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Navigational support for families with children who have special developmental needs

Improving connections between clinicians and other providers of navigational support will ensure that they can do their best for children, youth, and families living with neurodisability and that their work is visible and valued on the health care continuum.

ABSTRACT: We describe a province-wide quality improvement initiative aimed at the experience of families who have a child with neurodevelopmental special needs (neurodisability) as they seek to connect with needed services and supports. We used patient and family navigation as the strategy of primary interest. Navigation seeks to make disconnected services and supports more accessible and individualized to each patient's and family's needs. Three barriers that reduce the efficiency and effectiveness of existing resources in BC were identified: the nature and scope of navigation and navigational work are not well known or well understood, providers of navigational

support are not always aware of others who provide support or the details of their work, and service providers whose primary role is clinical interventions aimed at children and youth are often unaware of or unfamiliar with family support navigation providers. Ways to improve family support navigation services and experiences include providing parents with peer-to-peer supports, tailoring navigational approaches to the patient's and family's needs, providing a centralized resource that navigators and other providers can easily use, ensuring navigators remain connected to one another, simplifying the system of services and supports, developing closer connections with existing provincial resources such as HealthLink BC 8-1-1 and BC 211, and raising clinical service providers' awareness of dedicated navigators and agencies. We argue for closer collaboration between those who provide navigational support as their primary role and those who provide it as a secondary or incidental role within a primarily clinical or therapeutic role, and we provide useful information and resources to enable clinicians to bridge this gap.

Children and youth with special developmental needs (neurodisability) represent up to 9% of the general population of children in Canada.^{1,2} The terms *neurodisability* and *neurodevelopmental disorders and disabilities*^{3,4} encompass developmental delays, autism spectrum disorder,

attention deficit hyperactivity disorder, and intellectual disability, as well as medical conditions associated with developmental challenges, such as cerebral palsy, fetal alcohol spectrum disorder, Down syndrome, and other genetic conditions. Affected children and youth require services and supports to promote and optimize their developmental potential; address challenges with mobility, communication, learning, and daily living skills;⁵ and address issues with social-emotional-behavioral functioning, which frequently co-occur.⁶ Parents and families may themselves require services and supports to enable them to fulfill the crucial role they play in nurturing healthy development.⁷

Services and supports for children and youth with neurodisability are usually needed over the course of the childhood years and into adulthood, often from a diverse array of sources. There is ample documentation on how families struggle to identify and access the services and supports they need over time and to navigate the terrain of systems that may be obscure, siloed, and poorly coordinated.⁸⁻¹¹

Patient navigation has emerged as a useful strategy in health care and is relevant to most forms of complex care, including childhood neurodisability. In this context, we expand the focus of care and services to include medical, rehabilitation, education,

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and social services, all of which affect the healthy development and well-being of affected children and youth. Patient navigation seeks to make disconnected services more accessible, coordinated, integrated, and individualized to each patient’s and family’s needs. Those in navigator roles assist individuals and families by providing information and emotional support and by working to reduce existing barriers.^{5,12} Physicians may not see themselves as navigators, but by providing longitudinal care in community settings, they have an important role to play: supporting patients and families in navigating the existing patchwork of programs and agencies, and helping them identify and connect to needed services and supports.

Our aims are threefold: (1) to raise awareness among physicians in BC of the vital role that family support and navigation can and should play in the life and experience of these families; (2) to disseminate the most salient learnings from our work in this area; and (3) to summarize the key resources that physicians, particularly family practitioners and pediatricians, need to know about to work in synergy with existing navigational resources.

Improving navigational supports and services

With support from the Kids Brain Health Network, work to date has examined how navigation support services for children and youth with neurodisability and their families currently work in BC and has been aimed at improving the status quo through engagement and collaboration with stakeholders. The project provincial advisory group, which included representation from the affiliated academic health centre, government (BC Ministry of Children and Family Development), community-based agencies with a central mandate to support families in which a child has a neurodisability, and parents of affected children and youth, determined at the outset that there was no need to create a new navigational support system for BC because many individuals and agencies

already provide navigation as a central part of their mandates. However, the provincial advisory group identified three barriers that reduce the efficiency and effectiveness of existing resources but are amenable to efforts to improve the situation:

1. The nature and scope of navigation and navigational work for this population are not well known or well understood in BC. This includes basic terminology and consensus about activities that fall in and out of scope.
2. Individuals and agencies that do navigational support work do not always know who else is doing this kind of work or the details of what others are doing (or aiming to do).
3. Service providers whose primary role is clinical interventions aimed at children and youth but who do navigational support work “off the side of their desks” are often unaware of or unfamiliar with the family support navigational players and agencies for whom this is a primary mandate.

