Family Navigation as a Model of Care: Moving Beyond the Barriers

by

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Approval

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Ethics Statement

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

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or

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Abstract

This capstone explores the disability landscape in British Columbia, Canada through a Fetal Alcohol Spectrum Disorder (FASD) lens mapping out why a Family Navigation model of care could facilitate access to and potential development of needed resources and services for families with children with FASD. A scoping literature review, critical analysis of literature gaps, and secondary data analysis of a quality improvement initiative at a single-site sub-speciality hospital were used to establish promising practises, limitations, and the resultant policy implications for British Columbia. This work was grounded in Critical Disability Theory and the Family Quality of Life theory to stress that within an ableist society we must continue to advocate for collaborative and concrete changes to improve outcomes for families and individuals with FASD throughout the lifespan.

Keywords: Fetal Alcohol Spectrum Disorder; Fetal Alcohol Syndrome; Neurodevelopmental disabilities; Family Navigation; Pediatric Navigation; Health Care Access

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As a settler, I respectfully acknowledge that I live, work, and learn on the unceded Coast Salish Territories of the xʷməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Səl̓ílwətaɬ (Tsleil-Waututh) Nations.

My deepest gratitude to the families who were able to participate. Thank you for allowing me to witness your journeys. Your stories matter.

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Acronyms

CDAS- Complex Diagnostic Assessment Summary

CDBC- Complex Developmental Behavioural Conditions Team

CDT- Critical Disability Theory

CYMH- Child and Youth Mental Health

CYSN Social worker- Children and youth special needs Social Worker

DTC- Disability Tax Credit

FASD- Fetal Alcohol Spectrum Disorder

FQOL- Family Quality of Life Theory

I.D – Intellectual Disability

KNIT- Navigators Improving Transitions

QI- Quality Improvement

RDSP- Registered Disability Savings Plan

Who am I?

My experience working directly with families and children with complex developmental needs was the catalyst to my pursuit of a Master of Public Health (MPH). I was drawn to the MPH program as it has allowed me to remain rooted in my passion for social justice while stepping out of front-line support roles into more macro level public health advocacy work.

Previous to my re-entry into academia I worked as a Fetal Alcohol Spectrum Disorder (FASD) Key Worker and in various other front-line support roles with a focus on children with complex neurodevelopmental disabilities. Children with such needs often require a ‘different’ type of healthcare where hospitals, doctors, and medications are not the crux of their health journey.

Social Positionality

My perspective, research, and analysis comes from a white, cis-gender, queer, able-bodied lens. This is especially important given the context of my work within disability justice. Nevertheless, neurotypical and/or able-bodied individuals should continue to work towards disability justice. Most of my work for the last five years has involved directly advocating for and supporting children with complex developmental disabilities.

Pursuing higher learning is and has been a privilege. My work within the Social Inequities in Health (SIH) stream in the MPH program at SFU has constantly pushed me to be critical and conscious of myself within those spaces. This capstone is a

culminating project that embodies my formative academic and professional experiences leading up to and during my MPH.

Public Health Core Competencies

CC8. Policy and Program Planning, Implementation, and Evaluation

SIH1. Critically assess theories that explain constructions of gender and sex, race and ethnicity, social class, and other markers of social location with attention to their intersections, historical and contemporary contexts, and relationships to health equity.

SIH8. Critically apply evidence to inform policy and practice initiatives aimed at promoting health equity

Context

Sunny Hill Health Centre for Children (SHHC) is a tier 6, sub-speciality hospital that is part of BC Women's and Children's Hospital located in Vancouver, BC under the umbrella of Provincial Health Services Authority (PHSA). The tiers of service framework defines tier 6 as offering in-depth, specialized services, often requiring multiple critical interdependencies (Child Health BC, 2019). PHSA coordinates and evaluates specialized health services across the province to provide equitable and cost-effective healthcare to communities. SHHC serves children from birth to age 19 with sub-speciality, interdisciplinary assessment, diagnosis, consultation, referral, and in select cases, treatment for children with complex disabilities.

The Complex Developmental Behavioural Conditions (CDBC) team at Sunny Hill provides assessments for children (0–19 years) with complex needs and challenges in multiple areas of functioning. The CDBC team was interested in understanding the

experiences of families of children who had been assessed and diagnosed with Fetal Alcohol Spectrum Disorder (FASD); and, in ascertaining the success with which families were able to access and implement recommended resources. This quality improvement project formed part of a larger Western Canada initiative aimed at improving coordination of care for children by implementing navigation services to support families as they move through the province-wide health service system.

Patient Navigators are often implemented to improve patient care coordination, patient education, and patient access to community resources (Luke, Doucet & Azar, 2018). Freeman and Rodriquez (2011) described the use of patient navigators as a strategy to minimize health disparities in breast cancer treatment uptake and outcomes in uninsured, African American populations. Since its creation research has indicated that patient navigation can improve continuity of care and connect families to recommended referrals and appropriate community supports with an emphasis on underserved populations.Patient navigation has since evolved to include supporting caregivers of children with developmentally complex needs.

Overview of Available Services in BC

The chart below highlights how families may access the various resources and service pathways, taken from the BC Government website (Ministry of Children and Family Development, 2019). Each disability listed below has its own webpage on the BC Government website dedicated to explaining available resources and funding. These resources below *do not* encompass all available supports; however, they were listed on the subsequent page after clicking on the hyperlink for each disability and

therefore could be interpreted as the only available services to families without further investigation. Definitions of each resource can be found below Table 2.

Table 2. Resources Highlighted on Gov.BC.ca

Autism Resources at a Glance	FASD Resources at a Glance	Intellectual Disability Resources at a Glance
Hyperlink labelled Contact a local Child/Youth Special Needs Office – through a Child and Youth with Special Needs (CYSN) Social worker you may access funding	Find a Key Worker or parent support in your community	Contact a Local CYSN Office A CYSN Social worker
Autism Funding – <6 years up to 22,000 per child/ year to help pay for eligible autism intervention services and therapies	Under a 'Related Links' headline Children and Youth with Special Needs *May* be eligible for CYSN Social Worker *IF* confirmed intellectual disability	Available resources through CYSN Social workers Respite Services and/ or 'Support Services'
Ages 6-18 families can access up to $6,000 per year per child to help pay for eligible out-of-school autism intervention services and therapies		
Hyperlink labelled Taxes and Savings – Instructions for the Disability Tax Credit and the Registered Disability Savings Plan		

Introduction

The healthcare system is often fragmented and complex leaving many families unsure of how or where to access appropriate services for their children. It has also been documented that even as demands increase for speciality services for children with complex needs, available resources remain stagnant (Masotti et al., 2016; Charlton et al., 2017; Rollins et al., 2018). "Family Navigators" have potential to facilitate efficient connections to services and to improve families' quality of care.

A major mandate of Family Navigation is the focus on families who are at high risk of receiving unequal access to supports and services. Navigation is an attempt to address how social determinants of health may limit access or create barriers to receiving equitable care. Social determinants of health are conditions which individuals are born, grow, and live within and are determined by power and systemic oppression and are inextricably linked to inequitable health access and outcomes. For example,

families with higher income have access to pay for private assessments, bypassing the waitlist for a public assessment. The current published wait times for BC Autism Assessment Network (BCAAN) is approximately 56 weeks (Provincial Health Services Authority, 2019) and the CDBC assessment waitlist, which was not published online, is currently just under one year. Receiving a diagnosis nearly a year before those who cannot afford to pay out of pocket gives higher-income families access to interventions far sooner than for others — precious months in the life of a young child. This inequity could be further compounded by the reality of higher-income families also paying for private intervention services post-diagnosis, bypassing early intervention wait times.

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used to describe a set of characteristics associated with prenatal alcohol exposure leading to life-long developmental, health, and behavioural challenges (Streissguth, Barr, Martin, & Darby, 2014). As an organic brain injury, FASD is a powerful determinant of health, especially as the presentation of ‘symptoms’ may vary greatly and there is no ‘best practice’ for interventions. However, receiving early diagnosis and interventions not only improve health outcomes for children with FASD (Streissguth, 2004 & Streissguth, Barr, Kogan, & Bookstein, 1996), but may also lead to the caregivers accessing much needed services for their own mental and physical health. Yet families of children with FASD encounter unique barriers to care including the negative label of FASD itself. Biological mothers, especially, may feel isolated from the healthcare system (Sanders & Buck, 2010) given the pervasive assumptions about a mother knowingly harming her child. While intervening on child protection issues as they are identified is paramount, it

should be stressed that not all mothers of children with FASD are abusive or neglectful and assumptions of that nature add to the stigma (Sanders & Bucks, 2010).

