


# Tactics and Strategies of Family Adaptation among Parents Caring for Children and Youth with Developmental Disabilities

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## Abstract

The stressors experienced by families caring for children and youth with developmental disabilities (DD) impact quality of life for all family members. Families employ creative practices to cope and thrive in the midst of such challenges. This study sought to understand the adaptive practices, tactics, and strategies engaged in by parents. We interviewed 39 parents of 46 children and youth with DD in Canada. Thematic analysis elucidated three categories of adaptations and twelve tactics and strategic actions at three ecological levels: *within the system—adapting with everyday tactics and strategies*; *within our family—constructing spaces of care*; *within myself—adjusting perceptions of adversity*. Our critical interpretation highlights an ecology of parental labor across varying psychosocial and health care service contexts in which parents strive to make a good life for their children and families. Nurses can empower and enhance their well-being by conducting holistic assessments and targeted family nursing interventions.

## Keywords

developmental disability, children, parenting, adaptation, resistance, health care access, family nursing, critical interpretivism, Canada

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## Introduction

### Background

Globally, approximately 93 million children and youth (5%) experience moderate or severe disability (World Health Organization [WHO], 2015). An estimated 53 million children under 5 years of age worldwide have a developmental disability (DD), with 95% living in low- and middle-income countries (Global Research on Developmental Disabilities Collaborators, 2018).<sup>1</sup> Caring for children and youth with DD, who have complex needs, presents substantial challenges for families around the world and requires coping methods for the particular stressors they face. Nurses caring for children with DD provide collaborative, holistic, child- and family-centered care by assessing and supporting all areas of their development and by offering support and education for their parents and caregivers (Olli et al., 2014; Wilson et al., 2017). Nurses in a variety of settings (including family and pediatric nursing in hospitals, clinics, rehabilitation centers, home care, and community and public health units) will have the opportunity to provide care to

children and youth with DD and their families; their professional practice will be enhanced by an understanding of the common experiences and adaptive strategies of these families. Nurses who recognize and appreciate those experiences can build trust with families of children and youth with DD (Nygard & Clancy, 2018).

### Prevalence and Co-Morbidities

In Canada, 3.7% of children and youth live with one or more disabilities, and 1.5% live with a severe to very severe disability (Statistics Canada, 2008). In Saskatchewan, the rate of child and youth disability is 3.9% (Human Resources and Skills Development Canada, 2011; Statistics Canada, 2008).

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Among Canadian children with disabilities, 37% have two or three disabilities, 26% have four of five, and 11% have six or more (Statistics Canada, 2008). DD accounts for the majority of disabling conditions in Canadian children and youth (Miller et al., 2012; Statistics Canada, 2008). Children and youth with DD access mental health services at significantly higher rates (39% compared to 14%) (British Columbia Ministry of Health, 2007). Neurodevelopmental disorders, mental health disorders, and other medical conditions are often co-occurring (American Psychiatric Association [APA], 2013; Brookman-Frazee et al., 2017; Joshi et al., 2010; Karim et al., 2014; Kim et al., 2011; Kogan et al., 2009; Simonoff et al., 2008; Stadnick et al., 2017).

### ***Stress and Distress***

Parents and caregivers of children with DD are at significantly greater risk of psychological distress and mental health problems as they balance caregiving and other responsibilities (Flynn, 2020; Guyard et al., 2017; Marquis et al., 2020a, 2020b). Stress and distress often come directly from the child's health condition, varying based on its severity, the degree of impairment and behavioral issues (Guyard et al., 2017; Hsiao, 2018; Statistics Canada, 2008). This stress is associated with lower quality of life for all family members, including decreased mental and physical health, decreased social functioning, increased depressive symptoms, increased psychological distress, increased sleep deprivation and fatigue, increased stigmatization, higher financial demands and expenses, un/under-employment, and poverty (Brehaut et al., 2011; Burton et al., 2017; Burton & Phipps, 2009; Dillenburger et al., 2015; Lukemeyer et al., 2000; Olsson & Hwang, 2001; Porterfield, 2002; Statistics Canada, 2008; Vasilopoulou & Nisbet, 2016; Zan & Scharff, 2015). Unfortunately, disability services often ignore the complex needs of parents, including ongoing support, emergency care, and respite (Tétreault et al., 2012).

### ***Manifold Parental Roles***

Systemic problems in the coordination and delivery of services mean that many parents of children with disabilities feel they must become highly involved in their child's care. For many, this entails becoming skilled advocates, topical experts, and system navigators (Green, 2007). Many parents feel forced to serve as mediators, providing an interface between the parts of a divided system (Matthews et al., 2021). Research suggests that mothers may also advocate for their children by serving as teachers and informants, helping professionals to develop their skills in working with children with disabilities (Aston et al., 2014; Ryan & Runswick-Cole, 2008; Van Hove et al., 2009). Parents may also act as advocates on behalf of all people with disabilities, act as "employers" and "managers" of caregivers, act as "diplomats" in communication, and make alliances with professionals to

help them to defend their child (Aston et al., 2014; Matthews et al., 2021; Ryan & Runswick-Cole, 2008; Van Hove et al., 2009). While advocacy work can be highly rewarding for parents, it can also become an exhausting burden and emotional stressor for parents (Chang, 2009; Fereday et al., 2010; Matthews et al., 2021).

### ***Parental Coping***

Parenting a child with disabilities requires the development of certain skills. Hartshorne and Schafer (2018) reported that parents of children with severe disabilities require exceptional skills in key areas: building communication, establishing a routine, getting connected with supports, and learning acceptance, advocacy, and discipline. They recommended that professionals promote parents' confidence and creativity in the caregiving role. Of course, parenting children with disabilities also has its joys. Beighton and Wills (2017) reported that parents identified positive aspects of parenting children with intellectual disabilities, including increased sense of personal strength and confidence, changed priorities, greater appreciation of life, pleasure in the child's accomplishments, increased faith/spirituality, and more meaningful relationships. Other authors point to parental pride, a greater appreciation for the unique value of the child, personal growth as a result of parenting experiences, and a new perspective on life (Green, 2007; Schall, 2000). Beighton and Wills (2017) described these as "meaning-focused coping strategies" (p. 325) that help parents to adapt to stress. Peer support groups offer parents a sense of community, friendship, identity, recognition, solidarity, and positive ideology; they also provide role models, emotional support, and suggestions for coping strategies (Bray et al., 2017; Goodley & Tregaskis, 2006; Klein et al., 2019; Mitchell & Sloper, 2001; Morrow & Malin, 2004).

### ***Local Disability Service Network***

The disability sector in Canada has been characterized as fragmented, incoherent, and under-resourced, marked by uncertainty and competition rather than coordination (Boyce, 2001; Gelech et al., 2017; Matthews et al., 2021; McColl et al., 2001, 2017, Pedlar & Hutchison, 2000; Prince, 2004). Child disability services in Canada are provided by the health care, education and social services systems, and by non-governmental, community-based organizations.<sup>2</sup> Critics note that the Canadian system operates through a "patchwork of legislation, regulations, programs, providers and entitlements that requires considerable probing to reveal, and considerable patience to understand" (McColl et al., 2017, p. 7). In Saskatchewan, the disability service network in operates with an array of governmental and non-governmental programs, services, and funding sources (Gelech et al., 2017; Matthews et al., 2021). Research in this area suggests that this service system is highly resistant to meaningful change

**Table 1.** Interview Questions.

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Please tell me the story of your family, beginning where you feel is the start.

