The Allegory of Navigation as a Concept of Care: The Case of Childhood Neurodisabilities

L'allégorie de la navigation comme concept de soins : Le cas des troubles neurodéveloppementaux chez l'enfant

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Abstract

*Navigation encompasses a defined range of care concepts and practices, services and professions while also alluding to a broader set of care values, needs, and challenges associated with health inequities, social exclusion, and service fragmentation. In this article, we address some of these challenges by exploring **navigation as an allegory** that conveys the process of **making one's way through** a complex web of care. We briefly trace the history of this concept and revisit its emergence and development in the context of health and social care. Drawing on a targeted review of the literature on this topic, we anchor our discussion in the case study of navigation programs for children with neurodisabilities and their families in Canada. In conclusion, we call for a social ecological approach to navigation as a matter of care and concern that has salient relational and political dimensions warranting additional research attention and policy development.*

Résumé

La notion de navigation réfère à un ensemble de concepts et de pratiques de soins, de services et de professions, tout en s'inscrivant dans un système plus large de valeurs et de besoins en matière de soins. Elle réfère également à des préoccupations liées aux inégalités en matière de santé, à l'exclusion sociale et à la fragmentation des services. Dans cet article, nous abordons certains de ces défis en

explorant la navigation comme une allégorie qui traduit le parcours que doit suivre les familles pour se frayer un chemin dans un réseau de soins complexe. Nous retraçons brièvement l'histoire de ce concept et revisitons son émergence et son développement dans le contexte des soins de santé et des services sociaux. En nous appuyant sur une revue ciblée de la littérature sur ce sujet, nous ancrons notre discussion dans l'étude de cas des programmes de navigation pour les enfants atteints de troubles neurodéveloppementaux et leurs familles au Canada. En conclusion, nous proposons une approche d'écologie sociale de la navigation qui considère les dimensions relationnelles et politiques des enjeux de soins pour lesquelles une attention supplémentaire est mérité dans la recherche et l'élaboration de politiques.

Mots clés : navigation, coordination des soins, gestion de cas, disparités en matière de soins de santé, troubles neurodéveloppementaux.

The Journey Begins in the Wake of the Storm

Disoriented from the storm, the already weary travellers set forth without a clear destination in mind. At once they knew life would never be the same after the storm made landfall but could not fathom what would lie ahead.

The travellers found themselves threadbare and drained of energy as they stood on the docks, silently dreading the inevitable journey into the vast body of water ahead of them. Though they had heard of such whipping winds and pounding waves, they had never experienced it themselves before last night and felt unprepared. The storm surge continued to slap against the breakwater and the boats moored offshore swayed deeply, nearly keeling over. The travellers wondered whether the storm was over or just beginning.

A sailor stood nearby, observing the surge of emotions she had witnessed many times before from other storm worn travellers. She had been through such a storm herself years earlier. The sailor approached the travellers to find out where they were headed and offer guidance, quickly realizing they had no idea where to even begin.

The sailor recounted her own journey over the years, regrouping after a storm, navigating narrow passages and shallow shoals, and discovering beauty and adventure amidst moments of fear and exasperation of being lost at sea. Overhearing the conversation, a weathered sea captain joined in, sharing stories of faraway lands and nearby shores and describing the vessels that could provide passage to safe harbours.

With the support of these navigators, the travellers began confidently preparing for their journey and dreaming of new destinations. Though still exhausted from the storm and fearing unfavourable conditions, the travellers found themselves defining a new trajectory, propelled by a second wind of hope.

Introduction

In 2005, President Bush signed the Patient Navigator and Chronic Disease Prevention Act, which allocated funds for research and program development dedicated to patient navigation services that would improve healthcare access and outcomes in the United States (Freeman, 2012). Since then and from its inception in cancer care during the 1990s, the term *navigation* has become a high-profile concept in health and social care in North America (Freeman, 2012; Pedersen & Hack, 2011), particularly in the context of chronic conditions and complex care provision (Dohan & Schrag, 2005). Navigation supports and services have also been of increasing interest for caregivers and families of children with neurodisabilities and diverse abilities (see Filipe et al., 2021), such as those associated with autism spectrum disorders (ASD), Down syndrome, and cerebral palsy (Gardiner et al., 2022). Yet, as the concept has been used in various domains of care, its professional, practical, and temporal attributions have changed across navigation roles and programs. In other words, who acts as a navigator, their specific tasks and skillsets, and the intensity and length of time they remain involved in care varies substantially between the contexts within which navigation and related supports are provided (Carter et al., 2017; Desveaux et al., 2019; Gardiner et al., 2022; Ogourtsova et al., 2019; Tang et al., 2021). While some useful definitions of navigation roles and services have been widely adopted (as discussed below), we view navigation, broadly, as the process by which patients and families (or service users and caregivers) find their way through a *maze* of services and care provisions, with or without support along their journey (see generally Gardiner et al., 2022).