It is important to acknowledge that while much of the available research focuses heavily on FASD in the Indigenous community, this paper will focus on FASD in the general population — to challenge assumptions and biases regarding FASD diagnoses. Popova, Lange, Chudley, Reynolds, & Rehm (2018) acknowledged this gap in general population-based data and found a prevalence rate of 2-3% among school aged children (7-9) in Toronto, Canada. This newly established estimate is nearly triple the previous estimates (Popova et al., 2018) — and this study included 30% Caucasian children and no (listed) Indigenous children.

Exploring one element in the care system for children with FASD and their families, this capstone examines how a Family Navigator model of care could be used to facilitate access to and potential development of needed resources and services, and the resultant policy implications for British Columbia (BC). A scoping literature review using systematic approaches was conducted, and secondary data were analyzed from a quality improvement initiative of a sub-speciality hospital — to explore Pediatric Navigators as a primary model of care coordination. Two theories are also used to ground this work: the Critical Disability Theory; and the Family Quality of Life (FWOL) theory.

Theories

Critical Disability Theory

Critical Disability Theory (CDT) is not just about ‘understanding’ and ‘empathizing’ with how disabilities affect individuals’ lives but was theorized to also motivate and create action (Hosking, 2015). In this framework disability stems from social, economic, and environmental barriers created by an “ableist” society (Hosking, 2015). Ableism conceptualizes the prejudices and discrimination perpetuated against people with disabilities (Loja, Costa, Hughes, & Menezes, 2013). Ableist societies promote — consciously or unconsciously — the idea that people with disabilities are of less value than people who are neurotypical and able-bodied (Hosking, 2015).

During the late 1800s, those labelled ‘mentally retarded’ were often institutionalized for the entirety of their lives (Pelka, 2012 & Brown ,1984). The expansion of institutionalization has been argued to have been directly related to urban industrialization (Pelka, 2012 & Goodley 2013). Exclusion of individuals with disabilities certainly pre-existed industrialization; however, industrialization created a booming need for ‘fit’ bodies (Goodley, 2013). The conception of being disabled was heavily tied to societies’ ideas of how ‘productive’ someone could be (Goodley, 2013 & Pelka 2012). Not only were people with neurodevelopmental disabilities placed in so-called mental institutions (Brown, 1984) or the criminal justice system (Popova et al. 2011), but also were often understood through a narrative of personal tragedy (Oliver, 1990).

CDT arose when disability activists and scholars broke free from the binary medical model to embrace more social models of disability. The medical model

focussed on “suffering” and “curing”, while the social model is rooted in society being the main contributing factor to “disability.” Barriers such as inaccessible physical spaces, inaccessible forms of communication (braille, sign language), and rigidity in how people should ‘act’ are the main factors contributing to ableism. As the discourse shifted scholars began to discuss the challenges of working within both perspectives — as disabilities do not occur separately from the body, society or social relationships. Furthermore, critical disability theory views disability as more than social, economic and political disadvantage (Meekosha & Shuttleworth, 2009). Rather, critical disability theory involves an intersectional approach where representation and collaboration matters.

Thomas (2007) articulates disability as its own category of social oppression. Children are particularly at risk when they have disabilities given their reliance on others to advocate for their needs (Goodley, Runswick-Cole & Liddiard, 2016). If caregivers are unable to access or provide the care their child needs, it could have immense impact on long term health outcomes. Children with invisible disabilities — that is, disabilities that are not immediately apparent such as FASD, attention-deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD) — can be seen as misbehaving or ‘bad’ by individuals who are not aware of their challenges (Sanders & Buck, 2010). In response, Goodley et al. (2016) examined disability in creative and imaginative ways that normalized differing needs and abilities — suggesting that policies should be implemented to not only promote inclusion but also enact it. One important way to enact change is to ensure access to early intervention services without delay to promote healthy development and growth for children and families. Development for children with complex neurodevelopmental disabilities also should not

be seen as static. Instead, viewed through a critical disability lens, individuals with complex needs are capable of embarking on trajectories that support their continual development, fulfilling their potential as active and engaged members of society.

Family Quality of Life Theory

Quality of life is a multi-dimensional concept encompassing how individuals understand their experiences and determine at what standards they are living (World Health Organization, 2014). Many of the services provided within the disability landscape work within a model of care that stresses individual needs and includes caregivers as a way to support their children in reaching their individualized goals. To challenge that perspective, researchers have begun putting forward the theory of Family Quality of Life (FQOL) (Posten et al., 2003).

The FQOL theory (Poston et al, 2003) seeks to explain how the experience of each family member individually and together culminates in quality of life for all members. Interactions with and between members of a family (with or without a disability), their service providers, and society affect their perceptions of their quality of life.

The FQOL theory is conceptualized within individual and family categories, each with their own separate domains. The authors (Posten et al., 2003) describe the six individual domains as being: Advocacy, Emotional Well-Being, Health, Physical Environment, Productivity, and Social Well-Being. Meanwhile, the four family-level domains are: Daily Family Life, Family Interaction, Financial Well-Being, and Parenting. All ten domains overlap and connect — encapsulating how families determine and understand their ‘Family Quality of Life.’

When trying to develop and extend services for children with complex developmental needs and their families using a family-centred approach, one must see the family as a whole, complex, interconnected unit. FQOL theory helps enable support providers to establish goals to work towards to increasing quality of life not only for the individual with a disability but for the whole family unit together (Posten et al., 2003).

Literature Review

As more children are diagnosed with complex developmental needs (Charlton et al., 2018) more caregivers have expressed the need for support in accessing services and navigating the complex healthcare system. Receiving an early diagnosis and intervention services are protective factors that may improve health outcomes for children with developmental disabilities (Streissguth, 2004; Streissguth, 1996). Pediatric navigators have emerged in response to the needs for this population with a focus on families who may be at a disadvantage from a social determinants of health perspective. Navigators could play a crucial role in connecting caregivers with resources that they are eligible for to ensure that interventions began earlier.

This review uses systematic review methodology (Higgins, J. P., & Green, S. (2017) to focus on available literature on navigation services for families of children with complex developmental and behavioural conditions. Four major databases were searched, relevant literature was compiled, and critically appraised, and major themes were identified

Search Methodology

The databases Google Scholar, PubMed, CINAHL and PsycINFO were searched for literature published from 2013 through 2019. Given the broad terminology used in healthcare settings describing navigation-like duties — including care coordination, lay health professional, key worker, or health coach — preliminary searches were done using these terms. These searches uncovered considerable information that was ‘adjacent’ to navigation. For this reason, key terms for subsequent searches included variations using only ‘navigator’ or ‘navigation.’

The full key word search terms included: “Patient Navigator” OR “Patient Navigation” OR “Pediatric Navigator” OR “Pediatric Navigation” OR “Paediatric Patient Navigator” OR “Paediatric Patient Navigation” OR “Family Navigator” OR “Family Navigation” AND Neurodevelopmental Disorder OR Autism OR ASD OR Autism Spectrum Disorder OR FAS OR FASD OR disabilit*. A full scoping review chart and a Selection criteria Flow Chart can be located in Appendix A and B, respectively.

Limitations of current available research include single-site study locations (n=7) and single diagnosis studies, specifically ASD (n=7) which can lead to low generalizability. There were also two ‘key transition’ times identified in the literature on the implementation of navigation, namely, studies (n=3) focused on diagnostic wait times and studies (n=6) focused on post-diagnosis connections to community resources, making generalizability difficult.