Please tell me more about your family.

Please tell me the story of your child's disability.

Please tell me about what it is like to live in your community (urban, rural) as a family with a child living with a disability.

Please tell me about your experiences with the services (e.g., education, social services, health, mental health, rehabilitation) you need for your family.

Tell me about a typical day for you and your family. What do each of your family members do together?

What are the most rewarding aspects of raising your child?

What are the most challenging aspects of raising your child?

Who helps you take care of your child?

What do you think caused your child's disability?

What are your goals for your family?

What are your goals for your child?

What is it like for you to find the services you need for your child and your family living with a disability?

How do you get access to these services?

What services does your child and family need that you can't find?

What suggestions do you have for changes that would meet your child's and family's needs? (e.g., service systems, care from professionals, services delivery)

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(Gelech et al., 2017). This is troubling, as research has consistently shown that for parents to participate meaningfully in enhancing the well-being of their children, they must receive high quality information and professional support, which requires a coordinated, multi-agency approach (Mitchell & Sloper, 2001). Professionals and family members of children in Saskatchewan have consistently identified problems in disability service partnerships (Matthews et al., 2021). Parents of children with disabilities in Saskatchewan described the negative impact of systemic problems on their efforts to access appropriate and timely services, which necessitated substantial advocacy, negotiation, and mediation efforts by parents (Matthews et al., 2021).

### Research Questions

In sum, previous studies have explored numerous aspects of parenting children and youth with DD, including specialized skill development, the need to take on new roles, unique forms of parental labor, and various coping strategies implemented by parents to cope with stress and maximize their children's well-being. What is lacking is a unified theory of these adjustment processes that accounts for the different types of challenges, problems, and social processes parents face in the context of challenging and fractured service systems and how these adaptation techniques relate to specific environments (community, institutional, familial, self, etc.). How can we construct a unified model of family adaptation to childhood DD that attends to context and local challenges? What problems, unmet needs, and socio-political forces are implied by different adaptive processes? How do families mount a concerted coping campaign in the face of fractured and convoluted service systems that appear highly resistant to change? Answering such questions (and exploring the

complex interactions they entail) requires integrating experience-near data with critical perspectives attentive to the social, institutional, and political context.

### Methods

To address this gap, we conducted a qualitative study grounded in an epistemology of social constructionism and theoretical perspective of critical interpretivism, using a phronetic iterative approach and reflexive thematic analysis (Braun & Clarke, 2020; Crotty, 1998; Tracy, 2020). Our study explored the experiences of parents of children with DD in the province of Saskatchewan. We asked parents to share their experiences of family life (past, present, and future), parenting, caregiving, and accessing a range of needed services for their children with DD (see Table 1). In this paper, we present our analysis of the data focused on parents' strategies of adaptation.

### Theoretical Framework and Analysis

Our qualitative methodology employed a phronetic iterative approach, which is both inductive and deductive and "alternates between considering existing theories and research questions on the one hand and emergent qualitative data on the other (Tracy, 2020, p. 211). Our analytic practice was informed by Braun and Clarke's (2020) approach to reflexive thematic analysis. This analytic approach promotes articulation of the researchers' theoretical assumptions that inform data interpretation, and consists of six phases: data immersion and familiarization, coding, creating and refining themes, all while "reflecting, questioning, imagining, wondering, writing, retreating, returning. . . producing rich, complex, non-obvious themes" (p. 5). This reflective, iterative

approach to analysis allowed us to attend to the nuances of individual experiences while also being mindful of how these experiences are shaped by broader forces within the social landscape.

The first and second author both coded one initial transcript to check for congruence of codes, then each coded approximately one third of the transcripts, using a word processing program. The researchers met often to compare coding and discuss themes and patterns we noticed in the transcripts. An audit trail of analytic decisions was documented. A code book was developed and a senior nursing undergraduate student research assistant coded one third of the transcripts. The student research assistant had an undergraduate degree in psychology, was in their final semester of an undergraduate degree in nursing program, and had experience supporting people with disabilities. Analysis was guided by the question, “what techniques do parents employ to navigate this challenging system, access services, and promote the well-being of their children?”

Our view of these various adaptive practices was informed by Mattingly’s (2014) notion of the “good life” or “a life worth living” (p. 9). Mattingly proposed that parents strive toward the ethical or moral aim of their child flourishing and thriving—not merely surviving. In Mattingly’s ethnography of the daily lives of African American families caring for children with serious chronic medical conditions, they note that they experience an

unexpected and unwanted project of becoming. . .to respond to the call or needs of their vulnerable children, and to create a social world in which their children can be better cared for, becoming primary moral projects, often superseding their own personal dreams and goals. . .these are social moral projects that change shape over time, requiring the development of communities of care (p. 5).

Like Mattingly, we aimed to investigate parental adaptations within the context of the family unit. Moen and Wethington (1992) used the term “family adaptive strategies” to refer to “actions families devise for coping with, if not overcoming, the challenges of living, and for achieving their goals in the face of structural barriers. . .[whereby] families remain creative actors on a sometimes barren, sometimes hostile, stage” (p. 234). As we explored parents’ descriptions of surviving and/or thriving in the context of the local service network, we sought to attend to their negotiations with professionals, institutions, and service providers as well as transformations of family and self.

To better understand how parents interacted with the disability service systems, we drew on Certeau’s (1984) notions of strategies and tactics. For Certeau, abundant opportunities exist for ordinary people to subvert institutional rituals, requirements, representations, and rules and adapt aspects of these systems to their own interests and desires. Wherever parents seek services and supports for their children, they confront institutional gatekeepers, systems of rules, and pervasive power imbalances; however, the imbalance between

those who control service access and funding and those who seek assistance does not imply passivity or docility on the part of consumers. Parents have various means of resisting institutional forces, policies, or limitations and working to have their needs met by the system. They might invoke *strategic* forms of resistance, aimed at altering or reconfiguring the disability system as a whole to better meet their needs by directly influencing the operation of those in power. More frequently, they might engage in *tactical* forms of resistance and maneuvering, making creative use of the service system and deflecting its power without questioning its basic legitimacy or seeking to overhaul its configuration or design.

Lastly, as an organizational heuristic, we adapted Bronfenbrenner’s (1979) ecology of human development. To conceptualize the various adaptive processes we encountered in participants’ stories, we situated them within particular levels of human existence and experience: the levels of the ontosystem (the parent of a child with a disability), microsystem (family life spaces), mesosystem (service providers), exosystem (community organizations and sectors of health, education, and social services), and the macrosystem (socio-cultural attitudes toward childhood disability and inclusion). This helped us to construct an ecology of adaptation and allowed us to better understand what types of coping practices were being used to address specific sorts of issues.

