Filtered Out: LGBTQ Parents Engage with Special Needs Service Systems

by

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Abstract

Using ethnographic methods, this study started from the everyday activities and narratives of LGBTQ parents of children with 'special needs'. A critical approach to intersectionality was employed to consider how certain parents, children, and families are constructed as "different" or "not fitting" in particular settings and contexts, and what consequences follow (Crenshaw, 1991; Gibson, 2013). Fifteen parents and six key informants were interviewed, all of whom were based in the Greater Toronto Area. Methods used were drawn from institutional ethnography (Smith 2005) and discourse analysis (Gee, 2005; Riessman, 2008).

The study found that special needs services systems operate to 'filter out' potential service users at multiple points of contact, regardless of the intentions of individual providers or the written policies of organizations. Parents encounter interpersonal and text-based, procedural barriers that discourage, deny, and defer claims. As a result, parents do extensive 'systemwork' to improve the chances that their children will receive needed supports, and to fill in the gaps when they do not.

This institutional reliance on parental work and the resulting framework of competition means that what children and families receive is highly variable. Parents marshal whatever financial, social, and relational resources they have in support of their efforts. Often 'going private' is the only or best means of being able to secure or augment public services, however only some parents have the financial means to do so. For parents and children with fewer resources and privileges, it is more difficult to avoid being filtered out.

Parents reported particular vulnerabilities and strategies related to their LGBTQ identities as they navigated special needs services. Parent narratives reflected the ways that parents both contend with and reshape dominant ways of thinking about queerness and disability. The impact of dominant notions about 'desirable' children and parents could not only be seen in parents' narratives and strategies, but also in their reluctance to engage with special needs systems. This discursive background is thus another means in which parents are filtered out.

These findings have implications for users, researchers, and providers of special needs service systems, particularly those who want to make special needs service provision accessible and responsive to all.

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Chapter 1

Parents, Work, and Desirable Reproduction

How does social work -- as a profession and a body of knowledge -- think about parents? Social workers, individually, work with parents in many different ways and in many different settings, and are often given the role of working with parents and other family members on inter-professional teams. However the ways that social work theory and research address parents tend to be much more restrictive. Many social workers who spend time interacting with parents do not identify this work as at the defining core of their practice. Instead, it is common for these social workers to describe their roles and agencies in terms of work with "children" or possibly "families".

Indeed, emerging from the profession's strong historical and enduring connection to child welfare systems, social work has a long history of evaluating and working with parents – and mothers in particular -- from a child-centred, risk-focused, regulatory, or even diagnostic perspective (De Montigny, 1995; Donzelot, 1979; Hicks, 2011; Krane, 2003; Lessa, 2006; Little, 1998; Swift, 1995, 2010). Dominant social work theories, for example, highlight parents as the backdrop of staged childhood development in which personality and ways of relating to the world develop (e.g., psychodynamic theoretical approaches including attachment theory), a cause of adequate/ inadequate resources and "risk" for children (e.g., ecological and child welfare models), or a site of intervention often in support of goals for children or for family groups as a whole (e.g., family therapy models, parent support groups and training programs that follow cognitive-behavioural models). Some approaches have highlighted the impact of community and structural oppression on the family as a whole, however these have not necessarily addressed how direct practice with parents, in particular, might proceed (e.g., anti-oppressive practice). While feminist, structural, indigenous and queer social work approaches

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have offered the greatest opportunity for exceptions, a general rule can be observed across the domains of practice: **social workers work extensively with parents but use models and approaches that under-theorize the importance of this work and its relationship to a social justice mandate**.

In contrast, the present study starts from taking parents seriously as a beginning point for investigating service systems and social beliefs. As an ethnographic investigation of the experiences of lesbian, gay, bisexual, transgender and/or queer (LGBTQ) parents of children with designated 'special needs', this study and its findings take seriously the importance of parents' everyday experiences in the production, replication, and critique of institutional processes and social discourses. This opening chapter offers a starting rationale for the project and its theoretical and methodological orientation. Here, I situate the project and my own relationship to it: how did this topic come to be investigated at all? Then I outline the conceptual tools and literature that undergird this ethnographic investigation into the experiences of LGBTQ parents of children with 'special needs'. In particular, I attend to the ways in which mothering/ parenting work and knowledge can be marshalled to investigate larger social beliefs, and the theoretical and methodological resources that usefully frame such an investigation. Next I consider the widespread discourses that I summarize as 'desirable' reproduction and how they operate in the lives and interpretive context of LGBTQ parents and parents of children with 'special needs'. Finally, I outline how a critical approach to intersectionality – one that is rooted in everyday, contextual, and relational encounters – underlies the project's central research questions.

Terminological Note

Throughout this dissertation, the terms "LGBTQ" and "queer" are used interchangeably to designate people whose identities and/or relationships fall outside of heterosexual and/or

cisgender (non-transgender and non-transsexual) norms. There are many alternatives that may be more personally or politically appropriate to individuals involved in the study, and participants described their own relationships to these terms. Nevertheless, these terms are used since they are currently the most broadly accepted and intelligible within the communities discussed, including those of academe.

While "parents" appears as a gender-neutral term, caring labour is highly gendered as "women's work" in the current context. Nevertheless, the non-gendered term "parent" is used to indicate that I am not restricting my analytic attention to people who identify as mothers or fathers. "Parent" is elsewhere often presumed to be biologically and/or legally determined. This is not how I use it here. Instead, I use it to denote a self-proclaimed, enduring relationship identified as part of "family" in which everyday practices of caring work are done for children (often called "mothering" elsewhere). The study was open to people who were and were not legally recognized as parents and to those who had children come into their lives in many different ways.

Similarly, any terms denoting 'special needs' or 'disability' are necessarily contested and socioculturally contingent (see, e.g., Shakespeare, 2006; Snyder & Mitchell, 2006; Titchkosky, 2007). Following a politicized, social model of disability, this study presumes that when and how someone denotes 'special needs' is an act of social interpretation rather than an objective notation (Goodley, 2001; Kafer, 2013; Oliver, 1990, 2009). 'Special needs' discussed in this dissertation included but were not limited to sensory, neurological/psychiatric, developmental, intellectual, and physical realms of identified difference (see Chapter 2 for a summary of the diagnoses that participants discussed). Further, while I use the phrase 'special needs' due to its institutional and social dominance in the current context, I retain scare marks around 'special needs' when applied to people rather than service systems. I do so because I do not believe that

individuals and groups so designated have anything particularly special or unusual about their needs, but rather that their embodied activities call upon institutional responses that have not been broadly anticipated or provided for. Indeed, the very designation of particular individuals and their needs as "special" denotes a distancing and marginalizing process from the presumed "us" of the reader/writer or speaker/listener (Michalko, 2009). It is exactly the texts and interpersonal encounters in which such designations occur that are central to this dissertation's research questions and methods.

