

### Editor's key points

► Providing care for children and youth with mental health or developmental and behavioural (DB) disorders is increasingly part of daily practice for providers within the primary care setting. Family doctors are uniquely positioned to provide longitudinal care but encounter barriers that affect access to services, service quality, and health outcomes for these children and their families.

► The complexity of care required for these families has prompted movement toward an integrated health care model but currently most primary care providers do not practise in this setting. The current model requires family physicians to refer families for diagnosis and then provide longitudinal care after diagnosis without ongoing support from specialists. Additionally, some DB and mental health centres have limits in terms of number of visits allowed and the age range and geographic area served.

► Primary care physician training might require expansion beyond the identification of DB and mental health concerns to the longitudinal care and resources these families will require over time. Developmental pediatricians and mental health specialists in an ongoing relationship with a group of primary care teams might facilitate ongoing communication about a child's trajectory over time, and allow direct and timely access to reassessments to address emerging comorbidities.

► This study's findings underscore the need to reform the current model of care through improved system integration, to identify what facilitates these models, and to build sustainable capacity among family physicians and other specialists to better support primary care providers in meeting the needs of these patients and their families.

# Caring for children with mental health or developmental and behavioural disorders

## Perspectives of family health teams on roles and barriers to care

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### Abstract

**Objective** To inform a shared care model between developmental and behavioural (DB) and mental health specialists and primary care physicians by having members of primary care family health teams (FHTs) report on strengths of and barriers to providing care for children with DB disorders and mental health concerns.

**Design** Qualitative study using semistructured focus groups.

**Setting** Academic and community-based FHTs in Toronto, Ont.

**Participants** Primary care physicians, nurses, allied health professionals, and family medicine trainees within the participating FHTs.

**Methods** Nine focus groups were conducted with FHT members, and transcripts were analyzed for key themes using an inductive thematic analysis approach.

**Main findings** Eighty-four participants across 9 sites were interviewed. Six sites were academically affiliated and 3 were community based. Participants described their roles in the care of children with DB disorders as primarily "referral agent" but also as "long-term supporter" and "health care coordinator." Family health team members expressed the desire to "learn" and "do more" for these children but noted numerous barriers to providing care, captured in 4 overarching themes: limited training beyond how to screen, lack of service knowledge, limited time and communication, and cumbersome access to mental health and dual diagnosis services.

**Conclusion** Primary care physicians are in the unique position of being able to provide longitudinal care for children with DB and mental health disorders. However, they perceive barriers to providing care that can affect access to services, service quality, and health outcomes for these children and their families. The health system might benefit from addressing these barriers by providing more training for primary care physicians in the longitudinal care of children with mental health and DB disorders, and by improving communication between FHTs and DB and mental health specialists regarding service navigation and emerging comorbidities. A shared care model integrating DB and mental health specialists into primary care might be one approach that warrants implementation and research.

# Soigner des enfants souffrant de problèmes de santé mentale ou de troubles du développement et du comportement

## Points de vue d'équipes de santé familiale sur les rôles et les obstacles dans les soins

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### Résumé

**Objectif** Élaborer un modèle de soins partagés entre des spécialistes des troubles du développement et du comportement (TDC) et de la santé mentale et des médecins de soins primaires en recueillant les commentaires d'équipes de santé familiale en soins primaires (ESF) sur les forces et les obstacles relatifs à la fourniture de soins à des enfants souffrant de TDC et de problèmes de santé mentale.

**Type d'étude** Étude qualitative au moyen de groupes de discussion semi-structurés.

**Contexte** Des ESF universitaires et communautaires à Toronto (Ontario).

**Participants** Des médecins de soins primaires, des infirmières, d'autres professionnels de la santé et des stagiaires en médecine familiale au sein des ESF participantes.

**Méthodes** Neuf groupes de discussion ont été formés avec des membres des ESF, et la transcription des discussions a été analysée pour dégager les thèmes principaux à l'aide d'une approche d'analyse thématique inductive.