### *Rigor in Qualitative Research*

Acknowledgement of our theoretical positioning serves to meet the criteria of “goodness” or worthiness of qualitative research by making plain how meaning was generated through the epistemological and theoretical position, choice of methodology, data collection, analysis and interpretation processes, and the representation of voices (Arminio & Hultgren, 2002). Transparency and systematicity are two markers of quality, met by providing sufficient detail to allow for judgment of rigor and congruence in qualitative research, including epistemological and theoretical positioning, reflexivity, analytic decision-making, and any changes of course (Meyrick, 2006). While a discussion of coding and theme development and the creation of a codebook among researchers were used as tools in our analytic process, Braun and Clarke (2020) argue that “coding reliability” is not a requirement for high quality, trustworthy reflexive thematic analysis and a “data saturation” criterion is not required or consistent with it (Braun & Clarke, 2019). Good thematic analysis is demonstrated by compatibility and consistency of theory, method, analysis, data quotations, and analytic assertions, as well as a “convincing and well-organized story about the data” (Braun & Clarke, 2006, p. 96).

### *Recruitment and Procedure*

Recruitment was completed in partnership with a community-based organization with a province-wide service network focused on promoting the inclusion of people with

intellectual disabilities. Recruitment was conducted by distributing the study call to participate through electronic messages, newsletters and online posting on a website and social media. Word of mouth referral through informal networks between families resulted in additional recruitment and representation of a range of DD. Recruitment and data collection took place over 8 months in 2016 and 2017.

Interviews with each of 39 parents of 46 children with DD took place in family homes (3), an office on a university campus (2) or by telephone (33). Telephone interviews allowed us to access a sample across the province, and may have allowed the participants to feel comfortable sharing sensitive information about their family lives (Novick, 2008). A demographic questionnaire was completed by the researcher with each participant. Interviews were conducted using family-story and semi-structured interview guides (Table 1). Interviews lasted approximately 70 minutes (range=45–125 minutes) and audio-recordings of the interviews were transcribed verbatim. Transcripts were assigned a code number and any identifying information was removed. Participant data was stored securely on the University of Regina campus and server. Our study received approval from the University of Regina Research Ethics Board. Informed consent was obtained from each participant and cash honorariums of \$50 CAD were provided. A list of local resources for support in the case participants became distressed after the interviews was provided in the debriefing form.

## Participants

Most participants were women (87%), living in two-parent families (90%) with post-secondary education (87%) (see Table 2). More than half lived in urban settings (67%) with past or present education or employment in health or education fields (59%) and had two or three children (67%). A wide range of family incomes was represented. Participants were 39 parents of 46 children ages 11 and under (41%) and youth ages 12 to 24 (59%) with DD. Half (52%) of the children and youth had one DD and half (48%) had two to five. Nine children (20%) had a mental disorder in addition to DD.

## Findings

Throughout the interviews, parents positioned themselves as actors and advocates striving to create a good life for their children with DD. We organized their strategies into three themes, each consisting of several categories: *within the system—adapting through everyday tactics and strategies; within our family—constructing spaces of care; within myself—adjusting perceptions of adversity* (Figure 1).

### *Within the System: Adapting through Everyday Tactics and Strategies*

Parents noted that caring for the needs of children and youth with DD occurred in the context of a complicated disability

service system. They had to be savvy to figure out the puzzle, and learn how to work within, and manipulate, the system as it currently existed. Such tactical approaches centered on learning how to best work the system and required parents to invest a great deal of labor into becoming familiar with the culture, language, and practices of this medico-educational system. These tactical adaptations included *employing savvy, influencing, managing impressions, and sacrificing*. Parents also engaged in the strategic adaptation of *advocating for change*.

**Employing savvy.** Parents described developing practical knowledge of the disability system through persistence. One parent described the process of finding information as

*like finding a needle in the haystack. There was no easy way for me to find programs. . . I went on the internet. . . I couldn't commit the days and days and days of detective work. . . I know the jargon, or the lingo. But if you don't know. . . It's shrouded in mystery. . . If you don't stumble across it, and if you don't do it in time. . . (Family A, cerebral palsy, age 19)*

Seeking information proactively was necessary. Being able to use the right language and knowing what services, referrals, and other supports to ask for was helpful. Being a health professional proved useful at times. One parent shared,

*we wouldn't have had any access to that if my partner hadn't been more aware of what's out there and which doors to pound on, if there wasn't somebody else helping you out. (Family B, intellectual disability, age 21)*

Parents reported many hours searching the internet for resources. Parents learned new skills (such as nursing care and therapies) while navigating the system, advocating for their children, fundraising, and providing care, akin to being a case manager. Lengthy travel to access services was a reality for parents who did not live near service locations. Families might pay out-of-pocket in order to get the right person or the right services when there was a long wait for public service or the family did not qualify for financial assistance. Sometimes families refused services which they deemed unsuitable or unnecessary (e.g., publicly funded assessments and therapies in home, clinic, and school settings) or with providers that did not match well with their child. The costs of these services (and sacrifices to pay them) were outweighed by shorter wait times and choice of a provider their child was comfortable with. Negotiation and advocacy work here took place at the level of advocating for the right care for their child with individual health providers, educators in the classroom, and service gatekeepers. With such a sharp learning curve, certain parents were better prepared for immersion within this institutional field.

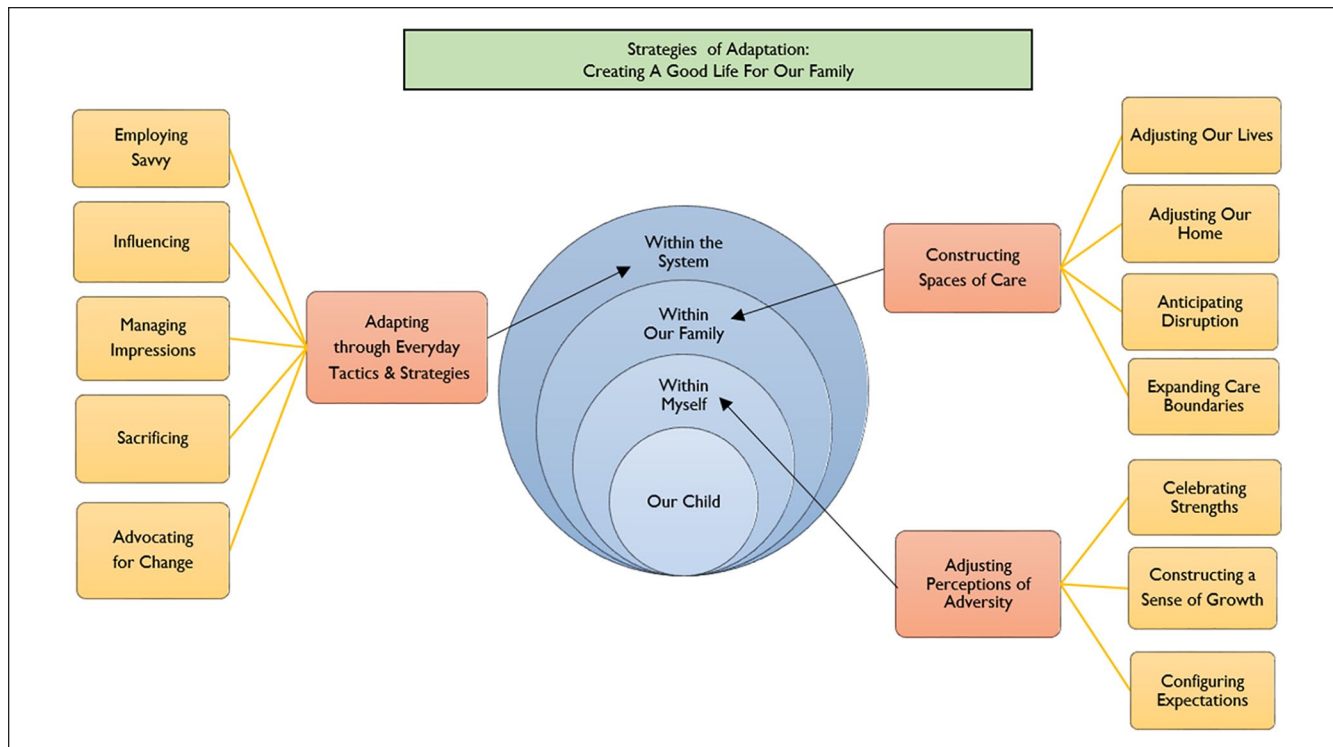
**Influencing.** Tactical approaches to working effectively with the service system also entailed the purposeful and active development and management of key relationships. Parents