Our aim in this article is to review the history and implementation of navigation programs as a model of care with a particular focus on the context of neurodisability. Drawing on our experience in conversations with health and social care professionals, researchers, and families of children with neurodisabilities, we sought to tell a story of navigation in everyday language that captures deeper ethical, relational, social and philosophical connotations. To this end, we suggest that navigation of services and supports for families of children with neurodisabilities may be usefully framed as *an allegory of care*. That is, a figurative depiction of what it means and entails to be *steering course*, *finding guidance*, and *making one's way through* a complex web of care, which comprises multiple services, treatments, and interventions as well as different interlocutors, programs and institutions (Luke et al., 2018). The allegory of navigation carries important ethical and political meanings. At the same time, it encourages more creative and critical approaches to its conceptualization and theorization in the health and social care domain, where metaphors, analogies, and other tropes have been used as ways of making sense of the complexities of care and for very different political ends (see Pacheco & Montenegro, 2019). The allegory of navigation also allows for more fluidity and integrates multi-layered perspectives and experiences which may not be as easily ascertained in a traditional, deductive scientific depiction. While the narrative we have developed is not exhaustive and is subject to the authors' own experiences and interpretations, we hope that this allegory sparks the imagination of readers and makes clear connections between the idea of navigation and components of complex systems of care.

Figure 1

Graphic Depiction of the Allegory of Navigation as a Concept of Care (Image created using app.diagrams.net)
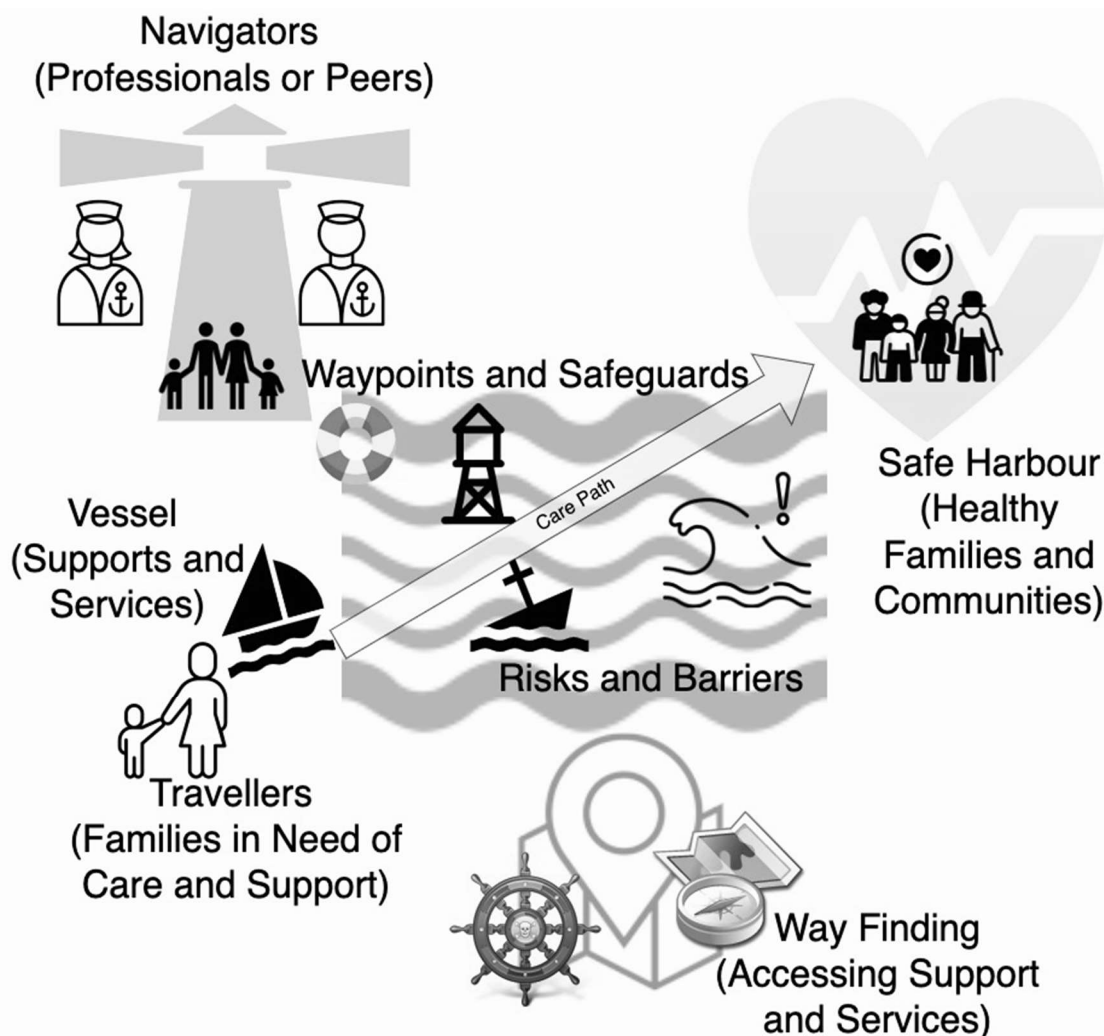
In our allegorical depiction we borrow from commonly used maritime metaphors (e.g., Markoulakis et al., 2016) to tell a story representative of the context within which children with neurodisabilities and their families navigate their way through care. The family, represented by the travellers, begins their journey through care after learning of their child's developmental concerns. This launching point could lead the family through well-travelled channels or uncharted waters, hopefully leading to a safe harbour (i.e., a state of stability or growth for family health and well-being). The care paths (i.e., bodies of water); services, practices, and supports (i.e., vessels); and systems, policies, and programs (i.e., weather) are representative of factors affecting individual and family well-being (Zuna et al., 2011). The roles of the peer and professional navigators and systems of navigation involve supporting families to find their way through the bodies of water – sometimes smooth but often choppy — by picking the right vessel according to the forecast.