One hundred and six original studies were identified in the search and 78 were excluded for being grey literature, “navigation adjacent,” navigation for adult populations, or navigation for a medical condition leaving 28 full text articles to be

critically appraised for relevance. From the 28 full text articles 12 were included in this review

Table 1. Family/Pediatric Navigation Studies

Reference	Study Design	Diagnoses Specified	Location of Study
Broder-Fingert, S., et al. (2018) USA	Hybrid type I randomized effectiveness -implementation trial Study Protocol	ASD	3 Urban Primary Care Clinics- in three US states
Broder-Fingert, S., et al (2018) USA	Mixed Methods Process Evaluation	ASD	Set within the RCT (Above) by Broder-Fingert, et al (2018)
Charlton et al. (2018) Canada	Environmental Scan Qualitative Study	ASD	Snow Ball Sampling- Large rural population
Conroy, K., et al (2018) USA	Quality Improvement	Non-specific	Single Site- Urban Primary Care Hospital
Feinberg, E., et al (2016) USA	Randomized Pilot Trial	ASD	Single Site- Developmental and Behavioral Pediatrics specialty clinic in an urban hospital
Fishman et al., (2016) Canada	Evaluation Data Collection Tool Validation	Mental health - A single Navigation program located	Single Site- Navigation Program- within an academic health science centre
Guevara, J. P., et al. (2016) USA	Pilot intervention	Majority referred as a result of “failure to attain developmental milestones for a given age (92%) and/or failure on a developmental screening test (80%).	Single Site- Urban pediatric clinic
Koushik et al (2015) USA	Program development abnd Retrospective electronic health records	ASD	Single Site - large, public academic health care system
Luke et al., (2018) Canada	Environmental Scan	“Children and youth with complex health care needs”	Cross-Canada
Magana et al (2013) USA	Cross-sectional study	ASD	State wide recruitment through service provides/ agencies supporting families with children with ASD
Markoulakis (2016) Canada	Program development	Mental health diagnoses	Single Site- Academic Health Science Centre
Roth, B. M., et al. (2016) USA	Randomized Control Trial	ASD	Single Site- Multidisciplinary clinic

Moving away from Medicalization

Patient navigation began within hospital settings primarily for oncology patients in the United States. Given the success that patient navigation has had for health outcomes in cancer care (Robinson-White et al., 2010) it has begun to be adapted to provide support for families of children with various complex health care needs, including developmental disabilities. This new adaptation, appropriately coined Family Navigation (Feinburg et al. 2016; Broder-Fingert et al., 2018 & Markoulakis, 2016), is moving away from the individualization of “patient navigation” — towards more family-centred language. Patient navigation largely existed within hospital settings and healthcare systems, while Family Navigation involves a multitude of systems. Caring for a child with complex developmental needs encompasses all caregivers, professionals, and support persons who are involved and the shift in language reflects that. Language is an important factor in family’s engagement and experience with their child’s care team and for many children with complex needs, their ‘team’ exists largely outside the scope of typical primary healthcare.

Families Steering their Care Needs

A major component contributing to the success of any new intervention is the target population’s desire and utilization of that specific program. The complexity of the healthcare system often necessitates the need for navigators and the desire for navigation was therefore resounding (Markoulakis, 2016; 2015; Feinburg et al., 2016; Guevara et al., 2016; Charlton et al., 2017). Furthermore, a family’s ability to ‘steer’ their own care is complex. Having family resources including time, finances, and strong advocacy ‘power’ often affect levels of care (Markoulakis, 2016; Charlton et al., 2017).

Families with multiple experiences of adversity or oppression were found to have delayed identification of autism, more unmet care needs, and lower levels of utilization of available services (Magana et al., 2016). Furthermore, families who were typically viewed as more ‘marginalized’ were found to label navigation services as more ‘useful’ (Roth et al., 2016) or ‘excellent’ (Koushik et al., 2015).

Several studies (Roth et al., 2016; Feinburg et al., 2016 & Guevara et al., 2016; Markoulakis, 2016) found engagement with Family Navigation to be high overall; however, Guevara (2016) and Roth (2016) specifically found higher levels of engagement amongst families with more cumulative disadvantage. Families with access to a Family Navigator were also more successful with scheduling and completing appointments and diagnostic assessments (Feinburg et al., 2018 & Roth et al., 2016). Perhaps families with access to Navigators felt more empowered to advocate and involved in directing their child’s care.

The Family Navigation model may improve overall family satisfaction (Markoulakis, 2016 & Koushik et al., 2015). Yet data on long-term child health outcome measures were not available. While satisfaction with navigation support was evident, new programming and attendant evaluations need to focus on more than satisfaction (Markoulakis, 2016).

Traversing Fidelity

The objectives of each program include navigating families through complex systems; however, there were variations amongst their mandates, eligibility, and required navigator qualifications. Navigation has been implemented with professionals

with varying educational backgrounds and experience including nurses, social workers, lay health workers, or peers with “lived experience” (Luke et al, 2018). The role of navigator often depended upon the milieu in which the program existed. Some studies focused on improving assessment and diagnostic wait times for children with ASD (Feinberg et al., 2016; Koushik et al., 2015; Magana et al., 2013) while others focused on post-diagnosis connections to early intervention programs (Broder-Fingert et al., 2018; Guevera et al., 2016; Roth et al., 2016; Markoulakis et al., 2016; Koushik et al., 2015 & Magana et al, 2013). Regardless, fidelity and scope of practise were common concerns throughout the literature (Guevara et al. 2016; Broder-Fingert et al 2018).

Family Navigators must deliver a certain standard of care to ensure that families do not ‘fall through the cracks’ (Charlton, et al., 2017). Broder-Fingert et al., (2018) engaged professionals in the developmental disability landscape to investigate how fidelity to such standards for navigators as a profession could be improved. Major concerns included insufficient monitoring, inadequate training, and difficulties engaging families. Strategies to address these concerns included mandatory refresher training annually, supervised navigation interactions (Broder-Fingert et al., 2018), and fidelity checklists (Guevara et al., 2016).

Overall, however, there was a lack of standardization across navigation programs (Luke et al., 2018) including variations in scope of practise, diagnosis eligibility and administration of intervention times. The lack of standardization and fidelity has made documenting potential successes difficult.

Hitting Road Blocks

Even once navigation services are implemented there are still challenges in acquiring appropriate services for families. The rationale behind navigation services has been for early intervention to mitigate unnecessary delays in receiving needed supports. One of the first challenges has been described as getting referred for an ASD assessment by a primary care physician (Magana et al., 2013). Caregivers described voicing concerns to their primary care physician and being met with resistance in receiving a referral for an ASD assessment (Magana et al., 2013). Once families did receive an ASD diagnosis they were tasked with the reality of navigating onto waitlists for scarce resources (Brodger-Fingert et al., 2018). In eastern Canada, families then found themselves in need of services that were 'non-existent' either because of eligibility mandates or geographic location (Charlton et al., 2017). Families also identified that mental health service providers saw their child's developmental delay and their mental health needs as 'two separate issues' (Charlton et al., 2017). Furthermore, communications across professions and programs were identified as added barriers to continuity of care (Brodger-Fingert et al., 2018 & Koushik et al., 2015).

Even with the implementation of a Family Navigator some of these road blocks may still exist unless the scope of practise includes advocacy. 'Non existent' services, waitlists for resources, and poor communication between professionals will continue to limit families' access to the most effective early intervention services. When implementing a Family Navigator program, agencies must consider embedding the navigator in a way that can reduce these types of barriers as well.

Conclusion

Major themes within the literature include: a paradigm shift away from patient navigation services to a more family-centred navigation approach; high demand from families for navigators; challenges with fidelity and accountability to families; scarce or non-existent resources to navigate to; and minimal available research on long term outcomes and demonstrated cost effectiveness.

Overall, the available literature shows that navigation has decreased time to diagnosis, and has increased access to services post-diagnosis, overall satisfaction, and high-level engagement specifically for families with cumulative disadvantage. Navigation is an emerging model of care within the complex developmental disability landscape. The literature remains minimal regarding the efficacy of these services and is heavily focused on children with ASD. Generalizability may also be limited as many studies were localized within one clinical setting. However, given findings were similar across all studies and echoed themes found in the single-site evaluation perhaps this combination of multisite research is generalizable to these specialized populations. Further research is needed on long-term heath outcomes and cost effectiveness of navigation in different clinical and community settings. There is also merit in moving research towards other complex developmental disabilities other than ASD.

Critical Analysis of Silence

The scoping review highlighted that the focus on navigation services was mainly on families of children with ASD. However, other neurodevelopmental disabilities are equally important and worthy of research. Most prevalence rates for FASD are focused

on specific populations, notably Indigenous children or children in foster care or in the care of the child welfare system (Lange et al, 2013). Recently, Popova et al. (2018) established an FASD population-based prevalence rate of approximately 2-3% among school-aged children (7-9 years) in Toronto, Canada. Prevalence rates of FASD are difficult to establish given the stigma attached to the diagnosis; therefore, many prevalence rates, including Popova et al., (2018) may be an underestimation.