Beginnings: Situating the Project

This study emerged from a series of experiences, observations, and questions rooted in my own "everyday"; these led me to explore this largely unexamined area of social work scholarship. Consistent with ethnographic and feminist methods, the story of how this project came to be is an important consideration for any reader or future researcher who strives to understand its rationale and my own positionality, weigh the resulting data and analyses, and integrate its findings into the context of other experiences and writings (Smith, 1987, 2005).

Prior to undertaking this dissertation research, I had experienced both social work and parenting in shifting and overlapping ways. I had been a social worker who often worked with parents within programs labelled "child and family work" where I relied upon child-centred theories and job descriptions that situated my interactions with parents as a necessary but taken-for-granted adjunct to interacting with children. I had also become a parent, a humbling and eye-opening experience that prompted me to revisit and revise some of my professional advice to parents over the years.[1]

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[1] For more detailed reflections on my experiences as both professional "expert" and "queer parent" with regard to children with disabilities, please see my chapter "Unsettling Expertise: Disability and Queer Resistance" (Gibson, 2014f).

These two experiences came together with greater urgency when my partner and I started trying to find special needs services for one of my children. In this search, we encountered multiple barriers and gaps in services and knowledge – even after I had spent years of working within these same systems and received extensive training in talking with professionals and navigating services. While I found that the professionals I worked with seemed to have good intentions and evident skills, they frequently expressed an inability to procure services for my child within their own institutions, expressed a lack of knowledge about other related institutions, bemoaned scarce resources and gaps as inevitable, and seemed fundamentally unaware of the time and effort that we, as parents, had undertaken outside of and exceeding actual meeting times. On an everyday level, I spent an astonishing amount of time and energy researching treatments and terms, making appointments, and following up on waitlists – work that I knew I had previously taken for granted as a practitioner.

Further, as a LGBTQ-identified parent, I was aware from my own experiences that systemic beliefs and practices about what constitutes "family" could come up at any time and cause additional work and emotional distress. I had learned this experientially from the earliest days of parenting. For example, when I went to a government service centre to start the employment insurance payments that would support my parental leave – a leave that had been approved by my employer and that I had understood to be a mere matter of bureaucratic rubber-stamping – I was immediately made aware of my parental "difference". Upon handing in my application, I was asked to wait with my infant daughter while various supervisors were recruited. They talked with me and each other as they tried to figure out how to fill out the existing forms for me, there categorized as a non-biological mother married to the biological mother while "second-parent adoption" paperwork was still in process. While these discussions proceeded, I worried about the prospect of having a delay or even a full gap in my family

income. More immediately, I fretted about whether I had enough bottles and diapers to cover the additional wait and the sleep-deprived presence of mind to make my case again and again, as the situation demanded. While this experience was not officially an encounter with special needs services, it taught me a lesson that was kept in mind throughout each later encounter with special needs service systems. As I struggled with each round of forms and institutional blockages, I was also facing the ongoing question of whether my family's particular history would "fit" with the institutional forms, or the providers' own understanding of who even "deserves" their time.

Finally, on a community level, I was aware of the presence of ableism in my own family's encounters with other parents, LGBTQ and not. In particular, I heard, and felt, the many "small" ways that LGBTQ parents can face pressures to be "poster parents" in the face of anti-LGBTQ sentiment. Since I was simultaneously involved with other LGBTQ parenting communities and researchers, I heard from others that they were also struggling to find their ways through disability service systems as LGBTQ parents. Many of these parents, like me, had particular combinations of privileges including professional training, and yet reported meeting endless rounds of institutional and informational gaps and blockages. As LGBTQ parents, many also reported uncertainty about engaging with dominant understandings of "normalcy" as represented in diagnoses and standardized assessments, and yet found they needed these same troubling ways of categorizing their children if they wanted to access any of the (possibly) available resources.

These observations in everyday experience became what Dorothy Smith and subsequent institutional ethnographers call "disjunctures": contradictions, misalignments or gaps that indicate that a particular area of social organization warrants further investigation (Campbell & Gregor, 2008; Smith 2005). Such disjunctures do not themselves constitute a research study, but

they form the starting point for investigating what social processes and discourses might lie behind these everyday experiences. In contrast to starting with a review of the literature, then, institutional ethnography begins in "actualities" of observation and experience (which may also include the reading of existing research).

As a starting doctoral student, I had planned to do my thesis project on LGBTQ parents' interactions with service systems, however this particular project was not what I had in mind. This project, instead, emerged from the disjunctures I observed, which had been, in turn, reinforced through conversations with other researchers, LGBTQ parenting community workers, and other parents of children with disabilities or 'special needs' – parents both LGBTQ and not. This project, then, emerged from an interest in investigating the ways in which special needs services and dominant discourse about reproduction operate, proceeding from the gaps and contradictions in everyday conversations and experiences. In Dorothy Smith's words, institutional ethnography proceeds from "a commitment to the actual rather than the conceptual" (Smith, 2005, p. 57).

As a result, I conceptualize my own experiences and location as a social worker who is also an LGBTQ-identified parent of a child with a designated 'special need' as an important starting point for this study, although it is not the only point from which this investigation might have proceeded. As I describe in greater detail in the next chapter on methods, participants and organizations that supported the recruitment of participants also knew about my own experiences with this topic to some extent, although only some participants asked for further details (usually around my child's age, gender, and particular diagnosis).

This is not to say that the findings have been "tainted" by my subjective experience, since the feminist ethnographic methods used do not follow a premise that "objective" research is either desirable or possible. Rather, this information on how I arrived at this project can help

to ground the study in a particular set of experiences and relations, as well as a time and place. Participants were talking to me rather than to anyone else – and many explicitly stated that they were talking to me about this because our experiences overlapped in some way. In the interviews and analyses, I was co-constructing an understanding of participants' experiences in ways that called upon and reshaped my own. In explicitly starting from my own history with this topic and the development of the current study, I and other critical ethnographers reject what Donna Haraway has called "the God trick" of so much institutional and academic writing: the flawed assertion that knowledge is gathered and presented from a disembodied and omniscient perspective (Haraway, 2004, 86-89). Instead of viewing existing research as a neutral background with "gaps" to be filled, such critical ethnographic approaches assume that research and objective-sounding abstractions also come from particular embodied experiences, and the ways that gaps 'appear' in this research often reflect social arrangements of power.[2]

While this project may have its inception in my own observations and experiences, the methods used and analyses completed expand its implications well beyond my own experience. Interviews with participants and key informants, bolstered by additional conversations and readings with other researchers (including those on my thesis committee) and colleagues at conferences and in the larger community, as well as the consideration and selective integration of related scholarly work, all expanded the empirical basis of this project beyond my own particular location and relations. The methodology used invites comparison and useful combination with other research on how service systems and discourses operate from other starting points and research questions. Given the large-scale impact of ideologies such as neoliberalism, ableism, and heteronormativity, the particularities of this study can connect up with other research studies that take place in markedly different contexts (Neysmith 2000;

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[2] See Craven & Davis, 2013.