**Table 2.** Characteristics of Parents ( $n=39$ ) and Children ( $n=46$ ).

Characteristics	N (%)	Mean (range)
Family constellation		
One parent	4 (10.3)	
Two parent	35 (89.7)	
Participating parent's gender		
Man	5 (12.8)	
Woman	34 (87.2)	
Community		
Rural (town or farm)	13 (33.3)	
Urban (city)	26 (66.6)	
Age of participating parent (years)		43.2 (30–60)
Level of education		
High school	5 (12.8)	
Certificate/diploma/some post-secondary	15 (38.5)	
Bachelor	13 (33.3)	
Master	6 (15.4)	
Field of education and/or employment		
Health	14 (35.9)	
Education	9 (23.1)	
Other	16 (41.0)	
Household gross income (CAD)*		109,854 (11–250K)
10,000–49,000	7 (17.9)	
50,000–99,000	9 (23.1)	
100,000–149,000	8 (20.5)	
150,000–250,000	13 (33.3)	
Gender of child/ren in the family with DD		
Girl	16 (34.8)	
Boy	30 (65.2)	
Age of child with DD (years)		13.3 (3–24)
3–11	19 (41.3)	
12–17	14 (30.4)	
18–24	13 (28.3)	
No. of children in the family		2.56 (1–5)
One	7 (17.9)	
Two	13 (33.3)	
Three, four, or five	19 (48.7)	
No. of children in the family with DD		
One	35 (89.7)	
Two, three, or four	4 (10.3)	
Ethnic identity of child		
European	41 (89.1)	
Indigenous	4 (8.7)	
Latin	1 (2.2)	
Children with mental health disorders**		
Anxiety disorder	8 (17.4)	
Depression or oppositional defiant disorder	3 (6.5)	
Children with developmental disorders		
Autism spectrum disorder	20 (43.5)	
Intellectual disability	9 (19.6)	
Attention deficit/hyperactivity disorder	9 (19.6)	
Other neurodevelopmental	10 (21.7)	
Down syndrome	8 (17.4)	
Cerebral palsy	4 (8.7)	
Epilepsy	2 (4.3)	
Other developmental anomalies	5 (10.9)	
Children with multiple diagnoses		
One	24 (52.2)	
Two	11 (23.9)	
Three, four, or five	10 (21.7)	

\*Two declined to answer (5.1%).

\*\*One child had two mental health disorders in addition to DD and eight children had one mental health disorder in addition to DD. None of the children had a mental health disorder as their only diagnosis.



**Figure 1.** Tactics and strategies of family adaptation among parents caring for children and youth with developmental disabilities. Note. Parents engaged in creative strategies, tactics and practices in their daily lives to cope with and adapt to barriers and challenges, and to strive toward the goal of a good life for their children and their families.

engaged in relationship building—in person, through notes, by text-messages—with services providers. They encouraged open communication and collaboration within the child’s care network and urged members to work as a team. In school settings, parents often had to teach the teachers as they worked to make their child visible as a non-neurotypical child, with unique needs, and deter perceptions of their child as a problematic:

*Kids with physical disabilities, you can visually see it. You can recognize it. Or a child with a syndrome where you can look at the facial features and know. But when it’s something that’s strictly mental health but your child is still functioning, it’s hard to get that help, like on the higher functioning end of the spectrum. (Family C, autism, age 12)*

As parents negotiated complex relationships with service providers and gatekeepers, they described the need to pick their battles, particularly in scenarios resistant to change, since there were many hurdles and limited personal resources to tackle all of them. Some accepted a questionable diagnosis in order to access needed services and resources that were only available with specific medical labels, and to have a place to start and seek direction for helping their child. Sometimes parents preferred a different tactical route, seeking second opinions when they disagreed with initial diagnoses. In both cases, parents’ attempted to effectively leverage

the relationships and options available to them as consumers of the system.

Parents reported they often networked with other parents—locally and afar, in-person and online—to facilitate their tactical capacities and best make use of local services. Other parents shared what they had learned through their own experiences within the service network and proved helpful in educating new initiates about access and availability. Here, tactical approaches to mediating the system are shared amongst consumers in an attempt to assist families in having their needs met. One parent explained how a parent of a child would bring along a parent of another child to their appointment with a health professional so they could also receive information. The advice of other parents helped them select treatment and program routes.

**Impression management.** Parents also described working to manage impressions of their child to influence how they were viewed and treated within the service system and the broader community. Within the social negotiations of everyday life, some parents struggled with not being believed or accused of exaggerating the needs and challenges of their children. When family, friends, and teachers did not observe the troubling behaviors and struggles, families reported difficult encounters where their own experiences as parents were delegitimized by those around them. One parent described naïve and upsetting criticism as “rampant” and

“extreme” and exacerbated by the fact that their child was “high functioning” and “looks normal,” without visible marks of disability:

*The teachers for quite a few years kept saying, “Do you have your child out of routine? Do you have structure? Have you tried disciplining them more?” Comments like that, that really make you doubt yourself as a parent. . . Suggesting that perhaps it is your fault that your child is behaving that way. . . these parents are struggling and then to be criticized in those ways is not helpful at all. (Family D, autism, age 11)*

Parents wanted their children’s need for support to be accepted and legitimated by educators and service providers, and access to valuable supports ensured. On the other hand, parents did not want their child to be reduced to their disability or construed as a “problem.” One parent explained,

*they don’t see them as a child first, they see the problems first. What always works well is to see the child first. Because the disability is a visible one. Then see the disability. It riles me a little bit. . . Not treating my child like they can’t do anything, because my child has so many abilities. (Family E, Down syndrome, age 12)*