Key concepts underpinning navigation, and range of terminology

Our understanding of the key components of navigation for children with neurodisability and their families emerged from activities undertaken to address barriers 1 and 2: a scoping review of the relevant

literature,¹³ surveys of service providers and families in BC during the course of the project (unpublished), and a virtual summit on navigation¹⁴ (with a subsequent summit regroup convened 8 months later). The main summit convened more than 120 professionals and families over the course of two half days and featured presentations from family members, service providers, and researchers about family support navigation for children and youth with neurodisability. Attendees also participated in various collaborations and facilitated exchanges, in which they considered what could be done to improve navigation supports and related activities for families and to build a provincial community of navigation.

Two main conclusions resulted from these activities. First, numerous terms are used to describe various interrelated activities related to navigation, as illustrated in the word cloud [Figure 1] that was created from the terms that were extracted; each term’s size is based on the frequency with which it arose in our scoping literature review. Our surveys and summits similarly showed that real-world professionals had job titles that comprised many of these terms.

Consultations with stakeholders and partners did not provide a single, clear solution for how to refer to this kind of work in the context of childhood

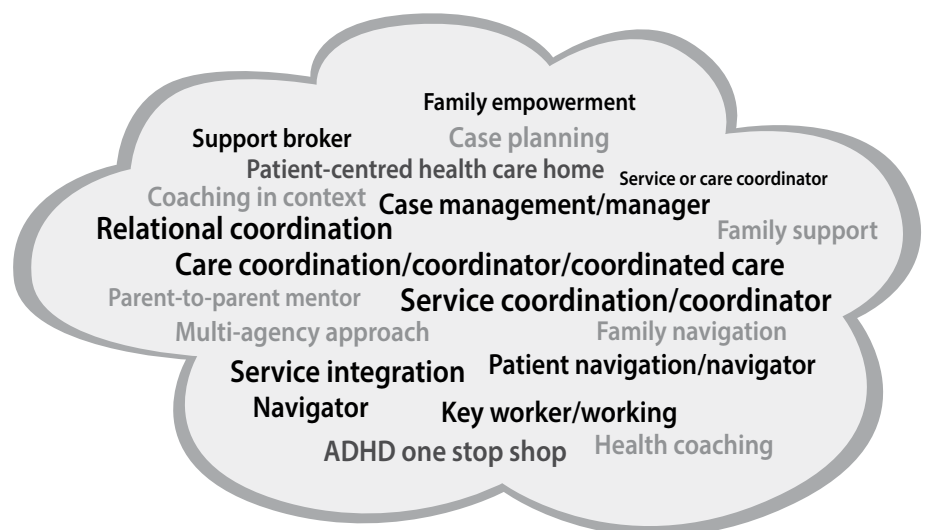


FIGURE 1. Range of terminology used for the navigation care coordination function.

Source: Created by Dr Emily Gardiner, 2019.

neurodisability. The term “family support navigation” emerged as a highly relevant hybrid term, even when used as a placeholder. That term can arguably be extended to include the closely related concepts of care or service coordination.¹³

Second, the aggregate of interrelated activities that constitute family support navigation was comprised of three fundamental components: providing functions, facilitating functions, and a set of guiding principles [Table 1].

The main learnings related to terminology and concepts of family support navigation are depicted in Figure 2.

TABLE 1. Domains characterizing family support navigation for children with neurodisability.

