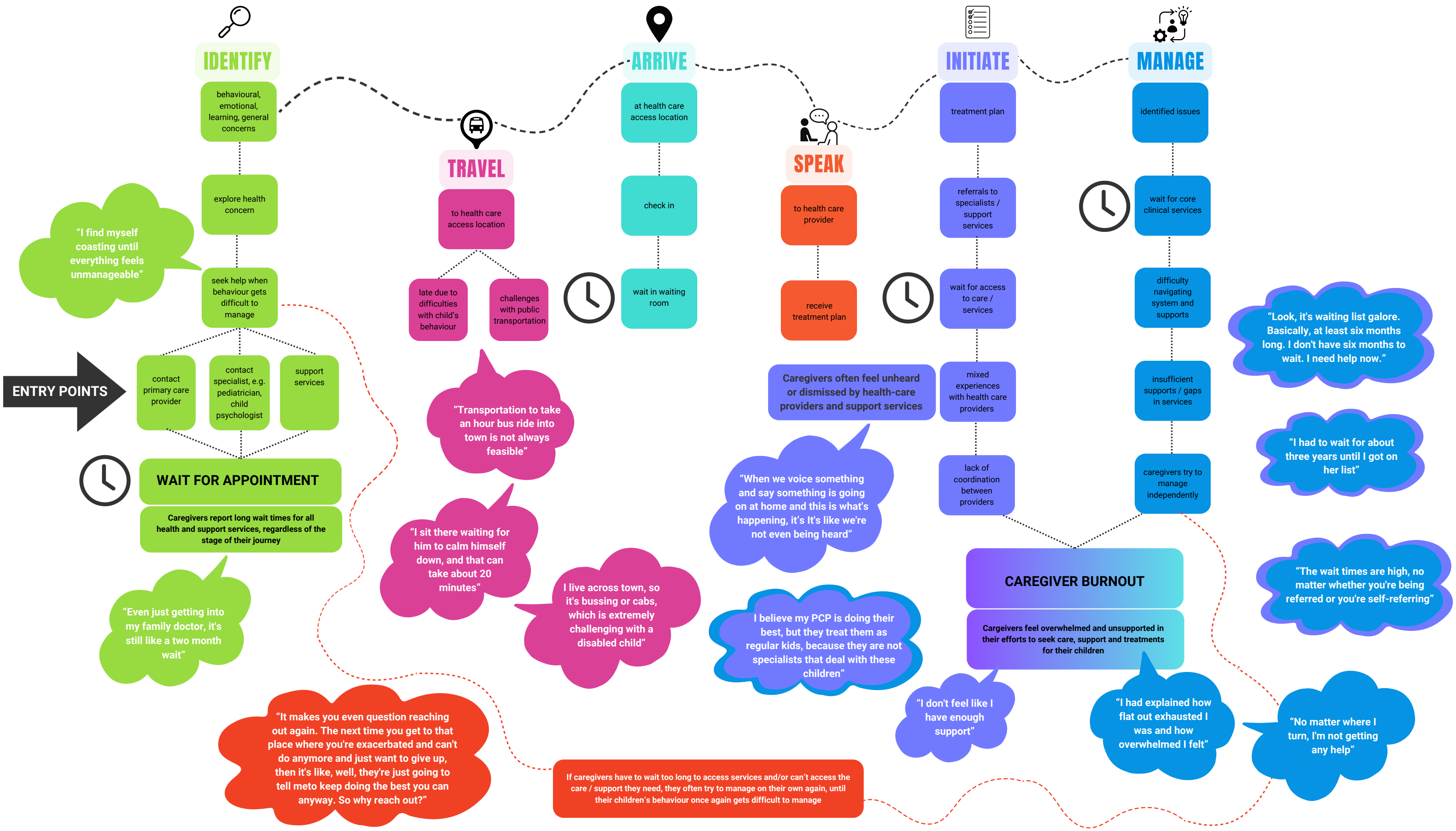
APPENDIX II

Provider Focus Group Questions

1. To what extent do the findings in the report align with your experiences providing care and support to families of children with emotional behavioural disorders and/or special needs? Are there any areas where your experiences differ?
2. Have you observed the same barriers and gaps in service that parents/caregivers reported, such as transportation challenges, long wait times, or difficulties navigating the health-care system? If so, how do these barriers typically impact the care you provide?
3. Do the reported issues with the lack of continuity in care and frequent provider changes reflect what you see in your work? What are the main contributors to these disruptions, from your perspective?
4. How do the findings about parental burnout and a lack of support align with what you hear from caregivers during appointments? Are there additional supports you believe would benefit these families?
5. Do you feel the findings about the complexity of accessing government assistance and community services are consistent with the challenges your clients face? How do these systemic barriers affect your ability to provide timely support?
6. The report mentions mixed experiences with health-care providers. In your experience, what factors influence whether families have positive or negative interactions with the health-care system?
7. In your experience, what are the key areas where caregivers struggle the most in managing their own well-being?
8. How do the challenges related to insufficient school support and the need for better accommodation reflect your observations? Are there areas where the health-care system could better support educational integration for these children? What approaches could improve collaboration between health-care providers, schools, and community services to support children with special needs?
9. Are there specific services or resources you think should be prioritized to close the gaps in specialized care for children with behavioural or emotional challenges?
10. How can we create a feedback loop that effectively incorporates caregiver input into improving service delivery?

APPENDIX III

Journey Map: Caregivers



IDENTIFY

behavioural, emotional, learning, general concerns

explore health concern

seek help when behaviour gets difficult to manage

"I find myself coasting until everything feels unmanageable"