**Principales constatations** Quelque 84 participants de 9 sites différents ont été interviewés. Six sites étaient affiliés à une université et 3 étaient communautaires. Les participants ont décrit leurs rôles dans les soins aux enfants atteints de TDC; ils se sont surtout qualifiés de «demandeurs de consultation», mais aussi de «soutiens à long terme» et de «coordonnateurs des soins de santé». Les membres des ESF ont exprimé le souhait «d'apprendre» et «d'en faire plus» pour ces enfants, mais ils ont relevé de nombreux obstacles à la prestation des soins, classés en 4 thèmes omniprésents: la formation insuffisante, qui se limite au dépistage; le manque de connaissance sur les services; le temps et les communications limités; et l'accès compliqué aux services de santé mentale et aux services de double diagnostic.

**Conclusion** Les médecins de soins primaires sont bien placés pour offrir des soins longitudinaux aux enfants souffrant de TDC et de problèmes de santé mentale. Toutefois, ils perçoivent des obstacles à la prestation de tels soins qui peuvent nuire à l'accès aux services et à leur qualité ainsi qu'aux résultats en matière de santé pour ces enfants et leur famille. Le système de santé pourrait bénéficier de l'élimination de ces obstacles en donnant aux médecins de soins primaires plus de formation sur les soins longitudinaux aux enfants souffrant de problèmes de santé mentale et de TDC, et en améliorant les communications entre les ESF et les spécialistes des TDC et de la santé mentale concernant la navigation dans les services et les comorbidités émergentes. Un modèle de soins partagés qui intègre des spécialistes des TDC et de la santé mentale dans les soins primaires pourrait se révéler une approche qui justifie la mise en œuvre et les recherches.

### Points de repère du rédacteur

► Les soins aux enfants qui ont des problèmes de santé mentale ou des troubles du développement et du comportement (TDC) font de plus en plus partie de la pratique courante des professionnels dans le contexte des soins primaires. Les médecins de famille sont particulièrement bien placés pour offrir des soins longitudinaux, mais ils sont aux prises avec des obstacles qui nuisent à l'accès aux services et à leur qualité ainsi qu'aux résultats en matière de santé pour ces enfants et leur famille.

► La complexité des soins dont ces familles ont besoin a suscité un mouvement vers un modèle intégré de soins de santé, mais la majorité des professionnels des soins primaires n'exercent actuellement pas dans ce contexte. Le modèle actuel requiert que les médecins demandent une consultation pour les familles aux fins de diagnostic, pour ensuite fournir des soins longitudinaux après le diagnostic, avec le soutien continu des spécialistes. En outre, certains centres de santé spécialisés en santé mentale et en TDC imposent des limites quant au nombre de visites permises, à la tranche d'âge et à la région servie.

► La formation des médecins en soins primaires pourrait devoir être élargie au-delà de l'identification des problèmes de santé mentale et des TDC, et inclure les soins longitudinaux et les ressources nécessaires à ces familles avec le temps. Des pédiatres spécialisés en développement et des spécialistes en santé mentale qui entretiennent une relation constante avec un groupe d'équipes de soins primaires pourraient faciliter la communication continue concernant la trajectoire d'un enfant au fil du temps, et permettre un accès direct et en temps opportun à des réévaluations pour aborder les comorbidités émergentes.

► Les constatations de cette étude mettent en évidence la nécessité d'une réforme du modèle de soins actuel par l'entremise d'une meilleure intégration du système, pour déterminer les éléments qui facilitent ces modèles, et pour renforcer de façon durable les capacités des médecins de famille et des autres spécialistes afin de mieux appuyer les professionnels des soins primaires et de répondre aux besoins de ces patients et de leur famille.