The concept and imagery of *navigation* work as an apt metaphor for both matters of care and matters of concern or neglect (Puig de la Bellacasa, 2010). On the one hand, it speaks to the ideal of equitable and timely access to continuous, integrated, and seamless care, that is, a complete cartography of what matters and counts in health and social care. On the other hand, *navigation* is a revealing allegory for what may be absent or perhaps neglected in contemporary systems of care, such as attention to relational aspects of caregiving, beyond medical concepts of improved adherence and compliance to treatment, or patient autonomy (Pols, 2015). This cartography of care illuminated by *navigation* includes, for instance, matters of wider social and community inclusion, health equity, engagement with and trust in existing services and programs, as well as socio-economic, environmental, and structural determinants of health (Filipe et al., 2017, 2021; Valaitis et al., 2017). These are factors that influence how people will seek and access care and whether the care they find is what they want and need. This reverts the debate to the ethical and political question of why care coordination and navigation are needed in the first place, and ultimately, who is responsible for caring for children with neurodisabilities in the wake of deinstitutionalization and the emergence of community-based care (Samuel et al., 2012; Trute & Hiebert-Murphy, 2013).

Navigation encompasses a defined range of care concepts and practices, services and professions (Gardiner et al., 2022) while alluding to, at the same time, a broader set of care values, needs, and quandaries, including concerns with health disparities and inequities, social exclusion, and service fragmentation. In this article, we trace the etymological and historical roots of this concept and its emergence and development in the context of health and social care — through maritime imagery — given its apparent fit with this phenomenon of study. Building on a targeted review of the literature on this topic, we also anchor our discussion in the case study of navigation programs for children with neurodisabilities and their families in Canada drawing on insights from literature on practices and ethics of care (see generally, Mol, 2008; Filipe et al., 2017; Pols, 2015; Tronto, 2010). We propose understanding navigation as a set of activities and a process that is to be innately embedded in what families, professionals, and systems do. This includes, as we show, a set of practices aiming at the reduction of (i) disparities in access to health and social care and (ii) the fragmentation of systems of care (i.e., lack of coordination and integration of services and responses). In the final section of this article, we call for a social ecological approach (Filipe et al., 2021; Hébert et al., 2022) to navigation as a matter of care with salient ethical, social, and political implications that warrant additional research attention and policy development.