Providing	Facilitating	Guiding principles
<ul style="list-style-type: none"> Information, advice, education, and intervention. A single point of contact for family. Emotional support (e.g., crisis support, counseling). Advocacy for specific individuals and families and for broader system change. Material/instrumental support. 	<ul style="list-style-type: none"> Access to resources. Integration/coordination of resources, supports, and services within and across disparate and complex services, agencies, and systems. Identification of individualized needs. Identification and reduction of barriers. Continuous and timely service engagement. Peer connections/networking. Transition planning. 	<ul style="list-style-type: none"> Client directed and family centred—family is at the centre (respect for family voice and expertise). Flexible and individualized to the family. Collaborative and cooperative. Relationship and trust based. Accessible and transparent communication. May be brief and time limited or a long-term partnership. Person centred. Safety and harm reduction. Culturally safe and sensitive. Trauma informed.

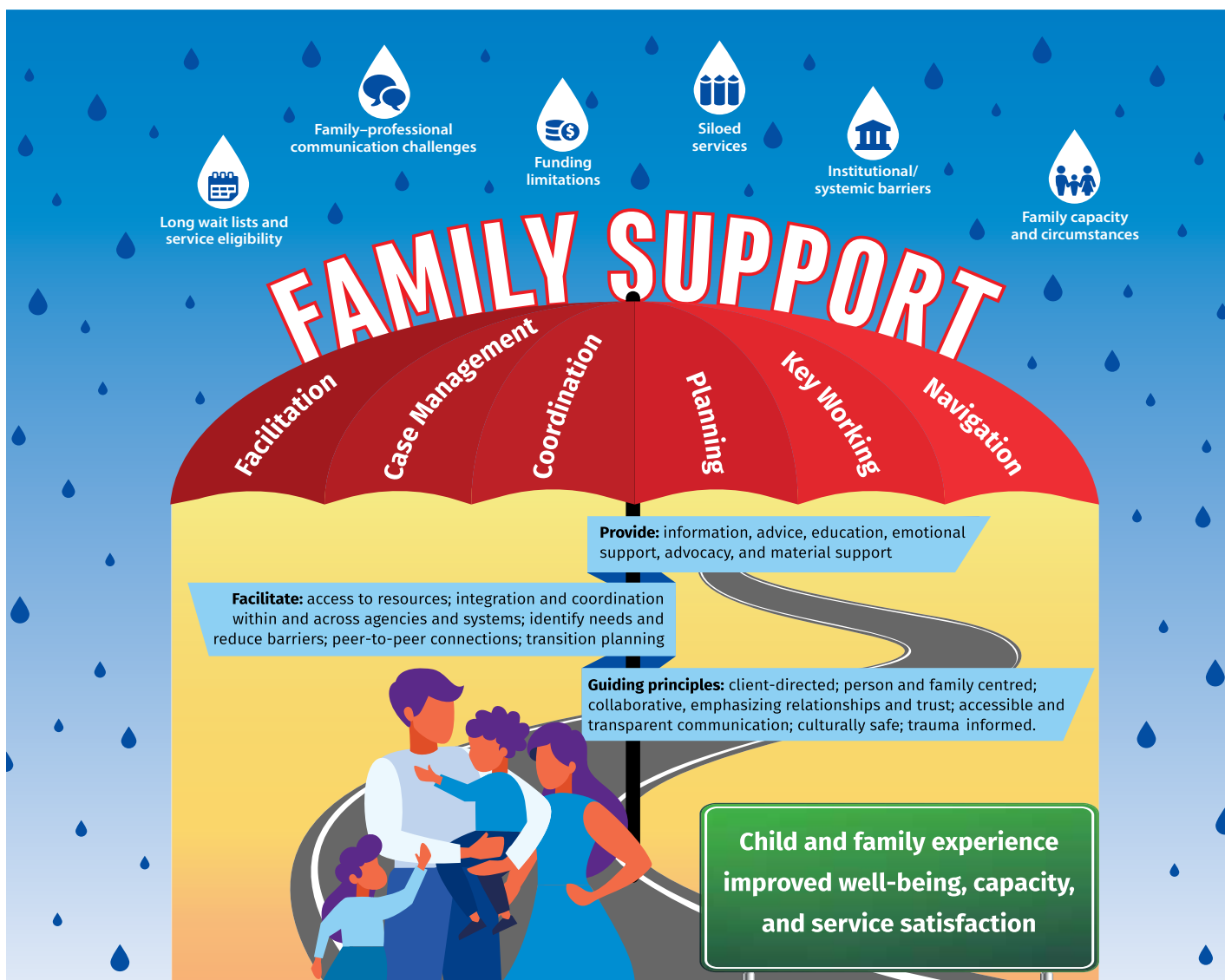


FIGURE 2. Synthesis of main learnings related to the nature, purpose, and terminology of navigation.