ENTRY POINTS

- contact primary care provider
- contact specialist, e.g. pediatrician, child psychologist
- support services

WAIT FOR APPOINTMENT

Caregivers report long wait times for all health and support services, regardless of the stage of their journey

"Even just getting into my family doctor, it's still like a two month wait"

"It makes you even question reaching out again. The next time you get to that place where you're exacerbated and can't do anymore and just want to give up, then it's like, well, they're just going to tell meto keep doing the best you can anyway. So why reach out?"

If caregivers have to wait too long to access services and/or can't access the care / support they need, they often try to manage on their own again, until their children's behaviour once again gets difficult to manage

TRAVEL

to health care access location

late due to difficulties with child's behaviour

challenges with public transportation

"Transportation to take an hour bus ride into town is not always feasible"

"I sit there waiting for him to calm himself down, and that can take about 20 minutes"

I live across town, so it's bussing or cabs, which is extremely challenging with a disabled child"

ARRIVE

at health care access location

check in

wait in waiting room

SPEAK

to health care provider

receive treatment plan

Caregivers often feel unheard or dismissed by health-care providers and support services

"When we voice something and say something is going on at home and this is what's happening, it's It's like we're not even being heard"

I believe my PCP is doing their best, but they treat them as regular kids, because they are not specialists that deal with these children"

INITIATE

treatment plan

referrals to specialists / support services

wait for access to care / services

mixed experiences with health care providers

lack of coordination between providers

MANAGE

identified issues

wait for core clinical services

difficulty navigating system and supports

insufficient supports / gaps in services

caregivers try to manage independently

"Look, it's waiting list galore. Basically, at least six months long. I don't have six months to wait. I need help now."

"I had to wait for about three years until I got on her list"

"The wait times are high, no matter whether you're being referred or you're self-referring"

"No matter where I turn, I'm not getting any help"