Captain's Log: Retracing the Emergence of Navigation in Health and Social Care

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Finding One's Bearings

Travellers may actively seek out the support of navigators for direction at any point in their journey. Navigators play different roles depending on their experience at sea and whether they have other tasks at hand. A navigator may provide guidance by pointing in the direction of the traveller's next waypoint, or they may accompany them for the whole journey. This may depend on the amount of time the navigator has to advise the traveller, the challenge of the trajectory, or the experience of the travellers themselves (maybe they just need a reminder of the route, rather than the company of an experienced sea captain).

Some travellers seek out the support of fellow travellers with recent experience on the same route to find out the state of the weather and where to find safe harbours. Not all travellers, however, seek out navigators. Some don't like to ask for directions, and still others may not foresee the complexity of the route ahead; hence, perhaps do not (yet) see a need for help in wayfinding

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The term navigation emerged in the context of oncology and cancer care in the United States in 1990. It is generally attributed to the work of Harold Freeman, a medical doctor who developed *navigation* as a strategy to improve breast cancer care and adherence to treatment among African-American women in Harlem, New York (Carter et al., 2018; Freeman, 2012). In its original medical formulation, a *navigator* is the person who facilitates access to services and accompanies the patient to follow-up appointments while providing emotional support, advocacy, and information/education, among other tasks. Freeman and his colleagues (1995) found that the introduction of a navigation strategy led to an increase in the rates of early diagnosis and a decrease in the rates of late diagnosis in breast cancer care leading to better prognosis as well.

Outside of cancer care, however, one may find earlier precursors to the concept and practice of navigation in health and social care. The idea of navigation partially speaks to the notion of *case management* developed by public health practitioners and nurses in the early twentieth century (Halfon et al., 1993; Ruth & Marshall, 2017) and to emerging disciplines in this field, such as social work, whose focus was on brokering and linking health care and social services (Cowin, 1970). Both nursing and social work models, at that time, provided care delivery and coordination with a focus on supporting those with long-term chronic conditions that were being managed in outpatient community settings (Kersbergen, 1996; Ruth & Marshall, 2017). Yet by the 1980s, the term *case management* had been the target of criticism. There was a pushback against its use as it alluded to notions of social control and monitorization of patients' behaviors while calling into question ways of talking and thinking about *cases* and cost reduction as opposed to the effective management and delivery of services (Kersbergen, 1996). This criticism

contributed to a reconceptualization of how case management operates. For example, Moore (1992) argued that the target of case management trends toward the coordination of services in the context of resource abundance but operates as a means of rationing access to services when their availability is low. In other words, the idea of case management seemed to obfuscate the need to address gaps in resource availability and in service coordination and integration at the level of public policy and health/social care systems.

Despite the aforementioned critiques, case managers continue to make up a part of some health and social care systems and although some would argue that navigation is a distinct practice from case management, the latter is not outmoded as a model of care and may overlap productively with navigation programs and supports (Kelly et al., 2019). While the definition and implementation of case management has evolved, our observations are that the critiques of case management were likely a catalyst for the emergence and development of the concept of *care coordination* that integrates principles of patient- and family-centred care (Lindeke et al., 2002; Trute & Hiebert-Murphy, 2013). Care coordination involves various activities and roles such as brokering services on behalf of individuals, coordinating and mediating services across agencies/sectors, facilitating transitions, informing families about and advocating for resources in areas where these are limited and/or difficult to access — as is the case of children with complex care needs and neurodisabilities (Bruder et al., 2005; Committee on Children With Disabilities, 1999; Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014; Rosenbaum et al., 1998; Trute & Hiebert-Murphy, 2013). Alongside calls for better care coordination and family-centred practice in the last three decades, the concept of navigation has migrated from cancer care to other areas of health and social care — ranging from chronic conditions and mental health (e.g., diabetes, sickle-cell disease, depression, substance use) (e.g., Markoulakis et al., 2016) to complex care needs and age- or group-specific service transitions (e.g., children with special and complex care needs and their families, youth and elderly people transitioning across services; Carter et al., 2017; Luke et al., 2018; Wells & Nuhaily, 2018).