Another parent described a different but equally problematic, pattern of viewing and relating to their child, where the youth’s own need to develop knowledge and skills is secondary and they are positioned as a pedagogical tool for the social and moral development of others:

*Everybody loved having my child in the classroom so much that they would fight over who got to help and who got to do things for them. I realized that the teacher was teaching the kids to see my child as their pet. . . It gave the kids this horrible idea about my child and I really disliked that. . . The [next] teacher managed to come up with activities that engaged my child, to participate fully in everything, seen as an equal member of the class. (Family F, cerebral palsy, age 15)*

Parents wanted their children to be included with others while also being uniquely supported. The complexity of the impression management and identity work undertaken by parents is apparent throughout the interviews. To gain entrance into the service network and appease gatekeepers, parents must position their child as different, dependent, and struggling—as “other” to their peers; however, to prevent social handicapping, isolation, and the potentially damaging aspects of clinical labels (see Mattingly, 2017), parents must also advocate to have their children seen as capable individuals with the same needs and desires as other children. Attempts at weaving this delicate balance of sameness and difference highlight the complex social, political, and moral nuances of everyday life with a disabled child.

**Sacrificing.** As they navigated the service system, parents described doing whatever it took to secure the support needed

by their children. Caring for a child with DD at times entailed parents sacrificing their own well-being:

*I have not been a healthy person for years. . . At the end of the day, there is just a lot of self-loathing because you feel like you’ve failed. (Family D, autism, age 11)*

*Sometimes I’m running on fumes for a whole week. . . I have nothing in me. I have no energy, I have nothing. Mentally, I’m just depleted on everything. I still have to keep going. . . There has been times. . . there was nobody around, and I didn’t know who to call and I never felt so helpless. (Family G, autism, age 6)*

In one case, a parent surrendered their child in order for them to receive all the services they needed when they were placed in the custody and care of the government:

*We were at our end of our rope. I was phoning mental health begging and pleading for help. . . I begged and pleaded for them to hospitalize my child and they refused. . . I ended up, we had to, we went to child protection and said we can no longer look after my child. . . When I was in with social services, they said to me, “So you’re telling me you can’t look after your child now? You’re just saying you’re done.” I said, “I have been begging for help. . . You guys have given me nothing. . . You’re not even going to make me feel guilty about this.” (Family H, intellectual disability, age 16)*

This parent made a heart-breaking difficult choice—a choice that brought judgment from professionals—in order to provide a good life for their child. Another parent shared similar stories:

*I know three sets of families that have relinquished their children to social services because they cannot care for them. . . There’s no one to help. They have other children. . . If you saw them after they relinquished their child to social services. A broken person. Their other child wants nothing to do with the parents that gave up their sibling. . . The other parent is spending time in the psychiatric ward. . . I think of what respite could have done for that family. (Family I, autism, age 19)*

In these stories of crisis and child surrender, we see the devastating consequences of unmet needs, mental health crises, and parental burden. Faced with a system that does not meet the needs of their children, parents are forced into a situation of tactical surrender.

**Advocating for change.** Not all negotiations within the service system remained on the level of tactics. At times, parents engaged in more strategic approaches to systemic change, engaging with internal decision-makers and controllers in an attempt to reshape the disability service system. On the local level, this involved going to meetings and writing letters to school boards and government officials, and went as far as lobbying the provincial and federal government, sometimes with children with DD themselves presenting to officials. As



they worked to promote fundamental change to the system itself, parents advocated for their own children and for all children with disabilities. Such confrontational, strategic forms of resistance are generally rare compared to the sheer volume of everyday forms of tactical negotiation. Not everyone was prepared to engage in these strategic initiatives or found themselves in a position to devote such time and energy to this cause. One parent shared,

*we're down to one job. Why? Because of advocating for autism. We scrape whatever savings we have. . . We'll continue the burden of autism, until the government realizes that they're not doing their jobs. . . I should give the government a bill for everything that we've done for our child since the diagnosis. (Family I, autism, age 19)*

The above discussion is not to suggest that parents reported no positive interactions with service providers or that their children received no valuable services. Rather, it is meant to highlight the amount of labor, savvy, advocacy, and sacrifice parents invest in navigating the service network and managing their interactions with and influencing gatekeepers and service providers. Tactical and strategic modes of “fighting” for their children was exhausting.

### **Within Our Family: Constructing Spaces of Care**

Parents described altering, adjusting, and adapting their family lives in various ways in order to care for their children with DD. Parents carefully curated and constructed physical and interpersonal spaces to support the material and psychological safety of all children. These adaptations rendered the home habitable for their children with DD as well as their siblings. Sometimes, such adaptations required extending the boundaries of typical familial care to meet the needs of multiple family members. Coping approaches within the family context included *adjusting our lives, adjusting our home, anticipating disruption, and expanding care boundaries.*

**Adjusting our lives.** Parents described altering their work life—reducing hours, stopping work, or altering their schedule—to accommodate the needs of their children with DD. Some parents reported switching schools or homeschooling to provide a safe and appropriate educational and social environment suitable for their child (sometimes to avoid bullying). Some parents moved from one city or town to another in order to be able to access services in that location or benefit from a smaller, closer-knit community. One parent shared how they moved to a place with fewer formal supports in search of valuable informal supports:

*There are so many services based out of those cities and so much more opportunities. I couldn't move to a city. . . I've had to go catch my child. . . Everybody knows who my child is. . . Somebody stopped my child and I don't even really know the person, but they knew who my child was. . . There's kind of that*

*community feeling of, “This is one of our kids”. . . I feel safe like that. (Family G, autism, age 6)*

Another parent’s vignette captures a host of such family adjustments and tactics. These included choosing to live in a small community and placing their child with DD in close proximity to the parent—in their own workplace—where they could be frequently available and encourage the team:

*We finally broke down. . . Our child needed full time care when I wasn't available and school wouldn't take them. If our child had a seizure. . . a fever. . . was screaming, they'd send our child home. . . I ended up leaving my position and moving. . . We chose the small town. . . I had my child transferred to my school. . . I was right in the building. . . They could just call me when they needed me. (Family A, cerebral palsy, age 19)*

Both major and minor adjustments to the life of the family were initiated by parents in pursuit of a “good” or “good enough” life for everyone in the family. Sacrifice and adjustment were not the sole purview of parents. Coping was a family affair that often required all members to act in support of a common good.