Like many disabilities, FASD is invisible, meaning that it is not inherently obvious that an individual has neurodevelopmental challenges. Children with FASD often develop secondary challenges as well, including mental health problems, disrupted school experiences, and trouble with the law (Streissguth et al., 1996). Children with FASD can also be perceived as neurotypical — which can create a tension between their disabilities and societal labelling of their behaviour as “bad.” Early diagnosis, early interventions and connections to social services are imperative protective factors (Streissguth et al., 1996), highlighting the importance of health initiatives geared towards families and children with FASD.

Autism has clear-cut funding available, up to as much as $22,000 a year per child (under 6 years old) in provinces such as BC. There is a history of advocacy in Canada, with families of children with ASD demanding (and obtaining) more supports and funding from governments (Shepherd & Waddell, 2015). But we must examine why these families were able to do that and with (relative) success. What makes these families inherently different from those supporting children with FASD?

Present discourse discusses the inherent preventability of FASD; however, 50% of pregnancies are unplanned (“Prevention of FASD”, 2019) and alcohol exposure prior

to pregnancy recognition may occur. The etiology of FASD being linked to prenatal alcohol exposure, seen by many as a choice, establishes the idea of “fault” that hinders research, funding, and level of support made available to children with FASD. This discourse also perpetuates the idea of who is ‘at risk’ of having children with FASD, which fails to challenge the stigmatization and oversurveillance of certain women, particularly Indigenous mothers (Hunting, 2012).

FASD prevention initiatives are very important to the overall health of women and fetuses; however, the ongoing public health campaigns on how to be (future) mothers in Canada has added to the marginalization of specific populations (Salmon, 2011). The history of FASD research has also constructed a landscape of shame and stigma attached to women and their bodies. The optics of ‘bad mothering’ (Salmon, 2011) and the ‘bad’ child with undiagnosed FASD makes advocating for equitable funding and available resources a seemingly impossible task. A diagnosis of FASD is a diagnosis for two. This is not to pit one group against another but to highlight that this inequity is real, and a child’s level of support should not be linked to ideas of morality (Salmon, 2011). Public blame and stigma also reinforce the narrative that certain families are less deserving of support and funding. Yet one of the most important protective factors is the availability of early interventions for children with FASD (Streissguth et al., 1996). Available resources and funding are sparse for FASD and Family Navigators could make the difference between a family getting connected or going without services.

Current estimates are that approximately 10% of children in protective care may have FASD, established from a tri-provincial Canadian study (Fuchs, D., & Burnside, L., 2014). Like any estimation of FASD prevalence, it should be cautioned as an

underestimation as Chasnoff et al., (2014) found a missed diagnosis rate of 80% among foster and adoptive children who were majority African American (50%), or white (32%) in a single site study in the United States. In a qualitative study aiming to understand the experience of both biological and adoptive families with children with FASD, Sanders and Buck (2010) described receiving a diagnosis of FASD as a ‘double edged sword.’ Adoptive families expressed feeling guilty over misunderstanding their child’s behaviours, while biological families felt immense guilt for ‘causing’ their child’s disability. In addition, Sanders and Buck (2010) highlighted the polarizing feelings adoptive families had towards biological mothers. Some expressed deep anger towards their child’s biological mother for ‘ruining their child’s life,’ while other adoptive parents acknowledged that biological mothers did not purposely harm their children (Sanders and Buck, 2010).

Available Grey Literature

Grey literature was identified during the scoping literature review (Masotti et al., 2015) and analyzed in combination with stakeholder feedback at Sunny Hill Health Centre for Children. A working list of services providing ‘navigation-like’ services can be found in Appendix C

The only available grey literature identified that discussed Family Navigation and FASD specifically was a report on a symposium held in Winnipeg, Manitoba (Masotti et al., 2015). The symposium involved input from 60 experts from various different stakeholder groups involved in FASD service provision. Results of the meeting were collected, analysed, and disseminated to create a blueprint of what the future supports for people with FASD could look like. Following the symposium, Masotti et al., (2015)

identified five steps in the implementation of Family Navigation for people with FASD: 1) “setting up community-based services”; 2) “attending intake and/or testing appointment with the family”; 3) “initial meeting with family”; 4) “initial navigator training”; and 5) “navigator fidelity monitoring and refresher training.” This symposium (Masotti et al., 2015) echoes the findings from the scoping review that highlight key challenges with standards of care and scope of practise (Broder-Fingert et al., 2018 & Guevera et al., 2016).

Listening to Families: 2018 Evaluation Report

Purpose and Goals of Evaluation

An outcome/impact evaluation was conducted to follow up with families who had been assessed at Sunny Hill Health Centre for Children (SHHC). During the family conference members of the diagnostic team provided a Complex Diagnostic Assessment Summary (CDAS) report to the family outlining their child’s clinical profile and recommending resources and services they could access. The clinical population of interest for this evaluation was families who had received an FASD diagnosis without an intellectual disability (ID) at SHHC between March 2017 and April 2018. For the purposes of this capstone only the evaluation material critical to the implementation of Family Navigators will be discussed. Relevant goals of the evaluation regarding the implementation of navigation services were to:

- Determine the success with which families were able to implement and connect with resources and services provided by the Complex Developmental Behaviour Conditions (CDBC) teams; and

- Learn about barriers and facilitators in order to work towards improving access to services

Methods and Data Collection

Ethics approval for secondary data analysis was obtained for this quality improvement project to be integrated in this capstone project. The evaluation was a cross-sectional mixed method design and data were collected via semi-structured one-on-one telephone interviews (n=15). For inclusion criteria, participants had to be legal guardians of children who had been assessed and diagnosed through SHHC from March 2017 to April 2018 with FASD and without an intellectual disability (n=56). The key informants were legal guardians: biological parents (n=5), adoptive parents (n=7), and social workers (n=3), of children assessed by the CDBC team. From the sampling frame 15 participants were randomly selected using the random function in Excel. The list of interview questions can be found in Appendix D. Inductive analysis was undertaken during data collection to refine questions iteratively, as the evaluator noticed repetitive codes and themes.

Data Analysis

Thematic analysis (Thorne, 2000) was used to identify and critically analyze narratives for each caregiver. Quantitative data were also extracted from the interviews in the form of the proportion of recommendations families were able to implement based on their CDAS. Quantitative data collection was coupled with the qualitative to enhance understanding of the family experience.

Limitations

Families were randomly selected to participate; however, after two unanswered voicemails requesting their participation or after a verbal refusal, another participant was randomly selected from the sampling frame. For this reason, selection bias is a factor to consider when interpreting the results and the generalizability of the findings. Given the small sample size, findings could only be summarized using qualitative analyses and descriptive statistics; given the cross-sectional design, causal inferences could not be made. There also could be many confounding variables that affect how well families connected with the services and resources recommended to them, which cannot be fully accounted for here.

Results

Descriptive statistics were used to describe families' connectedness to local resources, based on recommendations made by SHHC.

Proportion of Services Families were Connected To

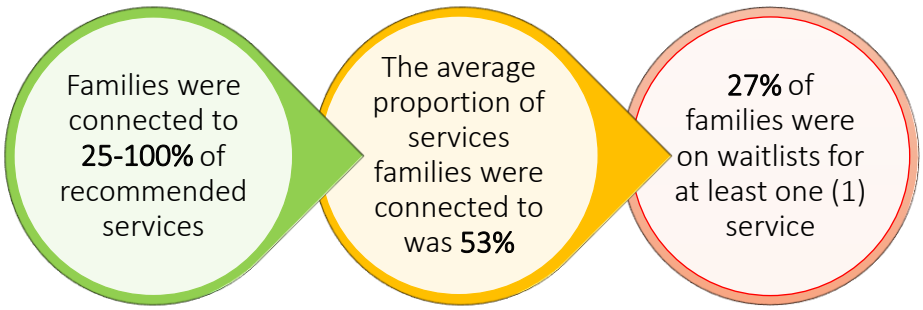
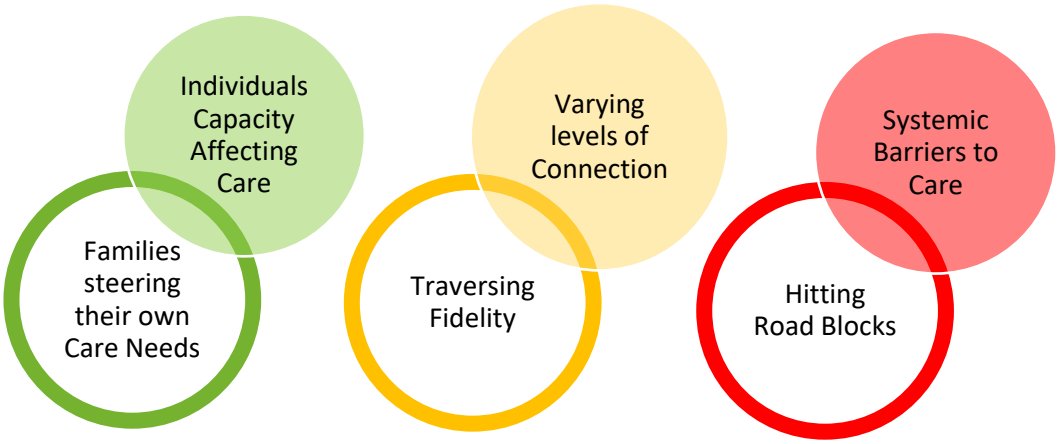