Navigation as a Model of Care: The Context of Children with Neurodisabilities and Complex Care Needs

> **Identifying the Body of Water and Deciding Who to Invite Aboard**
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> *Taking stock of what journey may lay ahead for travellers begins with getting a sense of the size of the body of water in which they are about to set out on. A small stream may present few challenges aside from some wet boots, an ocean may be daunting, and a river navigable — but who knows what might be around the bend? Travellers may also need to reflect on how prepared they are to set sail. Do they have adequate rations for everyone they will take aboard for the whole trip? Or are their sails already tattered and torn? Who will be there to join the travellers and how will they support their journey?*

There is a longstanding need for navigation programs and supports for families to address the common experiences they need to navigate and the barriers they face in their journey of steering through a complex web of health and social care services and jurisdictions (Salvino et al., 2022). These challenges include long periods of waiting for assessment and services, gaps in service provision, concomitant fragmentation and duplication of services, difficulties in accessing and identifying suitable services, and issues arising from moving between (and transitioning into) different services situated across agencies and sectors (Halfon et al., 1993; Hodgetts et al., 2015; Majnemer et al., 2002). However, how navigation support is operationalized, depends on a variety of factors. For example, in a recent review of emergent concepts in the context of childhood neurodisability, Ogourtsova and colleagues (2019) identified at least four concomitant variations of the aforementioned terms and activities, including care coordinator, navigator, coach, and key worker, which they sought to tease apart. Citing earlier work in this field, the authors argued that care/service coordinators work both within the healthcare system and across systems (i.e., social care and education) embarking in "an ongoing longitudinal relationship" with the family (Ogourtsova et al., 2019, p. 121), whereas navigators will play those roles on a temporary basis that implies intermittent contact with clients and families (see Dohan & Schrag, 2005). However, in some cases, the role of navigators is not described as time limited. Some navigation programs report opportunities for long-term engagement in relationships and community building whereby families are joined throughout their development (e.g., Family Support Institute of British Columbia, 2021).

With no single, unified definition of navigation in the literature, generic definitions of both navigation models and navigator roles abound (Desveaux et al., 2019; Gardiner et al., 2022). Our view is that a broad eco-systemic definition of navigation services, supports and programs should correspond with facilitating the journey of individuals and their families through care (Hébert et al., 2022). In a scoping review of navigation delivery models and roles in primary care, navigation is defined as a principle-based, task-oriented practice whereby

> an individual or a team engaging in specific activities that include the following concepts: 1) facilitating access to health-related programs and social services for patients/families and caregivers; 2) promoting and facilitating continuity of care; 3) identifying and removing barriers to care; and 4) effective and efficient use of the health care system for both patients/families, caregivers and practitioners. (Carter et al., 2018, p. 2)

However, in another scoping review, Gardiner and colleagues (2022) explored terminology used in the literature to describe supports connecting families of children with neurodisabilities to community services. They found significant overlap between navigation, service coordination, case management, case planning and other related roles, noting also that these terms are sometimes used interchangeably (Gardiner et al., 2022). Furthermore, the term navigation specifically has only recently been applied to the context of neurodisabilities despite obvious challenges that population faces in accessing and coordinating care across sectors (Gardiner et al., 2022). So, who joins families on their journey through care should perhaps depend less on the label assigned to those in a navigation role and more on how the process of navigation itself is conceptualized.

In an environmental scan of the Canadian context of paediatric care navigation for children with complex health conditions, Luke and colleagues (2018) found that the majority of navigators in the programs they surveyed were health professionals such as registered nurses, social workers,

and mental health professionals. Few programs employed lay persons with lived experience as navigators, but those that did were implemented in the context of mental health and addiction programs. Though perhaps less common, some navigation programs for families of children with neurodisabilities do train non-professionals (Feinberg et al., 2016) and peers (Family Support Institute of British Columbia, 2021; Luke et al., 2018; Shilling et al., 2013) as navigators. Peer support models are not unique to these families but have been highlighted as important components in navigation programs supporting a range of other populations as well (Markoulakis et al., 2018; Moadel-Robblee et al., 2021; Reid et al., 2020). In contrast to navigation services led by health and social care professionals, parent-to-parent peer navigation support for families of children with neurodisabilities operates through shared lived experience to transmit practical knowledge and provide emotional support through the journey of accessing services and navigating family lifecycle events and transitions (McCrossin et al., 2022; Shilling et al., 2013). Additionally, peer support offers opportunities to create a sense of belonging and reduced isolation, empowerment, and mutual support (Shilling et al., 2013). While peers may hold very relevant systems knowledge from the perspective of a user, they may not have the same knowledge, relationships, or credentialed powers held by health and social care professionals. As such, the navigational services offered by peers and professionals are likely to be complementary elements of 'wraparound' support for families. Who families choose to invite on their journey through care likely depends on the type of knowledge the navigator possesses (i.e., lived, professional, or both), the relative navigability of the systems they need to access, their current family lifecycle stage and related needs, and ultimately, who is available to help them navigate their experience and access the care and resources they seek.