**Adjusting our home.** The unique needs of children with DD impacted everyone in the home. One parent described how the “chaos and the horrific atmosphere is completely normalized” (Family D, autism, age 11) within the home after a period of time. Another noted “our household is absolute chaos. . . We walk on eggshells” (Family J, autism, age 15). Parents shared how their children’s typically developing siblings, while often displaying maturity, were nevertheless impacted by the needs of the child with DD. One parent shared,

*our other child has been going through counselling and we've been really mindful. . . how many mornings we would have our breakfast in the den and latch the door because my child would be on a tirade. Was it fair to the other child to hear that in the mornings? No. But that's what we had to do. It weighed heavy on our minds. It had to be done. (Family I, autism, age 19)*

To ensure the well-being on non-disabled siblings, parents described undertaking various protective measures. One parent recounted,

*at peak times living in the house we've also had to have a cell phone waiting for the other child at the back door with full permission to get out of the house. “Get yourself dressed and get out, even if you're next door, wherever. Make sure you're safe. Report in.”. . . I laughed when I was looking for a file and forgot we still keep all the razor blades, nail clippers, everything else in a locked cabinet within a locked drawer. (Family I, autism, age 19)*

At times, making the home safe and supportive for all family members meant managing childhood disability in ways that

parents' might not have initially preferred. In one family's case, choosing medication for their child's distress—with the risk of external judgment—was cast as a necessary move that benefited the family as a whole:

*It has completely changed our lives for the better. . . I don't care what anyone else says anymore. If you want to say I'm going to hell because I'm medicating my child. My child is functioning, leaving their bedroom, going to school, not hiding under a desk every day, not sobbing every day. That's what medication did. The siblings started to not be afraid. They were terrified. It all takes some time. We have to reprogram our whole family but its starting. (Family D, autism, age 11)*

Parents recognized the needs of all their children and employed a variety of maneuvers to support the development of a safe and supportive home environment for everyone. At times, this meant altering parenting strategies and the physical environment for the good of the family unit.

**Anticipating disruption.** Some parents shared their experiences with unpredictable, disruptive, self-harming, or violent behaviors displayed by their children with DD. Parents described how these symptoms of the children's neurodevelopmental and mental health disorders led to crises that required emergency services. These parents needed to find ways to manage these difficult symptoms and avoid triggering them. Some parents described their efforts to anticipate these scenes as

*trial and error. . . Learning how to tell those little details, dealing with them day-after-day. I've been able to tell how to adjust, to assess the situation, seeing what the triggers are. I'll help my child adjust, avoid them. . . I'll be able to change the circumstances a little bit. . . Its learning which battle to go for. (Family K, autism, age 5)*

*Our child gets really frustrated and has huge anger issues and we've learned over the years to read the signs but until we got to that point. My child is very volatile. We never leave them alone with another kid. . . inevitably my child would attack one of them. . . either physically or verbally. . . You have this child that is screaming constantly and has no worry as to who is going to be hit. . . (Family J, autism, age 15)*

Dealing with unpredictability and explosive behaviors required developing a keen eye for triggers and a high level of familiarity and communication with the child. Where these adaptive maneuvers prevented or deescalated problematic behavior, they proved highly valuable to the family and the child. Unfortunately, such skills required close acquaintance and deep knowledge of the child and were not easily transferrable. Disruptive and violent episodes made it difficult for parents to benefit from available respite services, since parents needed alternate caregivers that could be trusted to handle such unexpected situations in a competent

manner. In the absence of close, recurring contact with the child, adequate respite care was unlikely to be found within the public disability service system.

**Expanding boundaries of care.** The circumstances of caring for a child with DD at times necessitated expanding the typical boundaries of familial care. This involved relying on others beyond parents to provide care. Extended family members—especially grandmothers and aunts—were important sources of instrumental practical and emotional support, childcare, and respite, during times of daily stress and of distress. One parent described how their child's aunt was one of the few people their child was comfortable with; that aunt came to the family's home frequently to provide support. Another parent described the essential role their child's grandmother fulfilled:

*When my child is really in a dire state, they quite often want to see grandma. There's been a couple times where my child has packed up and gone and stayed with my parents for days. Just to give everyone a break. She's definitely a safe place. (Family C, autism, age 12)*

Expanding the boundaries of care was also evident in parents' discussions of entering into roles and contexts that are not typically the purview of and typical scope of parental responsibility (e.g., entering into educational and recreational settings to support their children with DD). While this sort of labor amounts to a tactical effort to take best advantage of existing supports and services, it also points to an extension of parental caregiving beyond the confines of the home and into the public and private institutions of the community. In expanding the boundaries of care, parenting moves beyond the persons (mom and dad) and spaces (home) with which it is commonly associated.

Parents' labor, tactics and strategies to afford a good life for their children with DD involved adjusting work and home lives, anticipating and/or trying to mitigate disturbances and crises, and expanding boundaries of care; however, such practical accommodations do not tell the whole story of adjustment in the face of childhood disability. Parents also needed to see themselves as performing their role in a good—or good enough—way.

### **Within Myself: Adjusting Perceptions of Adversity**

In addition to institutional and familial adaptations, parents shared how they made internal adjustments to cope with the challenges of raising children and youth with DD. This entailed shifting their perspectives, working to appreciate their child's positive qualities, and adjusting their expectations of their child, their family life, and themselves. Parents engaged in making meaning of their struggles through the strategies of *celebrating strengths, constructing a sense of growth, and configuring expectations*.

**Celebrating strengths.** One coping strategy involved focusing on the positive aspects of their situation to counter the struggles of challenging times. Parents described fostering gratitude and appreciation for their children. They proudly discussed the strengths of their children, such as intelligence, independence, determination, academic success, creativity, strong interpersonal skills, compassion, empathy, humor, athleticism, musical skill, and computer and technology savvy. One parent described their child as outspoken, “feisty,” a “spitfire” (Family M, Down syndrome, age 11), and another described how when their child put their mind to something, they didn’t give up, displaying “the most drive and determination of anybody I’ve ever met” (Family N, autism, age 14). In their daily lives, parents worked to balance attention to their children’s strengths and deficits. They also worked to establish their children as unique individuals—to prevent them from being defined by their struggles or their clinical labels.

**Constructing a sense of growth.** Throughout their narratives, parents also constructed a sense of personal and familial growth through suffering and challenge. Parents described how they learned from their unique children. One parent shared,

*my child has taught me patience. . . We don’t take things for granted anymore. . . It’s benefitted me specifically as a parent. You look at things a lot differently. . . I really changed. Some for the good. Some for the bad. We don’t look back. . . My child has really taught us a lot. . . Every day is a learning experience. (Family M, Down syndrome, age 11)*

One parent described how the growth and development of another child was also shaped by the relationship with their sibling with DD:

*The understanding and acceptance. It was miles and miles ahead of the general population. . . To have such a built-in skill set, just understanding and tolerance for humanity. With that and all the struggles we’ve gone through. . . I’m a much, much better person. (Family L, Down syndrome, age 7)*

Parents constructed their children as people who had invaluable lessons to offer to others because of their positive attributes, which were often intrinsic to their developmental differences. Parents expressed how they had experienced positive change and development in themselves as a result of caring for a child with DD. In constructing challenging experiences in this manner, the parents emplot personal and family stories using the narrative trope of “post-traumatic growth” (Good, 1994; Pals & McAdams, 2004). A common feature of narratives of chronic illness and disability, this rhetorical device helps to rescue personal and familial suffering from meaninglessness and infuse it with a sense of purpose and even advantage (Frank, 1995; see Gelech & Desjardins, 2011).