Smith, 2005, pp. 212-213). It is through a careful consideration of how a particular set of relations and discourses operate that such larger forces can not only be identified, but also challenged (Frampton, Kinsman, Thompson & Tilleczek, 2006).

Taking Parents Seriously: Starting From the Everyday

The relative under-theorizing of parents and parenting is certainly not restricted to social work, nor can it be understood apart from a gender analysis. Scholars of parenting and mothering have highlighted the many ways that mothering and other caring work – done by parents or others of any gender but situated in the domain of "women's work" in current North American culture -- is institutionally shaped (Baskin & McPherson, 2014; Collins 1993, 2000; Crittenden, 2007; Epstein, 2005, 2009; Gabb, 2005; Gibson, 2010, 2012b, 2014b, 2014c, 2014e; Griffith & Smith, 2005; Hays, 2007; Hequembourg, 2004, Kinser, 2008; Lewin, 2007; Lorde, 1984, 2009; Nelson, 1996; Rich, 1995; Roberts, 1998; Ruddick,1995; Vandenbeld Giles, 2014). Caring work, particularly as it occurs within kinship relations, is commonly portrayed as both "natural" and, simultaneously, in need of being highly regulated by "professionals". As described in Adrienne Rich's classic, *Of Woman Born: Motherhood as Practice and Institution*, the realm of parenting is highly contested in gendered ways, such that individual North American mothers are led to believe that any struggles they have raising children signify their own personal failings rather than structural inadequacies and unreachable standards (Rich, 1995). Indeed, psychological and educational theories have a long history of "mother-blaming" throughout professional discourses, including those central to social work. For example, as Karen Swift has identified, the widespread and apparently objective construct of "child neglect" obscures the crucial impact of poverty, racism, and sexism that leaves individual women both solely responsible for and unable to meet their children's needs (Swift, 1995).

Motherhood studies scholars have examined the many ways in which mothering practices contest and are shaped by dominant notions of motherhood across multiple social and institutional contexts. Often building upon the work of Adrienne Rich, scholars such as Audre Lorde (1984, 2009), Patricia Hill Collins (1993, 2000), Anne Crittenden (2007), Sharon Hays (2007), Dorothy Roberts (1998) have highlighted the many ways that motherhood experiences are shaped and curtailed by institutional forces, while motherhood practices can simultaneously offer opportunities to question and even resist such dominant beliefs and social hierarchies. Fatherhood scholarship has similarly identified the ways that caring work done by men meets different but nevertheless materially inadequate social valuations and supports, all of which can only be understood in conjunction with dominant discourses about "women's work" within the construct of kinship (Doucet, 2006; Stacey, 2006).

The intertwined effects of discourse and institutional practice on how we do (not) recognize caring labour in everyday life can be seen as a part of scholarship on social reproduction, more generally. Social reproduction extends beyond schooling or even parenting and refers to the work and processes that occur as a pre-requisite for the functioning of labour markets and states. While many conceptions of "politics" and "economy" restrict their analyses to prioritize the activities of corporate and/ or state-funded organizations and representatives, feminist political economy analyses highlight how these domains of social organization take for granted the activities done within what has been conceptualized as "the private sphere" (Luxton, 2006). In other words, the caring activities and other household labour that has primarily been done by women is seen as "not work" or as apart from and irrelevant to the functioning of state policies or corporate activities (Swift & Birmingham, 2000). Of course, this attentional neglect supports the interests of some groups in society, particularly those who can purchase or

otherwise rely on their social reproduction needs being adequately met -- at low or no cost -- by others.

For the purposes of this study, feminist political economist research on social reproduction are crucial, particularly those that address the impact of neoliberal ideologies and institutional practices (Abramovitz, 2010; Bezanson, 2006; Fox, 2006; Gavigan & Chunn, 2010; Gilmour, 2010; Swift, 2010). Feminist scholars have convincingly noted the ways that mothers and others doing "caring labour" are particularly affected by "privatization" or, alternatively, "reprivatization" strategies (Braedley, 2006; Evans & Swift, 2000; Kinsman & Gibson, 2014; Mosher, 2000, 2010; Vandenbeld Giles, 2014). Privatization has been a central part of discursively and institutionally dismantling core aspects of the post-war welfare state model by offloading state and other public responsibilities/ resources to the for-profit marketplace and/or unpaid labour of "the family". Applications of neo-liberal ideology have led to scaling back collective/state investments that support social reproduction (e.g., childcare, supportive housing, income support), and a concurrent exhortation that "families" and "the market" (usually women who are unpaid or low-paid in either case) should be responsible for meeting the needs of children, disabled people, the elderly, and anyone else who is not adequately supported through the labour market. As summarized by Christa Craven and Dana-Ain Davis:

> Neoliberal ideologies, with their shift away from advocating government responsibility for assuring social, political, and economic rights toward an over-reliance on consumption and the market to resolve social inequities, came to dominate corporate and governmental spheres in the late 20th century. The implications of this shift have been far reaching. The most profound effect, we would argue, is the impact on the everyday lives of those struggling to survive within widening economic gaps – gaps created by a seemingly unwavering political faith in the free market as the panacea for social inequalities. (2013, p. 1)

Such practices extend beyond national borders (Duggan, 2003; Fraser, 2009; Katz, 2001). Within a context of both globalized corporate practices and the concurrent discursive and institutional exaltations of Northern nation-states, transnational feminist researchers have

highlighted the ways that social institutions and dominant ideologies depend upon the availability of workers who provide caring labour beyond kinship. For example, there is extensive transnational migration from the Global South that Northern states rely upon in securing workers to provide care for disabled people and children in North American settings at low wages and in often exploitative working conditions, and with material and relational effects on their own kinship networks (Arat-Koc, 2006; Bryan, 2014).

However the ways in which neoliberal ideologies and institutional practices occur in a globalized context rely upon local, contextually-dependent practices. Possibilities for questioning and challenging these global trends must be similarly rooted in everyday experiences and particular contexts. Again, in moving away from abstractions and towards actualities, this project follows the tradition of critical feminist ethnography in which any division between "micro" and "macro" forces is rendered suspect (Smith, 1987). It is only through individual and everyday experiences that large-scale forces such as ableism can be seen in action. It is only through a consideration of large-scale forces that the particular form and meaning of everyday experiences can be understood. Indeed, scholars such as Craven and Davis (2013, pp. 1-3) argue that feminist ethnography can identify the "gaps" in neoliberal rhetoric through showing what people actually do when they need things that are not easily available – the approach taken here.