Choosing the Vessel

The body of water, the resources of the passenger, or simply what is most available may dictate the type of vessel needed for the voyage. Some routes have been identified as important enough to dredge a channel wide enough for large passenger ships to pass. However, the line up to get on the ship, or even to buy tickets, is often long. Other routes are at the edge of a new frontier and may require travellers to portage their canoe over land with all their gear to avoid risky open water crossings. If the traveller has a navigator to guide them, they may or may not be available to help with the portage, let alone the paddling

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Navigation programs may vary in relation to what they offer families, depending on the needs of the population being served. Examining our specific area of interest, navigation in paediatric settings typically involves emphasis on support for the family. Seen as a process, navigation can be defined as involving

> collaboration between a professional (e.g., nurse, social worker) or lay person (e.g., peer) with a patient and his or her family and/or caregivers to provide navigational support, including education, emotional support and logistical guidance, as they attempt to

navigate through a complicated maze of services, treatments, clinical interventions and/or programs. (Luke et al., 2018, p. 2)

Common approaches among navigation programs for families of children with disabilities and/or complex health conditions include the development of shared plans of care and shared decision making through facilitation of communication across a family-centred, interdisciplinary team (McAllister et al., 2018; Trute & Hiebert-Murphy, 2013). This is achieved through improving the quality of communication between service providers, family members, and institutions/agencies thereby enhancing individual, caregiver, and family confidence to access the health and social support services they require (Carter et al., 2017; Cordeiro et al., 2018; Feinberg et al., 2016; Trute & Hiebert-Murphy, 2013; Warfield et al., 2014). Engagement of individuals and families in care planning is commonly raised as a key issue in service coordination and navigation. Lindeke and colleagues (2002) provide an anecdotal example of 18 care providers at one meeting together with a family to share information and ironically to reduce the complexity of care planning. The authors raise concerns around the burden placed on some families to negotiate and coordinate care, while also highlighting the ever-expanding list of care coordination and case management roles in health and social care systems for children with complex care needs.

Navigating for the Individual, Family, and/or System

In addition to the active debate around who provides navigational support, there is also discourse around who *receives* it. Navigation delivery models and programs include individual and team-based approaches to support access to care through interventions at the level of the individual, family, and/or system. These categories of navigation are not universally defined nor are they mutually exclusive, and very well may depend on the identity of the navigator in relation to their profession or training or lived experience. Notably, in the case of paediatric health care there is little, if any, distinction between navigation services for the child and those for the family. For example, Appleton and colleagues (1997) described a navigation model whereby parent, child, and family goals around the transition to nursery school were integrated into a shared care plan coordinated by a navigator who provided continuity of care and fostered interagency collaboration. Two other studies found that connecting families of children with ASD to navigators decreased missed appointments through reducing barriers to accessing diagnostic and follow-up care and providing practical guidance, such as support with the magnitude of paperwork (Feinberg et al., 2016; Roth et al., 2016). Family navigators may be distinguished from patient navigators by their scope rather than their professional/quasi-professional identity. They are considered by some to hold an ecosystemic lens (see Filipe et al., 2021) through which their focus extends beyond the individual healthcare needs of the child to also attend to other family needs (e.g., housing, financial or social support) that have the potential to act as barriers to the child's access to care (Feinberg et al., 2016; Salvino et al., 2022).

System navigators may be conceptualized as those who hold a similarly broad lens but with a focus on creating trusting relationships and supporting communication between systems in order to facilitate access for individuals or families that require passage between them (Carter et al., 2017). Some navigation programs engage in a team-based approach rather than delegating navigation tasks to the role of a team member. These programs center around a single or primary point of entry, such as the office of a paediatrician or general practitioner, referred to as a

'medical home' where all relevant services are coordinated (Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014; Farmer et al., 2011; Zajicek-Farber et al., 2015).