**Configuring expectations.** Parents also described configuring their expectations of their children and themselves as parents. They expressed fostering an openness to a myriad of possibilities for their child’s life. This entailed adjusting their expectations in certain circumstances while letting go of their expectations or retaining high hopes for the future in other contexts:

*Often times parents. . . have kind of a world map of what their expectations are as parents and as a family. . . It can be devastating and it was for us. . . We just want our child to reach their full potential whatever that’s going to look like. (Family L, Down syndrome, age 7)*

*The program said, “Treat your child no different and your expectations will be high and they will succeed in life.” And that’s how we’ve looked at life. . . That’s our ultimate outlook for our child right now, to be as independent as they can be. (Family M, Down syndrome, age 11)*

Parents worked to create new narratives of what a successful child was in their unique family circumstances. Subjunctivity—the active maintenance of various positive endings to a story in progress (Good, 1994)—was inherent to this approach. Parents were ready to accept a non-typical path of growth and transition to adulthood and remained open to the surprises that lie ahead. Yet, they nevertheless felt optimistic about the future and the many pathways that could lead to a good life for their children with DD. Through the strategies of celebration, configuration, and construction, parents made new meanings of their experiences. Counter to prevailing societal attitudes about the challenges of caring for a child with DD, parents reimagined their nonconforming experiences of parenthood and childhood with themes of uniqueness, growth, and possibility.

## Discussion

Findings from our study show how parents adapt their lives in a variety of ways in order to adapt and cope with the challenges of caring for children and youth with DD. Our analysis and interpretation of interview data with parents resulted in three major themes: *within the system—adapting with everyday tactics and strategies; within our family—constructing spaces of care; within myself—adjusting perceptions of adversity*. Numerous subthemes described a range of active tactics and strategies employed by parents to create a good life for their children and families: *employing savvy, influencing, managing impressions, sacrificing, advocating for change, adjusting our lives, adjusting our home, anticipating disruption, expanding care boundaries, celebrating strengths, constructing a sense of growth, and configuring expectations*.

Previous literature primarily emphasizes the practical aims of parents of children and youth with DD, focusing on the relationship between parents and the service system,

institutions and professionals. Taking a critical-interpretivist approach, our study highlights the creative strategies and tactics they employ to meet the instrumental needs of their children and to pursue the socio-moral project of making a good life for their children and their families (Certeau, 1984; Mattingly, 2014; Moen & Wethington, 1992). For some parents, an additional ethical aim involved advocacy for the greater good, for other children and families. The moral work of impression management and identity work also pointed to parents' desires to construct their children as whole persons. Although they needed others to respect the legitimate needs of their children, they often resisted any reduction of the child to deficits, labels, or difference. A similar process of decentering disability within robust identities has been observed within acquired brain injury populations (Gelech et al., 2019). These pragmatic and ethical aims arise in the context of a problematic and fragmented disability service network of support. Drawing on a holistic, ecological model (Bronfenbrenner, 1979), we noted how parents' tactics and strategies were employed at different levels of the psychosocial context, including the intra-personal (within oneself) and inter-personal (within the family and service network) spheres.

The parents we interviewed described adjustments to their home and work lives, the circles of care around their children, and attempts to mitigate children's upsetting symptoms. They also described adaptive outlooks to their unique situations of parenthood and childhood. Mas et al. (2016), using an ecocultural framework, described how families of children with intellectual disabilities made accommodations in employment, schedules, and informal supports (especially extended family) to construct a daily family routine in which to realize their values, beliefs, and goals. Similarly, our findings link family practices to moral projects. Guyard et al.'s (2017) study of family adaptation found that among parents of children with cerebral palsy, financial support, material support, equipment, socioeconomic level, marital status, and parental qualifications were not significant protective factors, but that family functioning, respite care and a positive attitude correlated with less parental distress. The findings of these studies and ours point to the need to attend to the interrelations of parental values, beliefs, goals, attitudes and practices, family system functioning, informal supports, children's development and parental distress, in the context of the constraints of social structures.

Previous research has suggested that while first-person accounts and shared experiences of people with disabilities and their families are essential, these must be considered within broader critical social perspectives and calls for system changes (Gelech et al., 2017; Matthews et al., 2021). A critical analysis suggests that a fragmented disability service system assumes, and even requires sacrifice on the part of parents and families to meet the needs of children with disabilities. Despite its known cost to parental and familial

well-being (Hsiao, 2018; Marquis et al., 2020a, 2020b), this obligatory sacrifice seems to act as a glue within disjointed and undependable services and supports as parents contribute their time, energy and expertise to serve as unpaid mentors, educators, care aides, and case managers and extended family and community members step in to assist with the needs of the children. Parents and researchers have advocated for enhanced service provision to allow for the offloading of such labor and the enhancement of parental and familial well-being (Matthews et al., 2021). The persistent, central role played by parents within Canadian disability service systems raises questions about how motivated decision-makers are to shift responsibilities.

Ongoing research suggests that high parental involvement is an assumed part of the plan of care for children with DD in Saskatchewan (Matthews et al., 2021). Such sacrifice disproportionately affects families based on resources, geographic location, and family configurations. While parents are to be commended for their adaptations, we question the justice of a service context that requires such ongoing familial sacrifice—from relocations to unpaid care service and even child surrender. When faced with an institutional problem that consistently eludes remediation, we must begin asking different questions and attending to the benefits, costs, and incentives accruing to particular stakeholders (Foucault, 1975). Turning a critical eye to the state of mothers of children with disabilities, Jennings (2019) noted that the Canadian state continues to shift the responsibility and financial costs of complex care for children with disabilities to the private sphere, namely on mothers. Jennings asserted that this withdrawal of care by the state has harmful consequences for mothers, who sacrifice money, resources, personal pursuits and social support to provide complex care. Persistent problems with service fragmentation and inadequate resourcing constrain and hinder parents from fulfilling their practical and ethical aims. In a system propped up by obligatory sacrifice, families of children with disabilities pay an immense economic, social, and psychological cost.

Perhaps the most critical evidence of inadequate public support for families of children with disabilities are the stories of children being surrendered to the state. This occurrence in Saskatchewan is not unique within Canada. While the full scope of the problem is not known, an estimated 100 to 150 cases of children with disabilities whose parents gave up parental rights to obtain residential care were identified in the province of Ontario in 2005 (Marin, 2005). A report presented seven cases, representative of dozens of others, noting that the lack of public services and funds forced them to make a "claim that a child is in need of protection [that] is simply manufactured out of desperation. . . parents contrived to endure the painful experience of "abandoning" their children, solely to get the help they required" (Marin, 2005, p. 28). Marin described this untenable situation, a "desperate sacrifice" for competent parents facing the choice of abandonment or privation of care:

We are making her give up her rights as a parent even though she is not standing in the way of him getting the support he needs. We are doing this for no good reason other than bureaucracy, technicality and entrenched position. . . [Families] either had to declare that they are “unable to care adequately for their children” or bear the stigma of a judicial finding that their child is “in need of protection” (Marin, 2005, p. 1).

While the vast majority of parents of children with DD do not surrender their children, these cases emphasize the distressing outcomes of service deprivation in some cases.