Source: Created by Angela Chan Design for the BC Navigation Project research team, 2021.

Improving family support navigation services and experiences

The January 2021 navigational summit provided a number of main findings and takeaway messages regarding how key stakeholders view the path forward for improving family support navigation services and experiences in BC:

- Peer-to-peer supports are highly valued by parents.
- Navigation approaches must be individualized; there is no “one-size-fits-all” approach.
- There is a need for a centralized web-based resource primarily for the use of people engaged in navigational support work.
- Navigators want to remain connected to one another.
- There is a need to simplify the system of services and supports for children with neurodisability and their families.

These key points were affirmed at a BC navigation summit regroup in September 2021. It was also suggested that closer connection with existing provincial resources be developed (e.g., HealthLink BC 8-1-1 and BC 211 [<https://bc.211.ca>])—a free information and referral resource) and that knowledge translation for clinical service providers (e.g., community physicians) be conducted to raise awareness of dedicated navigators and agencies and to promote referrals to them. Knowledge translation is part of addressing barrier 3.

Key resources for family support navigation services

Information on navigational and family support agencies and organizations in BC was assembled from an environmental scan, surveys, material submitted at registration and during the course of both summits, and referrals from partners [Table 2]. It is not exhaustive but serves more as a framework, and it provides exemplars of organizations and agencies rather than a comprehensive list of all of them. We hope this information will better equip physicians and their staff in finding relevant resources within their own communities to help the children, youth, and families they care for.

Conclusions

Throughout this project, a distinction arose between professionals doing family support navigation work as a primary role versus doing it off the side of their desk, even though it is not a simple matter for many professionals to separate these two roles at the front lines of patient care. Side-of-desk assistance with navigation and support of families is often asked of providers whose primary mandate is clinical care of the child. Many providers will be asked to also help the child’s family navigate a complex, opaque, and disparate array of services, supports, programs, and providers—for example, “Where can we find help or support for their sleep issues?” or “How do we pursue our need for respite care?”—problems and situations that arise from or coexist with the child’s primary area of impairment or disability. Families want, and need, to know how to go about connecting to those who provide this help or support.

We have sought to bring explicit focus to the family support navigation work that complements a more traditional view of the child or youth as patient. The World Health Organization’s International Classification of Functioning, Disability and Health¹⁵ recognizes the patient’s environment as a key contextual factor affecting health outcomes; this is particularly salient in the case of children with neurodisability or other chronic complex care needs. In this context, “environment” refers primarily to the family, but also to available services and supports the child and family have to connect to. The role of family in contemporary child health care, particularly for those with disabilities, is well expressed by Dr Peter Rosenbaum, professor of pediatrics at McMaster University and co-founder of the CanChild Centre for Childhood Disability Research (email communication, 2 August 2022; see also^{16,17}):

“It is a truism in child health—but one too easily ignored—that the unit of interest for all health care providers must be the child’s family—the children’s ‘agents’ and advocates, who seek help on behalf of their children and are expected to carry

out the best of the advice offered by health professionals.”

Physicians straddle the divide between providing clinical service and helping families find and connect to services. Importantly, they do not need to provide all the family support navigation work themselves. In the United States, there has been interest in, and some programmatic funding directed at, establishing “medical homes” for children and youth with complex care needs, including neurodisability.^{18,19} This envisages the pediatrician, in close collaboration with allied disciplines and staff, providing an expanded range of services and supports, which extend to the care coordinating as family support navigation roles.²⁰ Innovative hospital-based models are beginning to emphasize the role of allied disciplines, such as social work, in providing longitudinal and supportive care to children and families, which will take the pressure off physicians.²¹ There may be scope to advance the navigational aspect of care in BC, even though the funding context for physician and allied professional services is very different in BC than in the United States.