Developmental and behavioural (DB) disorders are on the rise. The Canadian Paediatric Society estimates that global developmental delay and intellectual disabilities (ID) affect up to 3% of Canadian children.<sup>1</sup> The percentage of children and youth in Canada affected by behavioural disorders, such as attention deficit hyperactivity disorder (ADHD), or mental health disorders is estimated at 5% and between 10% and 20%, respectively.<sup>2</sup> In 2009, the prevalence of autism spectrum disorders (ASDs) among Canadian children aged 2 to 14 years was estimated to be 1.2%.<sup>3</sup> Taken altogether, these figures illustrate that providing care for children with mental health or DB disorders is increasingly becoming a part of daily practice for primary care physicians (PCPs).

Children with these complex health care needs affect the functioning of the family unit as a whole.<sup>4</sup> Therapy and caregiving needs of these children are high, and both public and private services are difficult to find and access.<sup>5-10</sup> The more severe the child's disability, the greater the negative effect on caregiver stress, employment, and finances.<sup>11</sup> For example, in a study by Lappé et al, families of children with ASD described the long and complex process they face in navigating diagnosis and acquiring services for their children as a "diagnostic odyssey."<sup>12</sup> The diagnostic odyssey consists of 3 main phases: prediagnosis, which is characterized by an identification of child difference; during diagnosis, which involves navigating the system to receive a diagnosis; and postdiagnosis, which is distinguished by the process of accessing services. Many individuals, including PCPs, pediatricians, DB specialists, therapists, social workers, and caregivers, are involved in this journey.<sup>12</sup> While typically diagnoses are confirmed by either developmental pediatricians or child psychologists, neither are easy to access: developmental pediatricians often have long waitlists, and child psychologists' services are not always publicly funded. There are simply not enough of either specialist to meet the need in Canada and worldwide.<sup>13-16</sup> These same specialists might not be available for consultation following the diagnosis. Families describe having to advocate for services themselves. In the study by Lappé et al, families expressed the wish that their health care providers would be more involved in their postdiagnostic journey.<sup>12</sup>

In Canada, PCPs are uniquely positioned to provide longitudinal care to families of children with DB concerns.<sup>17</sup> Other than PCPs, there is no single specialist—in health, education, social services or any other sector—mandated to follow these individuals across their lifespans.<sup>18</sup> In Canada, the defined roles of PCPs include expert, communicator, collaborator, leader, health advocate, scholar, and professional.<sup>19</sup> As such, PCPs are well placed not only to follow these patients throughout the growing years of childhood but also to support them through the often difficult transition to adult care. There

is an emerging field of primary care specialists for adults with ID,<sup>20</sup> with fellowships available for new graduates in this field.<sup>21</sup> Guidelines and tools for PCPs caring for adults with ID have been developed through the Developmental Disabilities Primary Care Program.<sup>22</sup> However, similar resources do not exist for PCPs caring for children with DB disorders or mental health concerns.

The complexity of care required for these families has prompted movement toward integrated health care models. In their idealized form, these models bring together primary care and other key services, including DB health, mental health, and other services. One such example in the United States would be the "medical home model."<sup>23</sup> In these models, PCPs are often the cornerstone, given their ability to follow children and engage in the management of longitudinal care for these families.<sup>24</sup> While the potential benefits of integrated care are lauded,<sup>25,26</sup> there currently is not a well-defined model to guide clinics in the underlying processes needed to support their sustainable implementation.

To inform an integrated care model between DB and mental health specialists and PCPs, we use qualitative methods to explore the perceptions of PCPs and allied health professionals about their roles in caring for children with DB disorders and mental health concerns, the barriers they face providing care, and the support they require from specialists.

## — Methods —

### Setting

We approached 12 family health teams (FHTs) for the study: 6 academic FHTs, situated in a large urban centre and focused on serving populations with barriers related to the social determinants of health for participation, on the basis that the need for DB services in their inner-city catchment area had been previously identified clinically, and 6 non-academic, community-based FHTs, which serve similar populations across the city in high-risk neighbourhoods with similar populations. All 12 FHTs were approached by the study team in person, by telephone, or by e-mail to participate. All 6 academic and 3 of the 6 community-based FHTs agreed to participate.