Regardless of the level at which the service or program is offered or received, navigation and care coordination programs share challenges in implementation. Funds are often not dedicated to navigation services or standalone service coordination roles. Instead, the role of navigator is often tacked on to the responsibilities of a member of an interdisciplinary care team or primary care physician who may lack time, flexibility, expertise, or financial incentive to provide the service (Cordeiro et al., 2018; Lindeke et al., 2002; Zajicek-Farber et al., 2015). Moreover, some have indicated concerns around a lack of clarity of the navigator's role, and the feasibility of required tasks when considering the scarcity of available resources (Carter et al., 2017). This raises questions, explored in detail below, about the wider social and political contexts in which navigation occurs.

Conceptual, Social and Political Dimensions of Navigation

Preparing for Inclement Weather

All parts of the navigation system are vulnerable, more or less, to the impact of weather. Even the saltiest sea captain may not venture out in hurricane force winds – they render the waters unnavigable. The travellers may be too weary to continue in anything but calm conditions with good visibility and no precipitation on the radar. Of course, unexpected storms may arrive and threaten to capsize the boat. The size and state of the vessel and its exposure to the storm, as well as the confidence and competence of the navigator behind the helm, dictate the collective capacity to handle the swells.

While hoping for smooth sailing, travellers may need to continue to adjust to extreme weather. Finding the right vessels and navigators will be important to help weather the storms. However, more broadly the travellers and their neighbours back home may need to explore how they can better prepare for sudden changes in climate.

The social and jurisdictional climate in which families navigate care creates the need for navigation programs and services in the first place and affects how those supports are delivered. We suggest that a social ecological perspective on navigation is necessary and a perspective that

warrants critical engagement through research and through political and public debate (see generally Erikainen et al., 2022). Below, we offer our reflections on the weather or climate in which the phenomenon of navigation as a service is emerging (Hébert et al., 2022).

First, we argue that understandings and experiences of navigation are institutionally, historically, socially, and ecologically situated (Filipe et al., 2021). They are idiosyncratic and dynamic rather than universal or stable. In other words, what navigation is, means, and does today — and, specifically, in the context of childhood neurodisabilities and social/health inequalities in Canada (Salvino et al., 2022) — is likely to differ from what navigation is, means and does in the context of oncology care and racialized health inequalities in the US, in which the concept was coined back in the 1990s (Freeman et al., 1995). For example, service navigators for families of children with autism in Ontario do not provide service planning, clinical support, or case management services, but do provide some support in accessing services and resources as well as peer mentoring (*Service navigation /Autism Ontario*, 2022). Likewise, navigation supports for and needs of children with neurodisabilities and their families will vary not only across but also within countries as the healthcare, social and education jurisdictions, provisions, and care providers involved significantly differ from region to region. Yet recognizing that navigational practices are locally specific logics of care does not preclude their broader significance (Mol, 2008); instead it means that we should value and learn lessons from what people already do to navigate and negotiate for resources in their everyday lives (Ungar, 2010). This includes the practices of parents of children with neurodisabilities who are, at once, caregivers, advocates, and the navigators of a maze of healthcare, social care, education, and rehabilitation systems – or the valiant sailors in a long quest for care.

Second, we suggest that navigation may be usefully conceptualized as an allegory of care, that is, a figurative depiction of what the process of *steering course*, *finding guidance*, and *making one's way through* a complex system of care means and entails for those involved (i.e., individuals, caregivers, families, frontline workers, peers and other navigators). In keeping with this maritime allegory, we see the emergence and development of this concept as a wave-like process in health and social care starting in early twentieth century with the first wave of *case management*, followed by a second wave of *care coordination* around the 1970s and 1980s, and finally, a third wave of *navigation* since the 1990s and at the turn of the twenty-first century. With each wave, the tide ebbs further away from a focus on the needs of health and social care systems in terms of efficiencies and management of *cases*, while flowing closer to fulfilling needs identified by the individuals and families seeking supports and services, lapping over the gaps and silos in systems of care. By proposing a broader periodization for the emergence of *navigation* as a concept of care, we seek to highlight its branched conceptual and professional history both within and outside health care. This implies moving from the medical concept of navigation attributed to Harold Freeman (Freeman, 2012) toward a social model of navigation that is inclusive of nursing, community health, social work, and grassroots individual/family contributions to its development.