Figure 1. Descriptive Statistics from quantitative analysis
** Recommendations were coded as implemented if they were on a waitlist since the initial connection had been made*

Themes Across the Evaluation and Literature

Qualitative analysis of the evaluation data yielded three major themes regarding barriers and facilitators in connecting to recommended services. The major themes included: Varying Levels of Connection, Systemic Barriers to Receiving Care, and Individual Capacities Effecting Care. The Figure below represents the themes found in both the scoping review and the evaluation data. A fully comprehensive chart of how themes in the evaluation were interpreted is provided in Appendix E.

Fig. 2 Themes Across the Literature and Evaluation



**Circles filled in with colour or those from the evaluation and themes outlined are those from the Scoping review*

Available Literature		Evaluation		Quotes from Evaluation	Divergence
Themes	Sub-Themes	Themes	Sub-Themes		
Families steering their own care needs	Advocacy Family Resources (Time and Money) Utilization / Desirability	Individual capacities affecting care	Advocacy Family Resources (Time and Money) Feelings and Perceptions	*"If things get complicated, I'd have to have the CDAS stapled to my butt!" – adoptive parent* *"I'm kind of a one woman show!" -adoptive parent* *"Because we were financially sound it's definitely more helpful because I don't need to go to work. I can be around versus parents working. It would be much more difficult."* *"I'm lucky I don't have to work and we're fairly high functioning. But I can see someone having to work full time or not have the resource mental or external to follow through on those referrals."* *"I did not want her to be sick with FAS."* *"I don't want her labelled."*	Evaluation: While the scoping review discussed families feeling overwhelmed post ASD diagnosis it was not an overarching theme in the evaluation. Rather the evaluation highlighted overwhelming feelings of guilt and shame specific to FASD for biological families
Traversing fidelity	Standardization Accountability Standards of care	Varying levels of connection	*Being Connected* *Being Connected, but…* *Feelings of Disconnection*	*"They just 'get him'. It's his comfort place (class room). The teacher is pretty amazing." – on their relationship with the current teacher* *"Umm… I'm not sure…. she's a very nice person and she did go do some stuff in the classroom, but I don't know... it's yet to be determined." – on a relationship with a key worker* *"…They called 911. That wasn't part of the safety plan… they kind of lost him at that point."—on relationship with their school workers*	Literature: Heavily focused on making connections to services post-diagnosis Evaluation: Findings showed that even a connection to services does not guarantee a strong connection with your subsequent worker or all families getting an equal standard of care
Hitting road blocks	Keeping up with demand Waitlists Navigating to services that do not exist Geographic location	Systemic barriers to receiving care	Keeping up with demand Waitlists Navigating to services that do not exist Geographic location	*"It doesn't take much effort to take a phone call or send a standard letter letting you know we've reviewed your file and that there is a long wait and we'll get back to you."* *"As of November 6, 2017 he was on a two year waitlist."* *"the (specific diagnosis) …. won't get funding which means we may have to hold her back another year…school is saying they can't meet her challenges."* *"We don't have a psychiatrist... She comes to town once every month or two months. When she comes she's fully booked. I think that's just the nature of where we live."*	

Discussion

The smaller program quality improvement project forms part of a larger Western Canada initiative, called Navigators Improving Transitions, aimed at improving coordination of care and services for children and families. In isolation, generalizability of this single-site evaluation can be a limitation; however, the results of this evaluation echo the extant literature. Navigation of the developmental disability landscape seems to be a pervasive challenge affecting most families with a child with complex developmental or healthcare needs. However, families marginalized by a diagnosis of FASD may experience challenges more frequently (and intensely) both pre and post-diagnosis, given the assumptions around personal choice and blame.

Family Navigators could ease frustrations over the self-referral process; however, that still left families susceptible to other systemic barriers. Following connection to community services, families still needed to build a strong rapport with at least one support professional. Families who expressed feeling fully supported tended to have one strong connection to a single professional who just “got it” and seemed to take on multiple roles. The challenge in cultivating a ‘go to’ person stems from the much larger systemic barriers to care that most organizations face including available resources, time, money, and large caseloads. Could a family navigation alleviate these concerns or just add another piece to the complex puzzle? Support services and funding differ across diagnoses and the need to focus specifically on FASD remains an important venture.

In BC, families with a child diagnosed with ASD can access up to $22,000 a year per child (with ASD) up to age 6, and $6000 each year after until age 18 (Ministry of Child and Development, 2019). But FASD is not recognized as requiring any additional financial support. Furthermore, children with ASD are given a ‘G’ designation at school, in BC, ensuring guaranteed supplemental funding for their additional educational needs. FASD again is not recognized as its own specific category for this form of supplementary financial support (Millar et al., 2017 & Popova et al., 2018) — although as per the BC Special Education Policy Manual: ‘in some cases, students diagnosed through the Complex Developmental Behavioural Conditions (CDBC) Network as children and youth with complex needs may be included in this category’ ("Special education services: a manual of policies, procedures and guidelines", 2016). Yet neurodevelopmental disability equity funding and support should be streamlined towards a needs-based model instead of the current diagnostic-based model.

Challenges and Tensions

Several areas of tensions have been identified in the developmental of a Family Navigation program. One major tension has been the expressed as the need for system change as an outcome — rather than just focusing on family experience in the system. This higher-level system change is an important goal and navigators can be utilized as a means to that end while simultaneously improving family experience.

The tension of systems-level change is illuminated further by the larger systems of care and the need to build relationships across different systems. Navigators can

work towards creating linkages across resources so transitions may go more smoothly for families, including into and within the education sector.

Last, there are tensions between the use of quality improvement initiatives instead of randomized control trials. This capstone brings together both and highlights that it does not need to be either/or. These two methods can be used in tandem to assess the needs of families.

Proposed Structure of a Family Navigation Model of Care

Similar to many navigation models within the available studies, Family Navigators could be most effective located within the regional CDBC diagnostic and assessment hospitals. This would eliminate the family having to make ‘another connection’ post diagnosis and allow navigators to build rapport with families during their assessment journey. This would also minimize families needing to divulge their experiences repeatedly. This would also allow the social workers with the CDBC team — whose mandate is to provide assessment, but who end up providing navigation — to scale back their administrative navigation duties and focus on providing assessment support.

Tri-ministry funding via the BC Ministry of Health, Ministry of Child and Family Development, and Ministry of Education would increase cross-ministry communication and allow for stronger advocacy ability in the absence of one Ministry being solely responsible for navigators. There could nevertheless be one independent body — such as the Provincial Health Services Authority — providing surveillance and holding overall responsibility of the Family Navigation program.

Policy Implications

The studies reviewed highlight an emerging area of need in early intervention policy development. Navigation services for families with children with neurodevelopmental disabilities are being piloted as a novel approach to family support. The extant research is also consistent in showing that implementing social and health policy changes to support navigation services may reduce health disparities among children with FASD and their families.

Policy implication 1: Family Navigation should focus on specific populations where research has demonstrated its usefulness and where efforts will be directed towards those most in 'need' of assistance, particularly families living with lower income. A family's eligibility would be established during their psycho-social assessment at the CDBC assessment with a Social Worker.

Policy Implication 2: A Family Navigation scope of practice should include ongoing evaluation and surveillance in order to establish efficacy in "real world" situations in the BC context. This includes tracking referrals, waitlists times, service utilization post-referral, barriers to access, and child outcomes.

Policy Implication 3: Establish a 'best practise' Family Navigation intervention with a fidelity protocol, including annual refresher

training, and ongoing supervision. The ongoing evaluation Policy Implication 2 would allow for documentation of this process.

Family Navigation could also establish efficient and efficacious ‘routes’ for families struggling to access available services. Families who faced cumulative disadvantage often rated Navigation as more helpful and had higher levels of engagement — and for this reason, the first policy implication focuses on families who have higher risk of having unmet needs.