### Participants

At each site, the medical lead was given information and an invitation to the study and disseminated it to all members of their site. At all sites, participants included PCPs, and most also included nurse practitioners, nurses, social workers, medical administrative assistants, and family medicine trainees. One focus group was conducted per site (N=84; **Table 1**).

### Procedure

A semistructured interview guide was developed for the focus groups. Questions were piloted with senior

**Table 1. Demographic characteristics of interview participants**

CHARACTERISTIC	PARTICIPANTS		
	COMMUNITY FHT MEMBERS (N = 20), N (%)	ACADEMIC FHT MEMBERS (N = 64), N (%)	TOTAL (N = 84), N
Sex			
• Male	7 (35)	24 (38)	31
• Female	13 (65)	40 (62)	53
FHT role			
• PCP	12 (60)	34 (53)	46
• Nurse practitioner	2 (10)	5 (8)	7
• Nurse	2 (10)	9 (14)	11
• Social worker	1 (5)	3 (5)	4
• Family medicine trainee	3 (15)	9 (14)	12
• Medical administrative assistant	0 (0)	4 (6)	4

FHT—family health team, PCP—primary care physician.

administrators at the academic FHT for content and clarity. The focus groups were conducted by 2 developmental pediatricians who were not involved in providing care at the participant sites. Participants were asked to describe their clinical role, level of experience and training, level of comfort and confidence, relationship to developmental specialists, and suggestions to improve their capacity to care for families and children with DB disorders. Each focus group session lasted between 30 and 45 minutes and was audiorecorded and transcribed verbatim. Lunch and a brief (non-accredited, continuing medical education) presentation on childhood anxiety was provided at the end of each focus group. This study was approved by the research ethics board at St Michael's Hospital in Toronto, Ont.

## Analysis

Transcripts were analyzed thematically, using an inductive approach in which themes were identified from the data using open coding methods outlined by Braun and Clarke.<sup>27</sup> Five team members read the first 6 transcripts and immersed themselves in the text to assist with the identification of themes. Quotes from transcripts exemplifying these themes were then systematically coded using Dedoose software by 2 undergraduate research assistants (one of which was R.G.) with training in health sciences and psychology and by a doctoral-level researcher (K.M.) not involved in data collection or clinical care. Discrepancies were resolved by consensus. No new themes were consistently identified beyond those in the original 6 transcripts. As such, saturation was

reached by the sixth interview, supporting the representativeness of the themes coded in the 9 interviews completed in total.

## — Findings —

Three main roles were adopted among participants: referral agent, long-term supporter, and health care coordinator. As referral agents, participants typically described screening for delays or problems and referring for further care if any were identified: "Once a child doesn't meet a milestone and beyond that I refer on." Also, "I find the behaviour problems difficult to manage, so I try to refer to somebody who knows how to deal with behavioural problems." Participants described their role as supporter: "I think a lot of times our role ends up being supporting the parents," and "I think there is a role for us to kind of provide ongoing support." Finally, regarding care coordination, participants said: "My role as a family doctor in this realm has always been as a coordinator of services," and "a family doctor is kind of problem identification and then care coordination."

Participants identified a variety of relevant disorders most commonly seen in their practices, including developmental disorders such as ASD, learning disabilities, communication disorders, and mental health disorders such as ADHD, anxiety, and depression. Comorbidity between DB and mental health disorders presented particular challenges for providing care.

Challenges in meeting the needs of children within a family medicine practice were voiced. Four overarching barriers to providing effective care were identified: limited training beyond screening; limited knowledge of resources and services; limited time and communication; and difficulty accessing mental health and dual diagnosis services.