One way would be to explore innovations for this kind of service to be office or practice based, such as employing “teams” for chronic condition care that include nurse practitioners and/or social workers.²² Even within current parameters, it seems feasible to explore whether office staff who are properly prepared and informed can assist with this role by helping identify the family’s needs and knowing what services and resources are locally available. Another approach would have the navigation support person based in a community agency but be more closely linked with one or more physicians and practices. This would require investment in establishing closer, deeper, and reciprocal links between these professionals. An important first step is for physicians to learn more about existing agencies and organizations, both those in the immediate community and those with a provincial scope, that provide family support navigation services as a primary mandate. One of our aims is to bring the existence and

TABLE 2. Navigational and family support agencies and organizations in BC.*

Agencies, organizations, and programs	Exemplars	Types of roles	Notes
GROUPED BY AGE/LIFE STAGE OF CHILD			
A. Pre-kindergarten (“early years”)	Child development centres (CDCs)	CDCs may have: <ul style="list-style-type: none"> • Family resource navigators • Early years navigators • Family support workers • Family service coordinators 	<ul style="list-style-type: none"> • Most communities have a local not-for-profit agency that delivers services to children and youth with support needs. They are often called CDCs but may go by a different name in some communities. • CDCs differ in whether and how they provide family support navigation. For a starting place to look for a CDC (or equivalent), visit the BC Association for Child Development and Intervention website (www.bcacdi.org/bcacdi-member-agencies).
	Infant Development Program (IDP) (https://alpha.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/assessing-child-development-38610)	The IDP is a home-based program serving children experiencing or at risk for developmental delays.	<ul style="list-style-type: none"> • IDP consultants will usually try to provide family support navigation services alongside serving children.
	Family Resource Programs of BC (FRPs) (https://frpbc.ca/)	Five core areas of service: <ul style="list-style-type: none"> • Family support • Play-based learning • Early learning and literacy • Parent education • Information and referrals 	<ul style="list-style-type: none"> • FRPs often help families who have children with developmental delays and differences to navigate more specialized services.
	Supported Child Development Program (SCDP) (https://alpha.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/assessing-child-development-38610)	SCDP consultants support primarily young children in early learning settings and school-aged children up to 12 years; they may, however, help with family navigational support.	
B. School age			<ul style="list-style-type: none"> • School-based supports are primarily to support the child’s or youth’s learning and participation. Some school districts may provide informal supports for families, and navigation.
C. Transition to adulthood	Services to Adults with Developmental Disabilities (STADD) (www2.gov.bc.ca/gov/content/family-social-supports/services-for-people-with-disabilities/transition-planning-for-youth-young-adults)	STADD navigators	<ul style="list-style-type: none"> • Help eligible young people with developmental disabilities, aged 16 to 24 years, to map out and pursue their vision for post-high school. • Not yet fully established in every region or community in BC.
D. Across the lifespan	Family Support Institute of BC (FSI) (https://familysupportbc.com/)	The FSI connects families to trained volunteers who have family members with disabilities, to share their experiences, expertise, navigational supports, and advocacy, and to provide guidance. The FSI also offers workshops and support groups.	<ul style="list-style-type: none"> • Committed to supporting families who have a family member with a disability of any kind. • Supports and services are free.
	Ministry of Children and Family Development (MCFD) (www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/children-and-family-development)	MCFD social workers in the Children and Youth with Support Needs program can provide family support and navigation services for eligible children and youth.	<ul style="list-style-type: none"> • Support availability and levels vary.

Table continued...

*This table focuses on providers who offer family support navigation services as a primary role, in contrast to providers whose primary role is clinical interventions aimed at the child, the goals of which are typically to ameliorate the effects of an impairment and to optimize functional outcomes.