### *Implications for Nursing Practice*

Our findings suggest that nurses should provide advocacy for individual parents and children with DD, as well as promote changes in policies and systems to reduce the need for arduous family adaptations. Nurses can acknowledge and celebrate the variety of strategies and tactics that parents utilize, and collaborate with them to improve their quality of life. Research with parents of children with profound multiple disabilities (PMD) has highlighted how parents strive to protect their children at the cost of their own mental well-being (Seliner et al., 2016). For example, parents of children with PMD want to be fully informed about the plan of care and to know that nurses have special competencies in order to trust that their children will be safe and allow them to accept the respite they need (Seliner et al., 2016). Parents of children with special health care needs face an invisible, unpredictable, and existential struggle (with the disability and professionals) that requires them to develop defense strategies; well-prepared nurses can lessen their suffering and promote self-expression and healing (Nygard & Clancy, 2018). Nurses should communicate clearly and engage in thorough, holistic assessments of the family context (e.g., financial strain, fatigue, and social support), information needs and caregiving expertise, and the well-being of parents of children with DD (Seliner et al., 2016).

A number of nursing interventions have demonstrated utility in supporting families of children with DD. Health promotion toolkits (e.g., assessment and monitoring guides, education sessions) designed for children with DD can promote family empowerment and relieve stress by supporting parental self-efficacy and self-esteem (Ghoneim, 2018). Nurses can support and empower families affected by childhood DD by employing interventions such as the Family Strengths Oriented Therapeutic Conversation (e.g., developing a nurse-patient-family relationship, welcoming family illness stories and beliefs, recognizing resilience, and offering information), which can improve parents' quality of life and satisfaction with health care services (Svavarsdottir et al., 2020). Family-focused psychoeducational group therapy, delivered by a multi-disciplinary team including nurses, can provide social support, increase parenting self-efficacy, and decrease anxiety and depression in parents of children

with DD (Zhou et al., 2019). Nurses can deliver mindfulness training to parents of children with DD, which can promote their psychological well-being (i.e., decreased stress, anxiety, and depression) and healthy parent-child interactions (Petcharat & Liehr, 2017).<sup>3</sup> Nurses with knowledge of the challenges and strengths of families of children with DD should be prepared to conduct holistic and tailored assessments and implement family nursing interventions to improve child and parent quality of life and well-being.

### *Limitations*

The study was limited by the homogeneity of the sample in some characteristics (e.g., participant's gender, family constellation, ethnic background), though it was more heterogeneous in others characteristics (e.g., children's ages, type of DD, parents' ages, education and income, family size, geography). The sample profile should be considered when transferring findings to other populations. Indigenous people represent 4.9 % of the population of Canada and 16.3% of the population of Saskatchewan (Statistics Canada, 2018). Indigenous children and youth represented only 8.7% of this study sample. The rate of disability among Indigenous (First Nations, Métis, Inuit) children, youth, and adults in Canada is higher than non-Indigenous people (Statistics Canada, 2019). There is lack of research on the prevalence and experiences of child and youth developmental disability among Indigenous families in Canada, living on and off reserve, who frequently face distinct barriers to accessing appropriate and available services, including provincial and federal jurisdictional disputes (Dion, 2017; Di Pietro & Illes, 2014). Future studies should engage Indigenous families and communities to address their research priorities regarding DD. Future research with larger subsamples of men and pointed questions (e.g., regarding fatherhood/motherhood) could compare gendered differences in parental adaptations. Data was collected by self-report (e.g., children's diagnoses) and retrospective accounts, which can be unreliable; however, “retrospective reflection allows the individual to contemplate and evaluate an experience with the benefit of accumulated knowledge” (Gibson, 2016, p. 9). Not every category of experience was recounted by all participants; however, in this research, both shared and unique experiences were valued and shed light on the many ways parents of children and youth with DD adapt, cope, use tactics and strategies, and strive for a good family life.

### *Conclusion*

The findings of this theoretically engaged study offer a unified model of family adaptations enacted by parents of children and youth with DD to pursue their moral projects of child and family thriving in challenging and stressful contexts. Parents described creative and arduous practices within the service system, within in their families, and within

themselves to attain the care their children and youth required to flourish. Kearney (2001) asserted that it is sensible to apply in clinical practice the findings of trustworthy, complex qualitative research findings, which can offer an understanding of the common concerns and pathways of particular life experiences. Nurses can anticipate the expected challenges that families of children and youth with DD might experience, the supports and services they might need, the teaching and guidance that could be helpful, and locate their progress on a typical track of coping (Kearney, 2001). Nurses who care for children with DD often focus on functional and developmental assessment of the child; they also provide education of the parents and caregivers to support the child's growth and activities of daily living (Olli et al., 2014). Our findings identify a number of key areas for nursing assessment of practical and psychosocial support needs of parents, children, and youth with DD to guide the selection of interventions to enrich their health and well-being.

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### Notes

1. DD are conditions that begin in early childhood during the developmental phase; are usually permanent; manifest in deficits or impairments in physical, motor, behavioral, social, learning, cognitive, language, speech, sensory (hearing and vision loss), psychological, and occupational functioning; and are often comorbid with other DD (APA, 2013; Global Research on Developmental Disabilities Collaborators, 2018; Miller et al., 2012; WHO, 2020; Zablotsky et al., 2019). Neurodevelopmental disorders include intellectual disabilities, communication disorders, autism spectrum disorders, attention-deficit/hyperactivity disorder, specific learning disorder, and motor disorders (APA, 2013). Psychosis, depression, anxiety, oppositional defiant disorder are other classifications of

mental disorders (APA, 2013). Cerebral palsy and epilepsy are nervous system disorders, and Down syndrome is a developmental anomaly (WHO, 2020). Analysis by Global Research on DD in 2016 included six DD types: attention-deficit/hyperactivity disorder, autism spectrum disorder, epilepsy, hearing loss, vision loss, and intellectual disability.

2. Canadian federal and provincial health care, education, and social services are publicly funded (through taxation). The Canada Health Act provides for publicly administered, comprehensive, accessible, portable, universal health insurance coverage (see Government of Canada, 2011). Disability and rehabilitation supports are also provided by non-governmental, community-based organizations that receive public, private, and charitable funding. This means that families do not pay out-of-pocket for basic disability services. Due to long wait times and limited quantity of services, some families may seek and pay for private services to access support more quickly and frequently than those offered by health care, education, social service, and non-governmental programs. Private and supplementary services that are not covered by public funding (prescription drugs, dental care, vision care, medical equipment, etc.) are paid for through employer benefit plans, private health insurance, and/or out-of-pocket. Some provinces provide special coverage for children and people with disabilities. Inclusion Saskatchewan's (2021) system navigation guide describes how disability services are offered and paid for in one Canadian province.
3. Studies cited in the literature review sampled from Australia, Belgium, Canada, Jordan, Qatar, Sweden, Taiwan, United Kingdom, and United States. Studies cited in the discussion sampled from Australia, China, Denmark, France, Iceland, Ireland, Netherlands, Norway, Saudi Arabia, Spain, Sweden, Switzerland, Taiwan, United Kingdom, and United States.

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