CAREGIVER BURNOUT

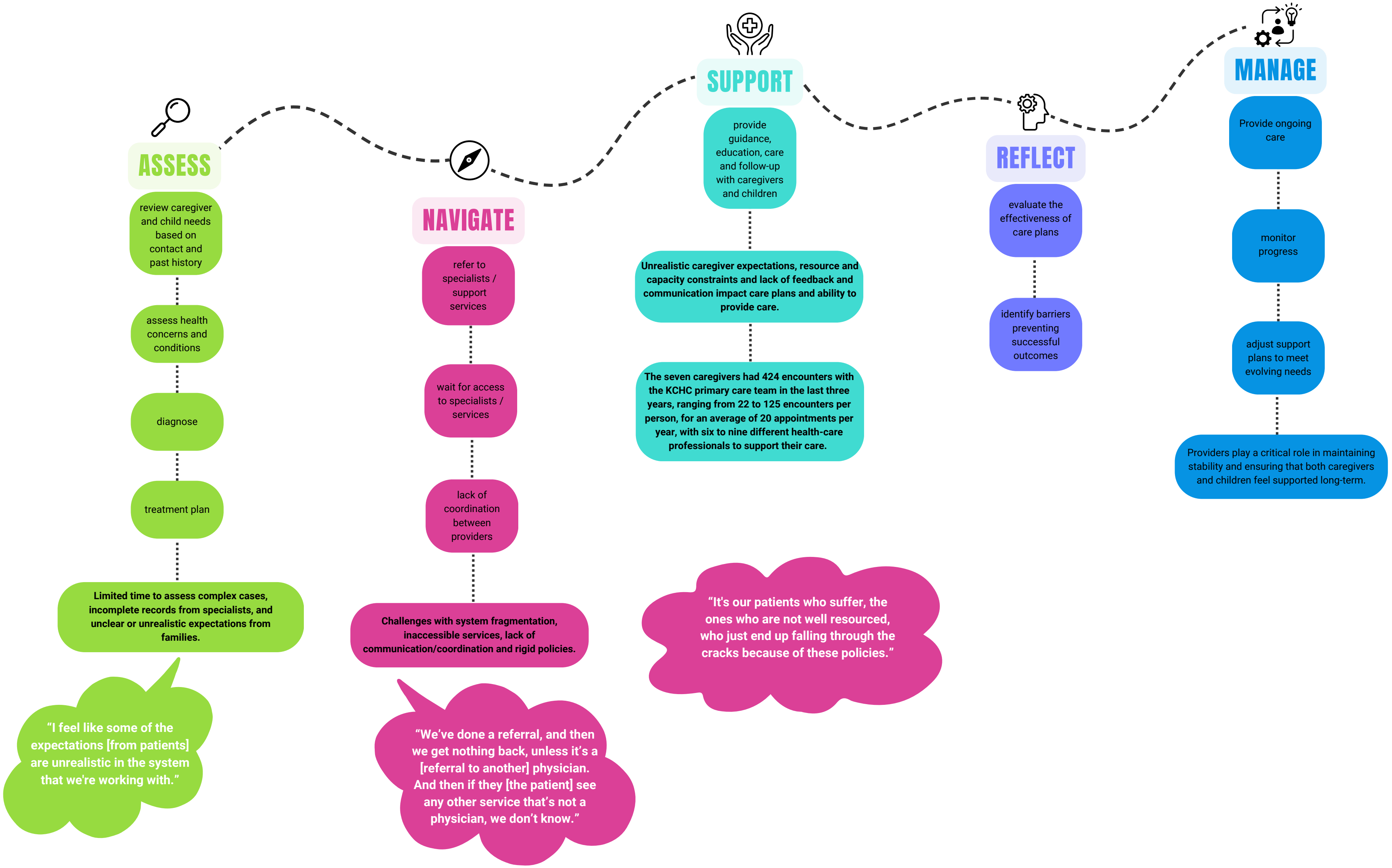
Cargeivers feel overwhelmed and unsupported in their efforts to seek care, support and treatments for their children

"I don't feel like I have enough support"

"I had explained how flat out exhausted I was and how overwhelmed I felt"

APPENDIX IV

Journey Map: Providers



ASSESS

review caregiver and child needs based on contact and past history

assess health concerns and conditions

diagnose

treatment plan

Limited time to assess complex cases, incomplete records from specialists, and unclear or unrealistic expectations from families.

> "I feel like some of the expectations [from patients] are unrealistic in the system that we're working with."

NAVIGATE

refer to specialists / support services

wait for access to specialists / services

lack of coordination between providers

Challenges with system fragmentation, inaccessible services, lack of communication/coordination and rigid policies.

> "We've done a referral, and then we get nothing back, unless it's a [referral to another] physician. And then if they [the patient] see any other service that's not a physician, we don't know."

SUPPORT

provide guidance, education, care and follow-up with caregivers and children

Unrealistic caregiver expectations, resource and capacity constraints and lack of feedback and communication impact care plans and ability to provide care.

The seven caregivers had 424 encounters with the KCHC primary care team in the last three years, ranging from 22 to 125 encounters per person, for an average of 20 appointments per year, with six to nine different health-care professionals to support their care.

> "It's our patients who suffer, the ones who are not well resourced, who just end up falling through the cracks because of these policies."

REFLECT

evaluate the effectiveness of care plans

identify barriers preventing successful outcomes

MANAGE

Provide ongoing care

monitor progress

adjust support plans to meet evolving needs

Providers play a critical role in maintaining stability and ensuring that both caregivers and children feel supported long-term.

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