### Limited training beyond screening

Irrespective of the number of years since their medical training, participants overwhelmingly reported not having the level of training they needed to feel confident in treating children with DB and mental health issues, with one physician referring to it as a "black box and mystery." Assessing beyond disorder-specific symptoms was a challenge: "We have our ADHD screening tools ... but beyond that they are having difficulty in school in learning or development beyond my ADHD checklist .... I feel a little bit naïve to what those things could be and how to screen for them." Participants also expressed a concern about not knowing "what's important to rule out and what's the important workup before we send the child down that path."

### Limited knowledge of resources and services

Uncertainty was experienced with what to do after a DB or mental health disorder had been identified.



For example, one physician noted that “it’s a knowledge issue. I don’t even know all of the services that are required, what it entails. So, to support a family appropriately, it would be nice for me to become a little more knowledgeable about that process.”

A substantial barrier for many participants was not being “familiar with all the resources that are available and that should be involved at the different milestones.” Numerous participants shared that it is difficult to stay current with resources and “understand what each resource actually does.” One participant commented, “Half the time I find I’m googling something and then going from there, especially with the changes in funding and what’s available, I have no idea now what a parent can and cannot access.”

Particular challenges were shared about where to refer when a child has symptoms that are at a subclinical or preclinical level and might not meet diagnostic criteria. Participants did not know how to access support for these children when they “have been referred and appropriately identified, appropriately assessed, [yet] the outcomes that they have are suboptimal.” Participants explained that “[the children] continue to struggle, and it’s hard, then, to follow those patients along because, really, there is nothing else we can offer.”

Participants also described confusion about not only the roles and what they could expect of the services and specialists to whom they referred their patients, but also about the role and expertise of the PCP. For example, one participant noted,

For a child with X problems, do they typically have ongoing follow-up, or is it a one-off consult and that’s kind of it for them? Because sometimes I don’t know if the parent was maybe not as strong of a self-advocate and then they slipped through the cracks, or if it’s just that there really aren’t resources for ongoing follow-up.

The children’s schools similarly had misconceptions about the role of FHT members such as nurse practitioners or PCPs: “Parents will mention that they’re looking for help with how to fill out forms for the school, do assessments for the school, and I don’t feel like I’m qualified to do that. I’m not very comfortable with it. I just haven’t seen enough or done enough training.”

### Limited time and communication

A third barrier that participants discussed was limited time and communication. The standard appointment time was often described as not being long enough to address mental health and DB issues. For example, one physician shared, “When I see a kid that I may have some suspicion of a DB disorder, I don’t have enough information within that very short amount of time in the visit.”

Time was also a barrier to consultation with other health care providers (experts and others on the child’s

team). In terms of access to expert consultation, participants reported having limited or no access to a “quick consultation” that would provide immediate guidance. Access to a quick consultation was typically present when the participant had an established relationship with that specialist. Many participants reported not knowing a DB specialist. For example, “I think we just don’t have a relationship with a developmental pediatrician where we could just call him and do a phone consult like we could with a general pediatrician, or with a multitude of other specialists.”

Beyond time, communication was also cited as a barrier after a referral had been made to another health professional. Participants shared that communication about patients was often limited to a single consultation note, with little information about any follow-up appointments, progress, or the plan. Limited communication hindered providing ongoing support for families, according to some participants, leaving them “in the dark.” For example, “If we don’t know what’s been recommended, then we may even see them and we don’t actually reinforce what’s been suggested.” Further, when communication occurred, the level of detail did not support continuity of care:

You probably wouldn’t get the response from the developmental pediatrician ... [only] from the consulting pediatrician. So, you’d miss a step ... get the summary. Which makes it difficult, because we’re often involved in filling out disability forms, child tax credit forms, and ... we don’t have all the information.

Communication was also affected by confusion about roles when other health professionals were involved. For example, as one participant noted,

When there is a developmental pediatrician involved, I don’t know what my role anymore is. So, I’m not sure if they’re going to do all the care coordination and liaise with the agencies in the schools, or if there are things being missed or if people are falling through the gaps, and that’s a piece that I struggle with quite a bit.