Having high-level knowledge of available resources and managing the logistics of making appropriate referrals are both crucial. However, the literature still identifies large case loads, ‘non existent’ services, and organizations ‘keeping up with demand’ as barriers to early interventions that are often described as out of a Navigator’s scope of practise. For this reason, policy implication 2 was suggested so Family Navigators could be used to facilitate incremental changes regarding systemic barriers through tracking referrals, evaluating resource availability, and monitoring waitlist times to ensure families most in need were receiving early interventions in a timely manner. Ideally, the Family Navigators would be monitored by a governing body, such as Provincial Health Services Authority, that has the ability to independently advocate for improvements in service access and allocation based on the established evaluation and surveillance data — and the ability to advocate for augmented services where there are shortfalls.

Last, policy implication 3 is crucial given that “best practices” have yet to be established for Family Navigation. To ensure accountability across professionals and to

develop a standard of care, many researchers advocate establishing fidelity checklists, annual refresher training, supervised family interactions, and/or follow up senior management to ensure families' needs are being met. Establishing these processes would ensure that children and families received more consistent care regardless of the navigator assigned to them.

Research Implications

Several studies included measures on time from referral to diagnosis and parent satisfaction with navigation services. But the need to establish outcome measures beyond this is paramount to ensure that children actually benefit from the intervention. Future research on Family Navigation should also include assessment of longer-term child and family health outcomes as these data were lacking in the existing literature.

> *Research Implication 1: A randomized controlled trial is needed: establishing child and family health outcomes; tracking long-term outcomes; and assessing cost-effectiveness of Family Navigation in BC.*

Conclusion

To provide the highest-quality navigation service, fidelity, evaluation and accountability are imperative. Including a strong focus on evaluation may also contribute insights into service utilization, future program delivery models, funding needs, and long-term impacts.

Researchers have cautioned against viewing Family Navigation as a solution in isolation separate from the challenges of the larger healthcare system. Without looking at the bigger picture we may continue to miss opportunities for improvement and provide inadequate services to families. However, given the high demand for Family Navigation, particularly with families who are more disadvantaged, this service should be implemented based on the information we currently have. Families are also asking for Family Navigation. So, implementing and evaluating this intervention can be a way for policymakers, above all, to ‘listen to families.’

As it stands, children with FASD and their families continue to live and move through a world that minimizes and stigmatizes their existence. The healthcare, education and social services systems must move towards ‘creating capabilities’ (Nussbaum, 2011) for these children and their families. Creating capabilities in essence means providing the tools that children need to flourish — while also empowering families to support their children on their health journeys. The current complexities of our healthcare system hinder access to early intervention services that are crucial in creating these capabilities. Knowing how crucial early interventions are to children with FASD (Streissguth, 2004), we must do everything possible to increase access — starting with Family Navigation.

Appendix A –Scoping Review Table

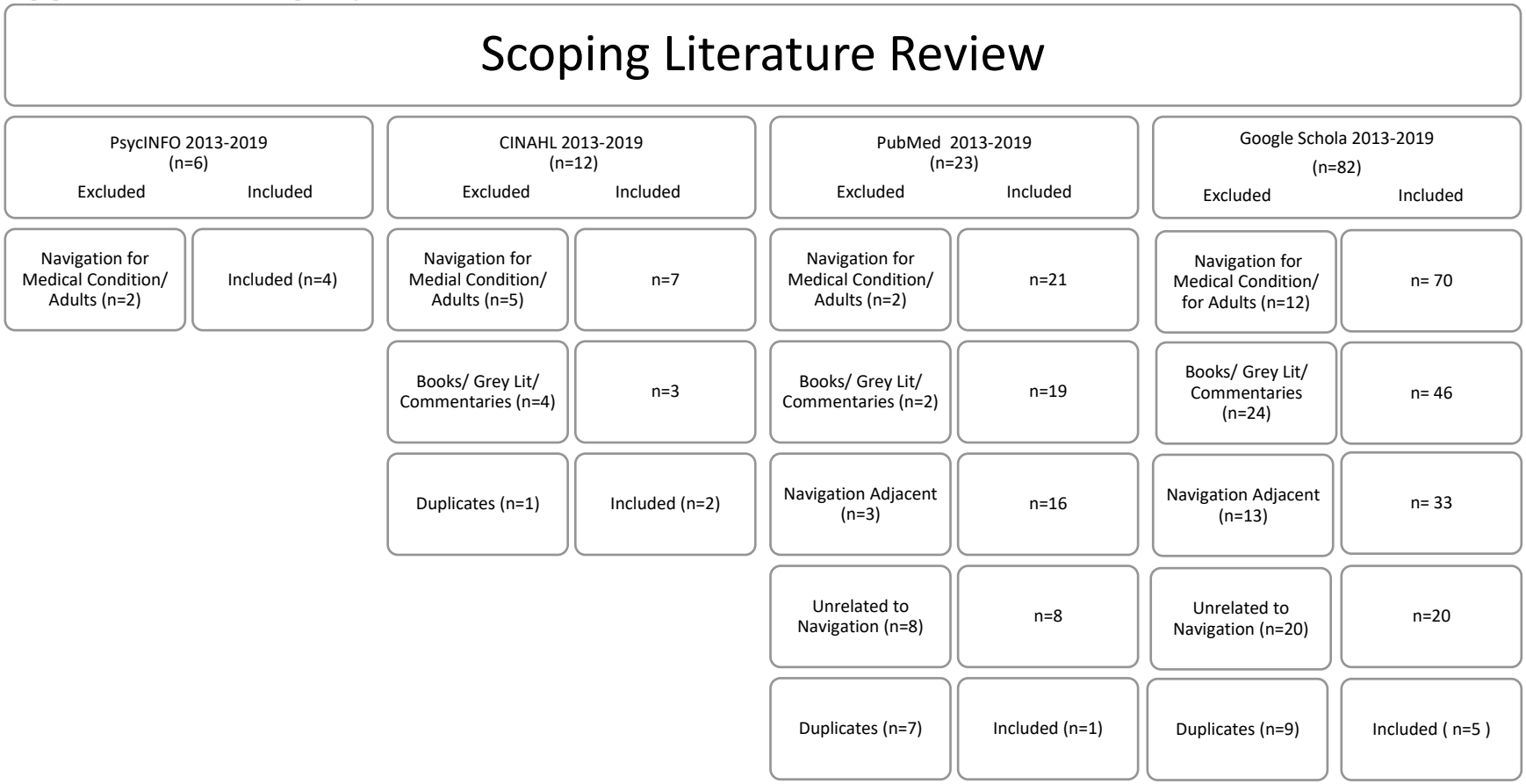
Table 1. Family/Pediatric Navigation Studies

Reference	Study Design	Data Collection/ Outcomes	Study Objectives	Diagnoses Specified / Location of Services	Themes
Broder-Fingert, S., et al. (2018) USA	Hybrid type I randomized effectiveness - implementation trial Study Protocol	Test the effectiveness of a pediatric navigation service for children with Autism	Parent reported measures- 3 times throughout the study. Primary surveys from navigators and clinic data - diagnostic interval and time to receipt of evidence-based ASD/recommended services	ASD - 3 Urban Primary Care Clinics- in three US states	No long-term health outcomes, however, do include outcome on engagement post-referral Navigator fidelity- at the completion of the navigator protocol. Defined as: 1) completion of the 3 home visits; 2) completion of Navigator log; and 3) adherence to motivational interviewing done by the navigators
Broder-Fingert, S., et al (2018) USA	Mixed Methods Process Evaluation	To identify potential failures in implementing Family Navigators	Semi structured interviews	ASD Set within the RCT by Broder-Fingert, et al (2018)	Areas of potential "high priority" failures in implementation: (1) setting up community-based services, (2) initial family meeting, (3) training, (4) fidelity monitoring, and (5) attending testing appointments
Charlton et al. (2018) Canada	Environmental Scan Qualitative Study	To identify available services and barriers to accessing services and to inform policy and practice to improve services for families of Children with Complex Health Conditions	Semi-structured interviews	ASD Large rural population	Barriers: Service availability, Organizational, Financial More training, and adequate program resources are needed to meet the growing need Improve family experience, long term health outcomes, and reduce costs
Conroy, K., et al (2018) USA	Quality Improvement	To have 70% of patients referred to EI were evaluated within 120 days of referral.	Clinic Data	Any diagnosis - Urban Primary Care Hospital	Rates of connection to EI improved substantially when referrals were centralized in the clinic and patient navigators were responsible for tracking referral outcomes, and interprofessional communication
Feinberg, E., et al (2016) USA	Randomized Pilot Trial	Examined the feasibility of using Family Navigation (FN), to improve timely diagnosis of ASD in low-income families from racial-ethnic minority groups	Children/parent dyads were randomly allocated to receive FN or usual care. The primary outcome was time to diagnostic resolution	ASD - a single Developmental and Behavioral Pediatrics specialty clinic in an urban hospital	20 FN children completed the diagnostic assessment, compared with 11 of 19 children receiving usual care High engagement, 17 of 20 families (85%) met with the navigator for the targeted three in-person visits
Fishman et al., (2016) Canada	Evaluation Data Collection Tool Validation	evaluated satisfaction with a navigation service	40 clients of a mental health and addictions navigation service for families completed the Navigation	Mental health - A single Navigation program located within an academic health science centre	The NAVSAT is a first of its kind mental health navigation service satisfaction scale. NAVSAT was used to evaluate client satisfaction through information accessibility, professional competency, and treatment appropriateness.