TABLE 2 (continued). Navigational and family support agencies and organizations in BC.*

Agencies, organizations, and programs	Exemplars	Types of roles	Notes
GROUPED BY CONDITION			
Autism spectrum disorder	Autism Information Services British Columbia (AIS BC) (www2.gov.bc.ca/assets/gov/health/managing-your-health/autism/autism_brochure_english.pdf) AutismBC (www.autismbc.ca/)	Autism support specialists Has a support program with staff who provide information and advice, including for life transitions, advocacy, and self-care.	<ul style="list-style-type: none"> Autism support specialists assist the growing number of BC families affected by autism who need support in making informed decisions about treatment options.
Fetal alcohol spectrum disorder (FASD)	Key worker and parent support agencies (https://www2.gov.bc.ca/assets/gov/health/managing-your-health/fetal-alcohol-spectrum-disorder/key_worker_parent_support_agencies.pdf)	FASD key workers	<ul style="list-style-type: none"> See link to key worker and parent support agencies PDF.
Mental health concerns	FamilySmart (https://familysmart.ca/)	Parent peer support program	<ul style="list-style-type: none"> Aims to help children and youth with mental health concerns by helping their family and other caring adults. Not aimed primarily at children and youth with neurodisability but is included because mental health concerns are prevalent in this population.
Permanent hearing loss	BC Early Hearing Program (www.phsa.ca/our-services/programs-services/bc-early-hearing-program/resources-support)	Guide By Your Side program	<ul style="list-style-type: none"> This free program offers parents navigational supports and guidance following diagnosis, particularly regarding language and communication needs, and provides opportunities to connect with other parents.
GROUPED BY POPULATION			
Indigenous	BC Association of Aboriginal Friendship Centres (https://bcaafc.com/about-us/friendship-centres/)	Various names: family connections worker, family navigator, outreach support worker	<ul style="list-style-type: none"> Local Friendship Centres typically have a variety of child and family services and programming; these may differ depending on location. Centres often include a role dedicated to helping families connect with child development services and supports, Aboriginal Infant Development Programs, and Aboriginal Supported Child Development Programs. To find a local Aboriginal Friendship Centre in your community, visit the BC Association of Aboriginal Friendship Centres website (https://bcaafc.com).
	Aboriginal Infant Development Programs (AIDPs) (www.aidp.bc.ca/aidp-programs)	AIDPs provide culturally sensitive support to families of young children (usually birth to 3 years) who are diagnosed with or at risk for developmental delays.	<ul style="list-style-type: none"> As with the IDP and FRP, a navigational family support role is usually part of the portfolio of services provided, even if it is not referred to as navigation.
	Aboriginal Supported Child Development Programs (ASCDPs) (www.ascdp.bc.ca/programs)	Designed to meet the needs of First Nations, Métis, and Inuit children who require additional support to be included in childcare settings, and their families. ASCDPs are developed with cultural values, beliefs, and traditions in mind.	

Table continued...

*This table focuses on providers who offer family support navigation services as a primary role, in contrast to providers whose primary role is clinical interventions aimed at the child, the goals of which are typically to ameliorate the effects of an impairment and to optimize functional outcomes.

TABLE 2 (continued). Navigational and family support agencies and organizations in BC.*

Agencies, organizations, and programs	Exemplars	Types of roles	Notes
GROUPED BY SETTING			
BC Children's Hospital (BCCH) and Sunny Hill Health Centre (SHHC)	Neuromotor Program complex care coordination (SHHC)	Care coordinator/social worker	<ul style="list-style-type: none"> Provides navigational supports for patients and their families. Supports the family across transitions from inpatient hospital to home and home to hospital. Helps the family navigate systems and supports local health care providers to care for the patient. Specialized care coordination service for children who require care from neurological, mental health, and complex and developmental behavioral conditions.
	Complex Care program (BCCH) (www.bcchildrens.ca/our-services/clinics/complex-care)	Nurse key worker	
	Connect 4 Care (SHHC and BCCH)	Care coordinator/social worker	

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scope of these providers to the attention of physicians. We hope the information in **Table 2**, while limited, will be a useful resource for physicians.

A final aim is to communicate some messages from this project that were heard consistently and that physicians should keep in mind: many families place importance on connecting with peers and peer supports during their journey; navigational supports defy a simple one-size-fits-all model, so it is important that options are available and families are empowered to seek what fits best for them; and navigators want to be better connected to each other and to clinicians to ensure that the work they do is visible and valued on the health care continuum and they can do their best for children, youth, and families living with neurodisability. ■

Competing interests

None declared.

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