The current study investigates the institutional and discursive forces shaping a particular set of parents' tasks and responsibilities under the construct of **"systemwork", that is, the activities which parents undertake in their everyday lives as part of satisfying systemic or institutional requirements in order to access needed resources for their children**. My creation and use of this term follows from Sheila Neysmith and colleagues' conceptualization of "provisioning" (Neysmith, Reitsma-Street, Baker Collins, & Porter, 2012), but restricts this

project's attention to a more narrow range of activities. Neysmith et al. use "provisioning" to describe "the work needed to realize the necessities and conveniences of life" (2012, 4), thus describing a wide range of activities done with the intent of obtaining needed resources for individuals to whom they have responsibilities. Here, "systemwork" designates the subset of provisioning that is directly connected to the requirements of professionalized and institutionalized service systems, with a focus on special needs service systems.

"Systemwork" also complements and refines institutional ethnographers' expansive understanding of "work":

> By institutional ethnographers, 'work' is used in a generous sense to extend to anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about. It means much more than what is done on the job. (Smith, 2005, p. 151-152).

Thus, "work" can be paid or unpaid, recognized or unrecognized, emotional or intellectual/ physical, and can include waiting or answering questions as well as filling in forms or asking question. This investigation of service users' work as they attempt to "hook up" to services builds on the concept of "lifework" used by Smith, Mykhalovskiy and Weatherbee in their ethnographic research from the standpoint of people living with HIV/AIDS (2006). A strength of institutional ethnography has been in its recognition and investigation of work that has been previously rendered invisible, particularly work that has been done by women (see e.g., Griffith and Smith, 2005). The unpaid work that parents, and particularly mothers, do is frequently rendered invisible; consider phrases such as "work-life balance" in which "work" refers exclusively to paid employment outside of "life" and the home (Gibson, 2012b). Similarly, while "service users" and "disabled people" have often been defined in terms of "not working", other ethnographers have identified the extensive work that disabled people and other service users engage in as they attempt to secure needed resources (e.g., Arndt, 2008; Barken, 2013; Campbell, 2008; Corman, 2008; Deveau, 2011; Traustadottir, 2008).

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In this study, 'special needs systems' include (but are not limited to) medical, educational, community-based/ recreational, supportive housing, and social service organizations and professionals that have at least some mandate and/or resources to address 'special needs' or 'disability'. The systemwork done by parents of children with 'special needs' certainly varies with the family's particular situation. However the very identification of a child's perceived difference as a 'special need' necessitates engaging with organizational systems, and such encounters demand particular activities of parents, all of which take time and effort.

The systemwork this study examines is not reducible to 'paperwork'. While systemwork would include filling out forms, it would also include attending meetings, picking up prescriptions, interpreting reports, filing insurance claims, documenting telephone conversations, scheduling and attending appointments, making follow-up calls, sending emails, implementing suggested interventions (e.g., giving medications, responding to children's behaviours in prescribed ways), making decisions on programs or plans, researching treatment/service options, addressing unexpected situations (e.g., emergency telephone calls), and integrating the emotional, physical, mental, and relational components of these various interactions and activities, all **in addition to** any paid employment and other everyday/ everynight work (Smith, 2005) of caring for their children and other people in their lives.

LGBTQ parents also have particular work that they also do to satisfy systemic requirements. Stephen Hicks has discussed how LGBTQ family members engage in different aspects of "kin-work" in response to institutional and cultural heteronormativity, here considered a subset of systemwork (Hicks, 2011, pp. 33-37).[3] For LGBTQ parents, this arena of systemwork can involve an additional layer of assessing and responding to institutional requirements in order to assert their relations and status as family members (and therefore

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[3] This type of kin-work also connects conceptually to what Finch has called the "display work" people do to enact "family" in a way that is recognizeable to others (Finch, 2007).

credible service users or 'advocates'), often prior and/or in addition to seeking resources or information (Allen, 2007; Bauer, Hammon, Travers, Kaay, Hohenadel & Boyce, 2009; Bergen, Suter, & Daas, 2006; Broad, Alden, Berkowitz, & Ryan, 2008; Brown & Perlesz, 2007; Connolly, 2002; Eady, Ross, Epstein, & Anderson, 2009; Gabb, 2005; Hequembourg, 2007; Hicks, 20011; James-Abra, 2012; Lewin, 2007; Luce, 2010; Mamo, 2007; McClellan, 2001; Mitchell & Green, 2007; Nelson, 1996; Pyne, 2011b; Riggle, Rostosky & Horne, 2010). Such systemwork might include selectively revealing or concealing family identities when facing forms and conversations which assume heterosexual/cisgender identities and relations; seeking to create officially-recognized family relations through adoption, marriage, immigration, and other documents when procuring resources based on familial ties; or explaining to multiple others how relations within the family replicate/depart from ideological expectations of "the Standard North American Family" (Smith, 1999).

This study strives not only to develop an understanding of parents' everyday systemwork, but also to understand the institutional relations and discursive ideologies that make this work necessary (DeVault & McCoy, 2006; McCoy, 2006; Neysmith et al, 2012; Smith, 2005). **In starting from parents' everyday experiences, this study asks that we see the impact of parenting and "caring labour" beyond its immediate effects on the "cared-for" children and adults or the parents themselves, and instead shift our analytic attention to the institutional practices and discourses that rely upon and shape this work**. Organizational and institutional practices of all kinds rely heavily upon the work done by parents, and particularly mothers. As Allison Griffith and Dorothy Smith described in their influential study of schooling in Ontario, the unpaid work done by mothers is heavily relied upon by educational systems (2005). Indeed, these authors argue that mothers who might have been unable to provide the same extent of "free" supplemental labour to schools – such as

'single' or 'working' mothers – are discursively and interpersonally devalued **because** they do not provide work that the schools are set up to require. Integral to the invisibility and potency of such assumptions of mothering labour is the role of what Griffiths and Smith describe as "mothering discourse", in which the developmental and educational attainment of children is portrayed as directly reflecting the efforts and skills of their mothers (Griffith, 2006). This mutually-reinforcing integration of mothering discourse and schools' institutional practice makes it almost impossible for people situated within schooling – whether as teachers, administrators, parents, or students – to identify the ways in which power operates upon mothers' everyday activities.

Once we take the work and knowledge of parents seriously, then, we get a different view of the ways in which institutions and discourses operate. Other aspects of social practice and ideology that are similarly "taken for granted" can be brought into the analytic frame. This study, therefore, offers a previously unexplored, empirical perspective on everyday practices and narratives that have more abstractly been considered as heteronormativity/ cisnormativity, kinship, caregiving, social service provision, and disability. Following ethnographic methods, this research is grounded in the everyday activities and narratives of LGBTQ parents of children with 'special needs' as a particular vantage point on larger social relations and interpretive frameworks.