### Access to mental health and dual diagnosis services

Accessing services was frequently considered “a very lengthy and cumbersome process.” Waitlists (eg, for psychoeducational assessments, speech language pathology, day care subsidies) were raised as an area of challenge, with mental health services being mentioned most frequently. “All those [mental health] programs are wonderful and look great in the list of recommendations but they don’t exist.” Another shared that “you really can’t wait for 6 months when the child is doing poorly at school and the school isn’t on top of it as well.”

Cost was also prohibitive: “If parents have private coverage or are willing to spend a lot of money then the process is quick and, otherwise, it’s frustrating and aggravating. I don’t feel we are helping these kids very much.” Navigation difficulties were magnified in the context of comorbid disorders: “You’ve got someone with autism ... a learning disability and then ... usually ADHD and usually what we have is a concurrent disorder. I would say the counseling piece has been very challenging ... and to get good psychiatric care.”

## — Discussion —

Our findings confirm that PCPs and their teams play a vital role in the lives of families of children with DB and mental health concerns. They self-identify as being a “referral agent,” “long-term supporter,” and “health care coordinator.” These roles have been described in similar studies of PCPs for children with ASDs and for children with mental health disorders.<sup>28</sup> Our study also identifies the perceived barriers experienced by PCPs in providing optimal care for these families. Limited training in DB and mental health disorders was identified as a barrier, which is consistent with other studies.<sup>29,30</sup> Limited understanding of these disorders evolves into limited clinical knowledge of the resources required to intervene. The myriad presentations and severities of these conditions also means that a one-size-fits-all approach is not successful for individuals.<sup>31</sup> In particular, DB and mental health services require that patients meet diagnostic criteria before they can access them; further, these services are decentralized and spread over different provincial ministries and agencies.<sup>32</sup> The difficulties in navigating services compound the limited understanding of the disorders themselves and the kinds of interventions needed. A study by Knutson et al found that families connect with fewer resources when they are followed by primary care providers, even when these providers have received additional training, than when they are followed by pediatric mental health providers, with the gap mostly attributed to lack of care coordination support at the primary care level.<sup>33</sup> These difficulties directly impede PCPs in their role as “long-term supporter” and “health care coordinator.”

In clinical practice, PCP visits are often not long enough to address all the complexities in one visit, and PCPs are often not compensated for the additional time it takes to communicate with specialists, access consultations, and discuss services with them. Primary care physicians must determine which health care provider will be responsible for follow-up on referrals, intake forms, waitlists, therapies, programs, and funding applications. Other studies affirm that PCPs often become the de facto responsible health care provider,<sup>34</sup> unless the families negotiate these services on their own.<sup>35</sup>

The system of care between DB disorders and mental health disorders was also identified as a barrier to

optimal care. The pathways for each are different and do not easily intersect. A study of high-functioning individuals with ASD noted that they are a “complex and underserved psychiatric population” who face barriers obtaining mental health services.<sup>36</sup> For individuals with ID, mental health practitioners often lack training and understanding of ID, resulting in barriers to receiving adequate mental health services in this population.<sup>37</sup>

## Implications

Our findings suggest that a revised model of primary care supporting children with DB and mental health disorders is warranted. In our context, PCPs are responsible for referring families for diagnosis, and then are tasked with providing longitudinal care after diagnosis. The current model requires PCPs to do so without ongoing support from DB and mental health specialists. Additionally, in our area, some DB and mental health centres have limits in terms of number of visits allowed and the age range and geographic area served, which makes it even more difficult to access and re-access DB care.

A revised model of care would require addressing the barriers highlighted. Primary care physician training might require expansion beyond the identification of DB and mental health concerns to the longitudinal care and resources these families will require over time. Developmental pediatricians and mental health specialists in an ongoing relationship with a group of primary care teams might facilitate ongoing communication about a child’s trajectory over time, and allow direct and timely access to reassessments to address emerging comorbidities.