As the need for navigational supports and services becomes clearer, the fog is also lifting on who has been providing navigation. If navigation is conceptualized as an add-on strategy and a temporary response to gaps in formal medical care (e.g., fragmentation/duplication, inaccessibility/exclusion), informal navigational labour and care coordination may be relegated to a second plan becoming an add-on duty of nurses and social workers as well as family members, caregivers, and even those individuals receiving care (e.g., Carter et al., 2018; Family

Support Institute of British Columbia, 2021; Reid et al., 2020). As noted by Tronto (2010), high-level management labour tends to be divided and ranked higher than everyday care-giving work in institutions of care. This division of labour, paired with the devaluation of care labour, which includes navigating services and supports, affords pressing questions as to (i) what navigation means/does as a practice and model of care and (ii) how navigational competence, training, and supervision/support ought to be developed.

Third, a renewed theoretical framing of navigation is needed that highlights its cross-cutting nature as a concept, practice, and model of care. Since its inception, the idea of navigation has been taken up and developed in different areas of health, social, and community care. Yet the very need for navigation programs is revealing of disparities in access to services and of unnecessary barriers to communication, access, and care coordination, particularly in the context of childhood neurodisabilities and family supports (see Salvino et al., 2022). The allegory of navigation tells a story about the development of care coordination practices and navigational support programs by practitioners, social workers, and caregivers, over the last decades, in the face of inaccessible and unnavigable systems. We suggest that the allegory of navigation tells a poignant story about visible and invisible aspects of care provision and navigation in terms of how care needs are assessed and met (Tronto, 2010) – and how risk and responsibility, responsivity and accountability are defined and attributed in the governance of healthcare. It is therefore crucial that we consider whether and how navigation models might help shifting accountability for healthcare outcomes and disparities, service fragmentation, and structural vulnerabilities to the institutional and governmental levels of decision-making.

Conclusion

In this article we have described the evolution of navigation as a concept, practice, and model of care with respect to the experience of families of children with neurodisability in Canada. It is debatable whether we need to arrive at a consensual, unified vision of navigation in relation to who should provide navigation services or determine a singular description of what those services entail, as there may be multiple care pathways leading to a range of desirable outcomes for children and their families. However, we must acknowledge that the provision of navigation services requires systematic political commitment and investment to respond to the need for adequate training, supervision and other support to equip navigators to handle the swells and weather the storms; as well as efforts to fill the gaps highlighted by the need for navigation in the first place and make the waters easier to navigate.

Key Messages from this Article

Persons with Disabilities, Family Members, and Caregivers. Navigation supports and services can be helpful in reducing barriers to accessing care through practical guidance and emotional support. The role of navigators and the support they offer will likely differ based on the mission or purpose of the service, availability of resources, and the professional or non-professional identity of the navigator.

Professionals. Supports and services for families of children with neurodisabilities are not immediately obvious, in part due to the complexity of accessing multiple systems of care and due to changing developmental needs. Navigators can tailor their support to families, accompanying them on their journey through care as well as through their family life experiences.

Policymakers. To reduce barriers to care, supports and services for families need to be more easily navigable. Navigators need to be adequately equipped to accompany families on their way finding journey.

Messages clés de cet article

Personnes handicapées, membres de la famille et soignants. Le soutien et les services de navigation peuvent être utiles pour réduire les obstacles dans l'accès aux soins notamment grâce à des conseils pratiques et un soutien émotionnel. Le rôle des navigateurs et le soutien qu'ils offrent sont variables en fonction de la mission ou de l'objectif du service, de la disponibilité des ressources et de l'identité professionnelle ou non du navigateur.

Professionnels. Le soutien et les services offerts aux familles d'enfants atteints de troubles neurodéveloppementaux ne sont pas toujours précis, en partie à cause de la complexité de l'accès à de multiples systèmes de soins et de l'évolution des besoins sur le plan du développement. Les navigateurs peuvent adapter leur soutien aux familles, en les accompagnant dans leur parcours de soins ainsi que dans leurs expériences de vie familiale.

Décideurs politiques. Pour réduire les obstacles aux soins, les soutiens et les services destinés aux familles doivent être plus facilement accessibles. Les navigateurs doivent être outillés de manière adéquate pour accompagner les familles dans leur parcours.

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Contributions

AMF, LL and DN developed the initial conceptual frame for this article. JM and AMF prepared the literature review and the draft for submission with input from LL and DN. All authors contributed to and approved the final version.

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