Desirable Reproduction? Dominant Discourses

Why start from the standpoint of LGBTQ parents of children with 'special needs'? First, in a diffuse, shifting, and multidisciplinary area of service provision such as disability, any gaps within and between texts (e.g., special education legislation) and practices (e.g., parent-teacher interviews) may be particularly evident. LGBTQ parents whose children have been identified as having 'special needs' are likely to engage with a variety of different providers, with increased

vulnerability to (and therefore experiential knowledge of) institutionalized inadequacies and interpersonal discrimination. After multiple and ongoing contacts with different professionals and policies, these parents can offer particularly extensive and wide-ranging examples of how systems respond to parents in general, and what particular systemic and discursive features result in the marginalization or exclusion of (some) parents and (some) children.

Second, researchers have seldom considered the perspectives of **any** parents on their interactions with special needs service systems, let alone those who have been otherwise marginalized (Farrugia, 2009; Fisher & Goodley, 2007; Goodley & Thegaskis, 2006). The proposed study thus offers a much-needed addition to research on parents of disabled children in particular, and service users more generally. This study moves beyond individual attitudes of service providers and instead explicates how institutional relations and policies operate from the perspective of these parents (Hicks, 2011; G. Smith et al, 2006). As such, findings offer empirical guidance for parents, service providers, and advocates who hope to make institutional arrangements more effective and just (Frampton et al., 2006).

Third, ideas of 'normal' and even 'desirable' children saturate our cultural responses to both parenting/ reproduction **and** disability (Douglas, 2013, 2014; Goodley & Thegaskis, 2006; Landsman, 2009; McGuire, 2013; Salmon, 2007). Categories and practices surrounding disability as "the rejected body", in Wendell's phrase (1996), reinforce certain beliefs about 'normalcy' and socio-bodily control. Discourses surrounding reproduction, including reproductive technologies, often include assumptions of idealized bodily 'normalcy' and 'health' in implicit contradistinction from disability (Bumiller, 2009; C. Thompson, 2005). For example, individuals filling in forms to obtain donor gametes or to adopt/foster a child face questions about what traits they would desire or accept (Hicks, 2011; Mamo, 2007). In the process, certain traits and certain children are deemed more 'desirable', and known or suspected disability is categorized under the rubric of 'risk'

and 'bad outcome'. Similarly, when parents interact with professionals who assess some of a child's needs or traits as 'abnormal' or 'exceptional', certain notions of the unexceptional or 'normal' child/person are produced.

In sum, throughout texts and practices that make up the services surrounding family formation (e.g., assisted reproduction, adoption, marriage) and those surrounding disability (e.g., special education, rehabilitation, diagnosis) we can identify dominant discourses on **desirable reproduction** and identify how these hook up with the institutional practices parents encounter (see Gibson, 2013). The implications of such discourses and their institutionalization spread far beyond this particular group of parents. They extend to policies, practices, and national-cultural narratives about who should reproduce and parent, and how, and who should be "reproduced" as members of a society and/or nation.

These notions of desirable reproduction have not emerged from a historical void, nor can they be easily disentangled from the institutions and practices of social work itself. Indeed, any consideration of who and what should be reproduced can be rooted in a legacy of eugenics. Eugenics was the term given to ideologies and practices that rose to mainstream European and North American prominence in the late nineteenth and early twentieth century whereby people worked to improve the "fitness" of a society through the promotion and suppression of reproduction by certain members and groups (Gibson, 2013; Reaume, 2014; Snyder & Mitchell, 2006). While eugenics as a scientific construct was coined by British statistician and epidemiologist Francis Galton in the early twentieth century, the belief that policies and practices should try to direct who populated the future of society was already deeply intertwined with colonial and white supremacist projects that far exceeded Galton's individual lifespan or professional influence (McLaren, 1990; Ordover, 2003). Indeed, critical disability studies scholars have highlighted the centrality of eugenics in the development of categorization systems and

diagnoses that then justified the institutionalization, sterilization, denial of medical treatment, and even the killing of disabled people across different places and times (G. J. Epstein, 2014; Kafer, 2013; Reaume, 2014; Snyder & Mitchell, 2006). Similarly, historians of sexuality and LGBTQ communities have also described the ways that scientific and institutional measures of evolutionary "fitness" (e.g., intelligence quotient scores), race, class, and gender non-conformity have been integral to the categorization and regulation of sexuality (Gibson, 1997, 1998; Gilman, 1985; Hegarty, 2007; Kinsman, 1987; Ordover, 2003; Rosario, 2002; Somerville, 2000; Terry, 1999).

It is crucial for social work practitioners and researchers to recognize the extent to which the profession of social work has been intertwined with eugenicist institutions and ideologies. As I have described elsewhere (Gibson, 2013), one of the most prominent Canadian social workers of the 1930s – Charlotte Whitton -- participated in the explicit advancement of eugenicist ideologies, and using social work research to this end (see McLaren, 1990; Moffatt, 2001). More generally, the Canadian advancement of social work practice and "expertise" has often been institutionalized in ways that reinforced eugenicist perspectives, such as the creation of institutions that segregated parents from children or removed some people from full participation in society, including the possibility of parenting. For example, eugenicist impulses have been central in the Indian Residential Schools system that led to the removal, maltreatment, and even death of many Aboriginal children. The impact of residential schools as a colonial and white supremacist project has been bolstered and supplanted by child welfare actions such as the removal of Aboriginal children from their communities, and reflected in ongoing over-representation of Aboriginal people in child welfare systems (Chapman, 2013; Quinn, 2007; Thobani, 2007; A. Smith, 2004). Additionally, practices of segregation, sterilization, and institutional regulation of people designated as having psychiatric, developmental, intellectual, physical, and sensory disabilities –

particularly when they are racialized and/or impoverished – have been perpetrated throughout prisons, immigration policies, education systems, housing policies, and healthcare systems where social workers have often been employed (Carey, Ben-Moshe, & Chapman, 2014). It bears mention that there have also been social workers who objected to and fought again eugenicist practices (Reisch & Andrews, 2002). Nevertheless, the legacy of eugenic regulation of reproduction and parenting can be seen across multiple domains of practice in social work as well as in allied fields such as public health, medicine, sociology, and anthropology.

While the terminology and the particularly explicit practices of eugenics have been largely discontinued in the contemporary Canadian context, **this study explores ways in which notions "desirable reproduction" continue to shape people's experiences, and how these are reproduced and resisted in people's actions and narratives**. When parents are navigating systems, filling out forms, and themselves narrating who they and their children are to either a professional or to a research interviewer, they are engaging with discourses that have long and complicated histories that denote reproduction as a space of normalization and professional scrutiny. For example, when LGBTQ parents are questioned for being "selfish" in having children outside of heteronormative frameworks, or when parents of children with 'special needs' are seen through a distancing lens – whether of sympathy or condemnation – these exchanges reproduce notions of who is deemed "desirable" as a parent or a child.

LGBTQ parents and parents of children with 'special needs' have separate but overlapping relationships to notions of desirable reproduction, and members of each group have their own range of possible responses to dominant discourses. However these both groups, and the individuals categorized in each, experience pressures to both explain and respond to the ways that their families are seen as undesirable in dominant discourses.