			Satisfaction Tool		
Guevara, J. P., et al. (2016) USA	Pilot intervention	To determine feasibility and outcomes of a patient navigation program on EI referrals among a diverse group of at-risk children	The main feasibility measure was the proportion of eligible families that enrolled and utilized the patient navigator.	Majority referred as a result of "failure to attain developmental milestones for a given age (92%) and/or failure on a developmental screening test (80%).- Urban pediatric clinic	87% of eligible families enrolled and participated in the program- high engagement and feasibility—particularly amongst 'high risk' families.
Koushik et al (2015) USA	Program development Retrospective health records for comparison	To create an interprofessional care model for the assessment and diagnosis of ASDs for children 24 – 48 months of age with low socioeconomic resources	Clinical registry for tracking eight-item parent satisfaction questionnaire	ASD - large, public academic health care system	Navigation needs are too high for social workers. Procurement of a patient navigator is essential at the onset of such a clinic.
Luke et al., (2018) Canada	Environmental Scan	To provide other organizations with information regarding setting up navigation programs and to fnform the implementation of a navigation care centre in Eastern Canada	Literature review Interviews	Children and youth with complex health care needs- Cross-Canada	Programs varied greatly by navigator role, method of delivery, patient/condition, location of services etc. Lack of standardization
Magana et al (2013) USA	Cross-sectional study	Explored disparities in age of diagnosis and service utilization among Latino children compared to non-Latino	Questionnaire on : age of concern/ report/ diagnosis; provider response; public services; knowledge about autism; services used and unmet needs; child and maternal characteristics	ASD	White families had more flexible resources than Latino families, which may have led to a greater ability to navigate the autism service system and thus take advantage of more services When accounting for differences in education levels and sources of knowledge about autism, the significant difference between White and Latino children was eliminated in the number of services received. This finding supports that social factors, such as socioeconomic status and race and ethnicity, are the main causes of disparities in health services and outcomes.
Markoulakis (2016) Canada	Program development			Mental health – single site academic health science centre	
Roth, B. M., et al. (2016)	Randomized Control Trial	To determine whether access to a Patient Navigator for children	"Usefulness of Evaluation" questionnaire	ASD – Single Site- Multidisciplinary clinic	Parents of children with Medicaid found the assessment "very useful" compared with non-Medicaid group.

USA	diagnosed at < 48 months would be lead to more appointments with needed services	“Services” questionnaire	The groups with immediate access to an APN were more successful with scheduling and completing appointments.

Appendix B –Scoping Review Selection Criteria Flow Chart



Appendix C- 'Navigation-like' services in British Columbia

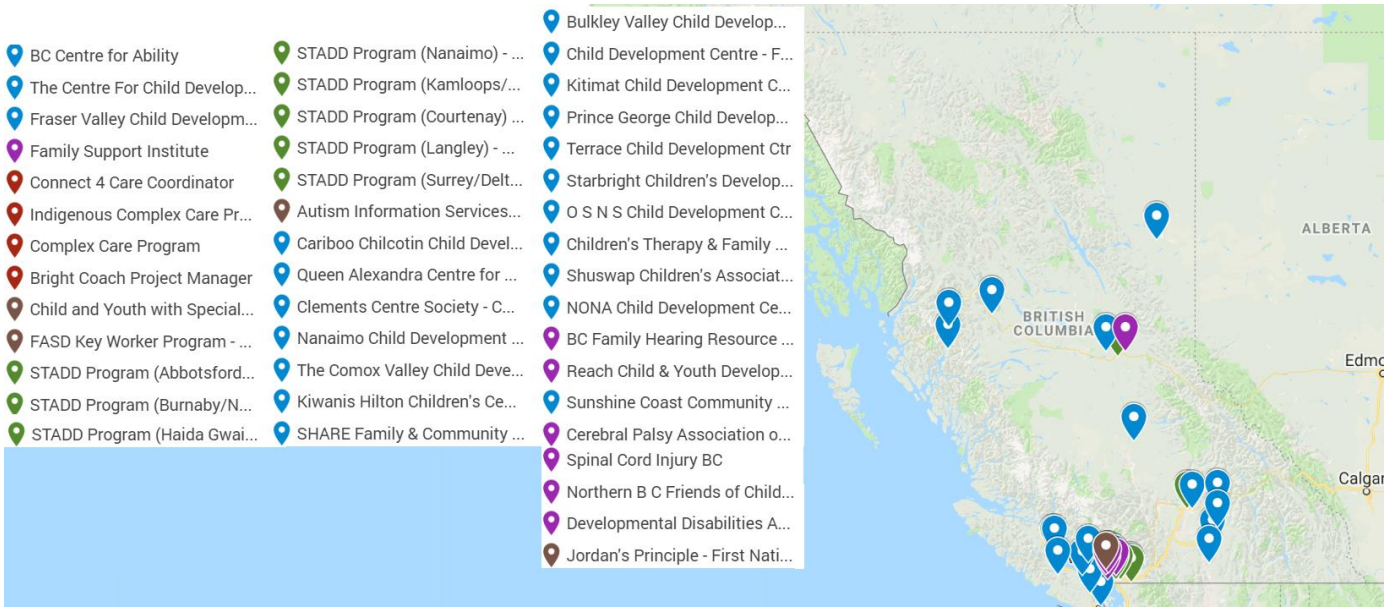


Figure 3 Compiled by Hodge K., 2018

Appendix D—Interview Question Key

Questions

1. Do you remember receiving your summary assessment document at Sunny Hill at your family conference on (Date)?

    a) Do you have all your other reports as well? (if applicable)

2. Were you able to use this document to help get connected to resources?

3. Did you have anyone who is helping you get connected to your resources? Ie. Key worker (already connected), Family member, friend, social worker

4. How do you feel you child's school done in following these recommendations?

    a) Did your child receive a (Designation specified in the CDAS)?
    b) Has your child had their Individualized Education Plan updated / made?
    c) Is your child being provided with a teaching assistant, individualized math support, social emotional groups (individualized based on what is in their CDAS)
    d) Is your child receiving Occupational therapy, speech and language etc. though your school?
    e) In a perfect world, what would your support at school look like?

5. Do you have a Key Worker now?

    a) How did you find them?
    b) Was it hard? (For those who did not have contact information given directly)
    c) How has that been going?
    d) In a perfect world, what would support from them look like?

6. Do you have a Social Worker?

    a) How has that been going?
    b) Have they been able to help find other available resources for you?

7. Does your child have mental health supports? a) Was finding your local office / contact person difficult?

    b) What helped?
    c) What has been most challenging?

8. Family Resources

    a) Have you been able to use the (websites, books) given to you?

    If no, tell me more about why you have not been able to If yes, what did you like most about these resources?

b) Did you find any resources that were not provided to you that were helpful?

9. Medical provider Follow up

a) I see (name) referred you here are you still connected to them?

b) I have (name) listed as your primary care physicians are you still connected with them?

c) Who would you call if you needed to discuss your child's health? Is that person a (Doctor, Nurse, walk in clinic etc.)?

10. How was your overall experience getting the assessment at Sunny Hill?

11. Are there ways Sunny Hill could make their recommendations easier to do?

12. Did you feel like you could call SH after your family conference?

a) If yes, do you remember who you would have called or did call?