Wissow et al identified possible ways to integrate children’s mental health in primary care through 2 main mechanisms: collaborative care with specialists and “task shifting,” which involved building capacity among PCPs to administer specialized mental health services.<sup>38</sup> A systematic review by Bower et al also reviewed different ways to improve treatment for children’s mental health in primary care, including increased education of PCPs, increased treatment by PCPs, other specialists providing treatment within primary care, and consultation liaison models.<sup>39</sup> This review identified that more studies of these models are required to look at cost-effectiveness, practitioner behavioural change, and outcomes specific to child mental health.

For children and families with developmental complexity, the College of Family Physicians of Canada has endorsed the vision of the Patient’s Medical Home, whereby patients can access comprehensive medical services provided by a team or network of health care professionals who are located in their community either physically or virtually, all through the hub of their PCP.<sup>40</sup> The current reality, however, is that most PCPs do not practise in this setting. In the United States, the “medical home model” has been specifically developed for primary care pediatricians to support care for children with

special needs; however, many are not able to access these models of care.<sup>41</sup> In Canada, multidisciplinary pediatric teams have been developed, such as social pediatric outreach centres for families living in poverty<sup>42</sup> and complex care teams for children with complex medical needs.<sup>43</sup> These do not link explicitly with primary care. We propose that future research build on these models of care, and that specialists work alongside PCPs not only to provide diagnoses but also to support PCPs in their roles as long-term supporters and health care coordinators. Future research could identify what facilitates these models and what builds sustainable capacity among specialists and PCPs together.

## Limitations

While the findings of this study provide some insights into the perceived barriers of PCPs to providing effective care for children with DB and mental health issues, results should be interpreted with certain limitations in mind. First, the interview guides were reviewed by physicians and not a diverse group of professionals within the FHT. It is possible that such piloting could have resulted in questions that were able to better elicit the experience of diverse professionals. Second, the perspectives shared reflect the views of those who self-selected to attend a focus group on pediatric care and might be biased toward the views of those with this identified interest. Third, developmental pediatricians facilitated the interviews, which might have prompted participants to share specific types of information or to focus on certain presenting issues. Fourth, participants included academic- and non-academic-affiliated FHTs, as well as participants with varying roles within the FHT (ie, family physicians, nurses, allied health professionals, and family medicine trainees).

While the variety of participants was a strength in terms of capturing a diverse and representative group of professionals involved in FHTs, we were unable to examine if themes might differ among the roles (ie, family physicians, nurses, allied health professionals, and family medicine trainees) or settings (academic and non-academic health teams). Examining if the themes derived differed by these factors might highlight where systems' strengths and opportunities for improvement exist. Future research is needed to better understand how roles and settings moderate perceived barriers in order to better tailor educational and system-level initiatives.

Fifth, individuals with DB and mental health disorders and their caregivers were not included in this study. Their experiences and perceptions receiving primary care might elucidate the relative effect of the barriers discussed and identify any additional barriers that they perceive. The model addressed in this study was limited to health care; however, we recognize that social and educational services also play a key role in integrated care for this population. Future research could

also include determining how these sectors intersect with the FHT and how they can also work together.<sup>44</sup>

Finally, we need future research to employ diverse methods that allow for the triangulation of findings, rather than rely solely on focus groups. Researchers could include individual interviews or document reviews to corroborate themes arising from the focus groups.

## Conclusion

There is no one specialist or sector in health, education, or social services mandated to follow children who present with complex DB and mental health disorders, leaving children and families to navigate complex systems of care across their lifespan. The PCP is the only stable source of care for families and the one they most often turn and return to. These findings underscore the need to reform the current model of care through improved system integration and to assess its effectiveness in supporting PCPs on the ground and meeting the needs of children with DB and mental health challenges and their families. 🌿

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### Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

### Competing interests

None declared

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