LGBTQ Parents[4]

In spite of the lack of consistent and reliable population estimates, there is strong evidence that a wide range of Canadian LGBTQ people are parenting (Bauer, Anjali, Pyne, Redman, Scanlon & Travers, 2012; Milan, Vezina, & Wells, 2007; Nelson, 1996, 2006; Tjepkema, 2008). Queer people become parents in a range of ways (R. Epstein, 2009; Mitchell & Green, 2007; Parks, 1998; Patterson, 2005; Stacey & Biblarz, 2001). Some have children within the context of heterosexual relationships which may or may not continue. Some have current partners with whom they can procreate without donor gametes or surrogacy. Some use donor gametes, from anonymous or known donors, and/or gestational surrogates, to conceive children (Bos, van Balen, & van den Boom, 2004, 2007; Gartrell, Rodas, Deck, Peyser, & Banks, 2006; James-Abra, 2012; Pyne, 2011b; Stacey, 2006). Some adopt children, domestically or internationally (Averett & Nalavany, 2009; Bennett, 2003; Erich, Leung, Kindle & Carter, 2005; Kindle & Erich, 2005; Ryan & Whitlock, 2007; Stacey, 2006). Some have children in co-parenting relationships (Rubin, 2009). Some start relationships with partners who already have children, and then either become parents to these children or retain a distinctive "step-parent" role (Brown & Perlesz, 2007; Hequembourg, 2004, 2007). A given person may have tried or used more than one means of bringing children into their lives.

LGBTQ people face considerable challenges as they access services to form their families. Many foster and adoption service providers express an unwillingness to place children with LGBTQ caregivers (Downs & James, 2006; Eady, Ross, Epstein & Anderson, 2009; Hicks, 2008a, 2008b, 2011; Jayaratne, Faller, Ortega, & Vandervort, 2008; Ross et al, 2009; Ryan, 2000). LGBTQ participants continue to report discrimination and/or inappropriate service

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[4] Parts of this literature review also appear in two of my publications: "Queer Mothering and the Question of Normalcy" (2014e) and "Intersecting Deviance: Social Work, Difference, and the Legacy of Eugenics" (2013), as well as in the comprehensive paper that preceded this dissertation.

recommendations when they tried to access fertility services (Ross, Tarasoff, Anderson, Green, Epstein, Marvel & Steele, 2014; R. Epstein, 2014; Epstein & the AHRA/LGBTQ Working Group, 2008). Transgender individuals report especially daunting barriers within institutions of all kinds, including fertility clinics and adoption agencies (Bauer et al., 2009; James-Abra, 2012; Pyne, 2011b; Ross et al., 2009a; Ross et al., 2009b; Ross et al., 2014; Ryan, 2009).

Beyond family formation, LGBTQ parents face widespread discrimination including public hostility which portrays them as "selfish" and "harmful" (Clarke, 2001; Grigorovich, 2014; Hicks, 2005). Indeed, opposition to LGBTQ rights legislation is often expressed in terms how LGBTQ parents will/do negatively affect both their own children and the future society or nation (Gibson 2014a). Arguments about LGBTQ parenting have been intertwined with debates on legal recognition for same-sex partnerships in countries including Canada, France, the US, and Australia (Butler, 2004; Herdt, 2009; Hosking & Ripper, 2012). Such public discourses can have profound effects on LGBTQ people, as do the related institutional demands and restrictions. For example, LGBTQ parents who seek legal protections for their families by legally 'adopting' their partners' biological children report emotional and financial hardship (Connolly, 2002; McClellan, 2001). Parents also report stress where access to such 'second-parent' adoption is unavailable and legal protections are inadequate for non-biological LGBTQ parents (Gartrell et al., 2006; Hequembourg, 2004; Stacey, 2006; Riggle et al., 2010; Ryan, 2009). Many LGBTQ parents develop strong advocacy skills out of necessity (Bos, Gartrell, Peyser, & van Balen, 2008; Broad, Alden, Berkowitz, & Ryan, 2008; Lassiter, Dew, Newton, Hays, & Yarbrough, 2006). Some mourn "ambiguous" losses when children incompletely recognized as theirs are removed from their custody (Allen, 2007).

In investigating the experiences of LGBTQ parents, researchers have documented many ways that people have created families and communities from vulnerable positions within a

shifting socio-legal context. However there are important limitations to the current research literature on LGBTQ parents. Samples have frequently been drawn from American or European jurisdictions which often provide fewer resources and legal rights than are currently available in Canada (Patterson, 2005; Vyncke & Julien, 2007). Most research has been focused on "lesbian" parents, fewer on "gay" parents, and very little attention has been paid to those with other non-heteronormative identities such as "bisexual", "transgender" or "queer" (Downing, 2013; Dozier, 2014; Eady et al., 2009; Garner, 2014; Hicks, 2013; Riggs & Kentlyn, 2014; Ross & Dobinson, 2013). The majority of research has used overwhelmingly white, middle-class samples (Moore & Brainer, 2013; Tasker & Patterson, 2007). Similarly, since much of the existing research has focused on "same-sex couples" as compared to "heterosexual couples" and/or "single parents", it precludes any consideration of bisexual or trans identities among parents (Pyne, 2011a).

There is considerable pressure on LGBTQ parents to highlight their own respectability and "normalcy" as parents. Lisa Duggan (2003) has attributed this shift directly to the ascendancy of neoliberal ideology and practice and dubbed it "homonormativity". Indeed, corporate interests have often co-opted the constructs and rhetoric of LGBTQ rights movements in the interest of expanding their consumer markets, and LGBTQ rights organizations have simultaneously adopted corporate models and partnerships. As Jane Ward (2008) has described, concepts and terms such as "intersectionality" and "diversity" have been similarly "mainstreamed" in ways that entrench the very class, race, and gender hierarchies they purport to redress.

The pressures of queer normalization differentially affect low income, racialized, immigrant, non-Christian, disabled, and otherwise "othered" LGBTQ individuals, for whom homonormativity or respectability may not be realizable goals (Gibson, 2014a; Logie & Rwigema, 2014; Riggs, 2007). Further, as Jasbir Puar (2007) has argued, state actors have exalted of the Global North and its nations – and justify military and corporate actions in the Global South --

using the rhetorical strategy of "homonationalism". Under homonationalist logic, the visibility and legal tolerance of certain (usually white, middle-class, and "respectable") queer people is used as a sign of a state's modernity, becoming both a means of privileging the Global North and of justifying war and other oppressive state actions (Butler 2008; Gibson 2014a; Puar 2007).

Thus state institutions and corporate interests collude in the construction of LGBTQ respectability that places a premium on "normalcy" for LGBTQ people's individual behaviours and communal demands even as the ongoing heteronormativity of legislation and institutional practice continues to influence LGBTQ parents on an everyday basis. As suggested in my own experience at the government office seeking parental leave, just because a parent is legally entitled to a state resource does not mean that it will be easily or reliably available, and LGBTQ parents continue experience their "difference" even when such legal protections exist (see, e.g., Epstein & AHRA working group, 2008).