13. Is there anything you've learned about you wish Sunny Hill had told you?

14. Are there resources you are still having a hard time getting connected to?

15. Who would you say is your 'go to' support person?

16. What do you still need?

17. What do you still want?

18. Is there anything else you think I should know?

Appendix E – Interview Quotes Becoming Themes

Primary Themes	Sub Themes	Supporting Quotations
Being Connected to Sunny Hill	Being Connected	"(Doctor) was great!... she gave me the most knowledge! I would call her" "(Case manager) was spectacular!... Priceless! She was so good to me!" "First time it felt like someone was advocating for us" "Sunny Hill (talking about an unnamed clinician specially) was able to catch some inaccuracies in our documents kudos to Sunny Hill for that!" "Quite good for teleconferences that was HUGE for me!" "They went through everything step by step… explained quite well! You guys were always there with me." "They've been great! (the social worker) gets back to me" "Felt like we could work through it" – feelings after the Family Conference
	Being Connected, But…	"Yet to be seen if the assessment will do anything other then funding… maybe because where we live, limited resources…. not because it was poorly done" "really thorough... in their sibling's case I didn't feel that so I'm glad" "Overall experience it was alright" "She (clinician) told us to go … it wasn't very informative" – on going to see another clinician That's vague. What does that even mean? Is it just meant if she's having a mental breakdown? I wish had had been more clear. There just seems to be a bigger gap that they didn't really account for. And having that quick snap shot... If we all had lots of money they have all worked out. They're good recommendations I just think in the grand scheme of

		things they can all be rolled out. They need things that we just can't provide. But that's like any assessment."
	Feelings of Disconnection	"We just wanted to get it over with…So we took the session that opened and in hindsight I should have just waited and that was a really hard time for (child)...I probably should have just cancelled and then I was upset for her. I should have just left. I just never had that kind of experience that tainted some of our views." – on a caregiver taking a cancellation appointment last minute instead of keeping her planned appointment time. A combination of the child having a hard time, and feelings of disconnection with the assessing professional
		"The only issue was in the time we were getting the assessments done I got a call from the Ministry the very next day. Just a little coincidental ….I know how things get mistranslated… Next time I'll lie because why would I be honest because it backfires." – *on feeling like someone from Sunny Hill must have reported her to MCFD*
Recommendations for Sunny Hill	Overwhelming Family Conferences	**"**They cover a lot… they cover more than you can absorb so I think that's why it's important other people do go. A key worker came for me."
		"The advocate was taking the notes. Because you could tell me something and in five minutes I'd forget. He's helping us, he's helping us with a few things."
		"Truthfully when you're going through any type of assessment you're being bombarded with so many terms and recommendations. You have so much going on and really that's not going to be your focus and you're gonna forget everything they tell you when you get home."
		"Umm…. I think maybe if there was an opportunity to sort of… I don't know if it's to ask further questions. Cause we did have that meeting where they explained everything and then that was it and finished. Some sort of way if we had any future questions that we could have a chance to get some additional information or answers that would be helpful."
		"They left it open to ask questions but at the time you're kind of blown away."
	Clarifying Recommendations	"Vague - What does that even mean by that?... What more could be needed? That's what I didn't know. Is it just meant if she's having a mental breakdown? I wish that had been a bit more clear? like if she's digressing?"

		"A referral say to mental health is very often not explained during the family conference — it's just like 'a referral here blah blah blah' so sometimes the follow through may not be there if the foster parent doesn't understand."
	Streamlining Referrals	"Short of them having a fast track – in a perfect world – if they had a program that my address just got implemented into and it would go directly to them (other organizations)." "Maybe its local coordination of services. I'm quite happy with Sunny hill. They do make it clear they're just assessment." "Sometimes there's a disconnect between what is recommended and what is actually real in the community…So sometimes …there's a little bit of compromise when it comes to implementing. We do the best possible." "Like ten years ago (discussing a wealthy family) …it was astoundingly-fewer waitlists, easier to implement everything."
Being Connected to Support Service Providers	Being Connected Having one person	"Our psychiatrist has a good rapport with the school.. he speaks with all the teachers every year." "I have one person at (location redacted) I can trust them!... Small town life… they get no one is perfect." "It's a really, really helpful place... with people where own age… the sister's she's never had." – on the one place they receive support "She had an amazing teacher last year. She did all the work for him… He didn't even realize there was anything 'wrong' with her." – on their past teacher "They just 'get him'. It's his comfort place (class room). The teacher is pretty amazing." – on their relationship with the current teacher "Awesome! They've helped so much. They've done everything through the school… the counselor is great."
	Being Connected But…	"They do a parent group every month. I find them a bit scary… the stories are a bit hair raising."

	Feelings of Disconnection	"Don't really feel comfortable down in (location) if she (Key Worker) wants to meet out of that area I don't mind I would be fine at (location)l – I haven't connected at all yet I do want to connect with her. Do some extra stuff." "Umm… I'm not sure…. she's a very nice person and she did go do some stuff in the classroom, but I don't know... it's yet to be determined. Unfortunately, the services in this town are geared towards bio parents and I kind of dropped the ball on it." "(Location) Key worker waitlist for 2 years... Child and Youth Mental Health is just a waitlist as well…. Occupational therapy and assessment very hard to get." "There's a bit of frustration about childhood development. You're filling out these one-sided documents (biased) that aren't accurate, and the parent has absolutely has no say – not a lot of two-way conversation. And I'm like, "this is not accurate." "They have an Individualized Education Plan but I'm not sure how much is implemented…the school is constantly having to deal with behavioural things its got to be exhausting." "I've used the document the resources have not responded yet." "I've had a really bad rapport with Ministry of Child and Family Development since I was a kid. " "I got pissed and called a superintendent and the behavioural consultant finally came to make a safety plan." "They called 911. That wasn't part of the safety plan… they kind of lost him at that point." "They said it wasn't considered mental health and closed our file" – once he got an FASD diagnosis." "I know the school didn't look at much… They basically told me they didn't have time."

Systemic Barriers to Receiving Care	Keeping up With Demand	"It doesn't take much effort to take a phone call or send a standard letter letting you know we've reviewed your file and that there is a long wait and we'll get back to you." "I'm already starting to freak out about September. What are their peers going to be like? Is the classroom teacher going to have as much time? Are they going to be monitored? " "Whenever I try to pressure a response from the team they say, 'well in the fall were going to do our best.'" – Occupatonal Therapy at school "As of November 6, 2017 he was on a two year waitlist."—for Key Worker "The (diagnosis) ….won't get funding which means we may have to hold her back another year…school is saying they can't meet her challenges." "Oh gosh… shorter waitlists" – on what they need "CYMH kept denying us and she called CYMH to accept us." "We don't have a psychiatrist... She comes to town once every month or two months. When she comes she's fully booked. I think that's just the nature of where we live."
Individual Capacity effecting Care	Advocating	"We've done our own research." "We did look that up for a conference. We could have gone but we didn't. When we researched it out it was really geared towards professionals in the field." "He was still in the process of the assessment so I self referred to CYMH." "Nobody's Perfect and coping with challenging behaviour groups. I did that on my own. I found that one on my own." "If things get complicated, I'd have to have the CDAS stapled to my butt!"

	Feelings and Perceptions	"I'm kind of a one woman show!" "I'm not afraid to ask for help." "I did not want her to be sick with FAS." "Services seemed to be geared towards Bio families" – Discussing hesitancy around Key Worker program "I don't want her labelled" "Is it challenging? Yes. Do I have days I want to rip my hair out? Yes… It doesn't make it any easier but since you know now (after being given a diagnosis) it's different." "I want to pull my hair out. The behaviour is totally different at home than day care." "I shouldn't even say it out loud… it would be nice if she stayed with (the new school)." "Crazy but helpful, we can work through it!" – regarding family conference and assessment "Shell shock at first… I know what to ask for now!"
	Resources (time / money)	"Because were financially sound its definitely more helpful because I don't need to go to work. I can be around versus parents working it would be much more difficult." "I'm lucky I don't have to work and we're fairly high functioning. But I can see someone having to work full time or not have the resource mental or external to follow through on those referrals." "MCFD tries to overload the work on me. I have enough appointments. To sit there and say I have five or ten more things to do… ya like no… we need some downtime to just be us. Trying to overdo it I don't do well… we just miss all our appointments because its too much on our plate." "His foster parent who are going to be his legal guardians are very involved in the school and very involved there they spend a lot of time there (at school)." "Working 10-630 she gets picked up. I have no time for me to

		do a lot of stuff.”

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