Further, social science researchers and political actors of divergent motives and affiliations have collectively pressured LGBTQ to demonstrate their own worth as parents in terms of their children's "normalcy". There has been a consistent focus among social science researchers on "normal" child outcomes as either validating or disqualifying LGBTQ parental rights.[5] Researchers and advocates who **support** LGBTQ parents have emphasized the "normalcy" of the children they raise. Researchers and advocates who **oppose** LGBTQ parents have long justified their position by highlighting the "abnormality" of their children, and of the society that such families would produce (see, e.g., Brown, 2002). "Ab/normal" in child outcomes has often been understood in terms of heteronormative, cisnormative, restrictively-gendered child identities and behaviours (Gurr, 2014; Hicks, 2013; Sedgwick, 1993). Indeed, the pressure on LGBTQ parents to produce "heterosexual" and "gender normative" children has been critiqued by a number of

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[5] For more detail on the pressures of normalcy and "good outcomes" for children as experienced by LGBTQ parents, see Gibson 2014c, 2014e, and 2014f.

scholars (see e.g., R. Epstein, 2005; Hicks, 2005, 2008a; Malone & Cleary, 2002; Stacey & Biblarz, 2001; J. M. Thompson, 2002). However the pressure to produce "normal" children in terms of other measures, including the absence of disability, has been almost entirely unquestioned by LGBTQ activists and researchers. The current project examines how such normalization pressures may influence LGBTQ parents of children that have been designated as outside the norm, as is the case for those with 'special needs'.

It is perhaps not surprising, then, that very little research attention has been paid to LGBTQ parents who have children with 'special needs'. Of the paltry research that does exist on this topic, most has focused on adoption experiences. Leung, Erich and Kanenberg (2005) examined family functioning in gay and lesbian-parented families of adopted children with 'special needs' and found that these families generally scored similarly to heterosexual adoptive families of similarly categorized children. Ontario research by Philip Burge and Margaret Jamieson (2009), while not focused on LGBTQ parents, documented experiences of queer applicants who had been urged to consider adopting children with 'special needs' in order to increase the likelihood that they would receive any child, given their LGBTQ identity. These authors also described experiences of other LGBTQ applicants who entered the adoption process specifically seeking out a child in the 'special needs' category. In general, accounts of LGBTQ parents of children with 'special needs' have largely been confined to literary/ experiential narratives rather than empirical studies (e.g., Briccetti, 2009; Flacks, 2008; June, 2009; Moraga, 1997; Winninghoff, 2009).

Parents of Children with 'Special Needs'

Able-bodied (or apparently able-bodied) parents of children with 'special needs' have multiple, simultaneous relationships to ableism in their everyday experiences. As noted by disability studies scholars, family members and friends of disabled people are often negatively

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affected by systemic ableism, even if they themselves are not disabled (Carey & Gu, 2014;

Gibson, 2014f; Farrugia, 2009; Fisher & Goodley, 2007; Goodley & Thegaskis, 2006; Jennings,

Khanlou, & Su, 2014; Kafer, 2013; Kittay, 1999; Landsman, 2009; Ryan, 2010; Salmon, 2007).

At the same time, the interests and perspectives of non-disabled parents and their disabled

children cannot be seen as synonymous. Parents have also done great damage to their disabled

offspring as a result of the privilege afforded to them through ableism, ranging from "speaking

for" disabled people, to the maltreatment, institutionalization, or even murder of their children

(Bumiller, 2009; Carey & Gu, 2014; Michalko, 2009). It is imperative to recognize the ways in

which parents sometimes benefit from compulsory able-bodiedness/ able-mindedness. This study

has deliberately asked about and analyzed parents' narratives as a way to gather knowledge about

parents' experiences within the discourses and systems investigated, rather than using their

accounts to explain their children's interests or experiences.

      The history of linking LGBTQ parenting to children of questionable but coveted

'normalcy' has particularly complex implications for LGBTQ parents whose children have been

identified as having 'special needs'. The tendency to look at defective mothering or defective

reproduction as a cause for children's differences also has a long and entrenched history. For

example, the diagnosis of autism was for many years described as "refrigerator mother

syndrome", in which the children's behavior was seen as the direct result of some mothers'

defective and damaging parenting practices (Douglas, 2013, 2014). In another example, the stigma

surrounding fetal alcohol syndrome spectrum has portrayed mothers as individually damaging

forces, particularly within Aboriginal communities, to an extent that has shielded larger social

forces such as colonization and poverty from attention and culpability (Salmon, 2007). In the

current North American context, mothers of disabled children are increasingly viewed as

"responsible for" their disabled offspring. This responsibility is attributed to mothers both in terms

of mothers being expected to attend to and arrange for their children's care with minimal supports, and also in mothers being seen to "be responsible" for having failed to prevent the production of disability in their children: through doing some "wrong" during pregnancy (e.g., through refusing prenatal testing), or through deciding not to terminate their pregnancies when an impairment was diagnosed (Bumiller, 2009; Gibson, 2012b; Landsman, 2009; Titchkosky, 2007).

Disability in dominant discourses is thus seen as universally undesirable and avoidable, leaving mothers and other parents of disabled children isolated without collective supports. This understanding of disability diverts professionals and parents alike from the possibility of expansive social critiques or responses. Such dominant perspectives have been critiqued by disability studies scholars as the "individual model" or "medical model" of disability (Oliver, 1990, 2009), the understanding of "disability as a problem" (Titchkosky and Michalko, 2012), or the "de-politicization of disability" (Kafer 2013, 9). Critical perspectives on disability, in contrast, redirect analytical attention to the ways that disability is made to appear to be purely about the body and therefore beyond social or political response, and what such strategies occlude. It is from this critical tradition that the current study draws its understanding and focus.

Instead of trying to objectively denote what disability is or is not, I therefore focus on how disability is made to matter. This approach pulls analytical attention away from diagnoses and impairments and towards what Robert McRuer has called "compulsory able-bodiedness" (2006) and Alison Kafer calls "compulsory able-bodiedness/sane-mindedness" (2013), sometimes here referred to as "ableism" (see also Campbell, 2012). This study conceptualizes the production of how disability is made to matter as social and relational. In so doing, it draws upon Kafer's "political/relational model of disability" (9) and Titchkosky's hermeneutic phenomenological investigation of how disability is made to appear in texts and interpersonal encounters (2007).

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Investigating Institutions and Discourses

In bringing together considerations of the discursive and the institutional, this study builds upon suggestions that have emerged within institutional ethnography and incorporates other approaches to strengthen conceptual weaknesses in IE. Building on work by Kevin Walby (2007), I contend that Smith's creation of IE as a radical rejection of "traditional sociology" has encouraged researchers using this approach to assume that their own studies are inherently "anti-oppressive" in their effects. This assumption can limit ethnographers in critically evaluating their own involvement and inevitable power imbalances in interpretation and research activities (i.e., researcher reflexivity). While IE theory is particularly strong in its objection to "objectifying" people as topics or "subjects" of research and its exploration of non-dominant viewpoints, **IE empirical research has not sufficiently attended to the ways that people within social relations – apart from the researcher -- make sense of their situations and identities**. The story that then emerges from IE studies is, too often, a singular account in which the researcher's interpretive work is both central and unexamined (Gibson, 2012c). The findings of such research can then be presented as neat, bounded, and inevitable, in stark contrast with the disjunctive actualities that launched the investigation.

This study incorporates other methods to **bring the meaning-making of parents themselves into the analysis** as a valuable form of knowledge on "desirable reproduction". In so doing this project builds upon narrative analysis practices that identify and analyze the ways that cultural beliefs and power relations infuse the accounts participants give in particular research encounters, while also looking for ways in which individual narratives reflect and resist dominant beliefs (Riessman, 2008). Other ethnographers have combined discourse analysis and narrative methods with institutional ethnography, often out of similar concerns about the limitations of IE methods, particularly with regard to data analysis (see Chapter 2).

Further, this study resists any neat division of "experiential" and "institutional" interpretations as it has sometimes been delineated in Smith's work (1987, 2005). The tidy and unquestioned demarcation of 'experience' has been critiqued across disciplines, notably by historian Joan Scott (1991), who has convincingly argued that 'experience' is itself produced through the discursive context in which it arises. Building upon the scholarship of Judith Butler, among others, discourse in this study is seen as "performative" and its effects are seen as simultaneously interpretive and material (Butler, 1990, 1993, 2004). Following Scott and Butler, the conceptual framework of this study views 'experience', including components such as 'identity' and 'meaning-making', as (re)produced through embodied, temporal human activities, including the production and reading or 'activation' of texts. In so doing, it relies on the concept of 'intersectionality' in which social categories (such as sexuality, race, gender, (dis)ability, etc.) are seen to operate simultaneously, such that any analysis that tries to disentangle one 'identity' at a time, or view them additively, is fundamentally artificial (Crenshaw, 1989, 1991; Collins, 1993, 2000 [1990]; Gibson, 2013). However, multiple iterations of 'intersectional' scholarship have been deployed and further specification is needed (Mehrotra, 2010; Davis, 2008; Hulko, 2009; Nash, 2008). This project falls within the 'anticategorical' tradition of intersectionality, as delineated by McCall (2005), in that the process and history of producing the identity categories is a part of the analysis.

Further, rooted in work of both Dorothy Smith (2005) and Judith Butler (1993, 1997,1999 [1990], 2004, 2005), and informed by critiques by Jasbir Puar (2007) and Alison Kafer (2013), this project rejects the common assumption that 'identity' is both stable and bounded by individual consciousness. Rather, intersectional identities are seen as (re)produced in social, relational, embodied, and temporal ways. Thus, the grouping "LGBTQ parents of children with 'special needs'" is not used as a monolithic category to be described. Rather,

institutionally-framed moments where people apply, resist, adopt, alter, and question these categories and their meanings are a core focus of analysis. Further, as described in the next chapter, such questions are seen as resolutely discursive *and* material, such that responses can be observed in the texts, stories, material surroundings, and embodied activities of people's everyday lives.

Central Questions

As an ethnographic study within a critical tradition, this project anticipated the unanticipated – that is, that methods and questions would shift and develop over the course of the research. It did, however, set out to address the following questions, which provided a touchstone throughout the methods, analysis, and writing.

i) How is the everyday work done by LGBTQ parents of children with identified 'special needs' shaped by their interactions with special needs service systems (including but not limited to healthcare, education, and community services and professionals)?

ii) What role do texts (e.g., diagnostic criteria, medical or behavioural plans, adoption certificates, legislation, etc.) play in these interactions and experiences?

iii) How do parent narratives connect with, depart from, and otherwise complicate dominant discourses on desirable reproduction (i.e., who should be a parent, who should be born or raised)?

iv) How do intersectional identities operate contextually and relationally, such that 'difference' attributed to one family member can combine with and complicate 'difference' attributed to another?

The methods described in the next chapter were selected to best address these questions, and to allow room for new questions to emerge. These questions overlap in the actual practice of research, and the findings attempt to draw connections between the different answers. The

ultimate goal was to present a nuanced and empirically-rooted picture of how service systems and discourses shape the everyday experiences of LGBTQ parents of children with 'special needs'. Further, this research seeks to identify what could be done to make these arrangements more just, for this particular group of parents but also more generally for the parents, disabled people of all ages and kinship arrangements, and service users, all of whom are trying to meet their needs and responsibilities when faced with neoliberal institutional pressures and concurrent discourses on "desirable" reproduction.

<u>Outline</u>

This thesis has been organized in the following way. Following this introduction to the project and its central question, I address the methods used. In this methods chapter I both consider the literature and rationale for the methods selected and describe the research processes I employed. The following four chapters – chapters 3 through 6 -- then address different aspects of the findings. The third chapter looks at the overall systemic arrangements that can be seen to organize the "systemwork" parents do, and the reason that parental resources and labour matter at all. The fourth considers the ways that parents experiences these services systems were influenced by their LGBTQ identities and systemic notions of "fit". The fifth looks in greater depth at the ways that parents used and experienced texts in their interactions with institutions and broader discourses. Then, the sixth chapter shifts to a close analysis of several passages of parent narratives to consider what these indicate about parental responses to discourses of desirable reproduction. Finally, the seventh chapter considers the overall conclusions that can be drawn from this study, and their implications for social work practitioners and researchers.

Chapter 2

Methods of Investigation

In order to answer the central research questions of this study I followed a combined methodological approach. Overall, and particularly when exploring the research questions on the "systemwork" parents do and the roles of texts within it, I relied most heavily on the methods and theoretical grounding of Institutional Ethnography (IE), based in the work of Dorothy Smith (1987, 1999, 2005, 2006) and elaborated upon by others. In considering the research questions that address discourses on 'desirable reproduction' and intersectional identities, and in deepening my analysis of the other research questions and making links between all of the findings, I continued to use aspects of IE ethnographic methods. However in these analyses I also turned to critical discourse analysis of narratives in an effort to focus on the ways that people made meaning of their experiences, and how they drew upon and refashioned available discursive resources, with particular implications for the distribution of material resources including social recognition (Gee, 2005, 2009; Riessman, 2008).

In this chapter I outline the methods used in this study. First, I describe the two main methodologies drawn upon: institutional ethnography (IE) and discourse analysis. I describe how they differ from each other and the uses to which each was put, but also outline the scholarly traditions within which I have situated my interpretation of the methods: the work of Dorothy Smith (IE) and the work of Judith Butler (performativity as used in discourse analysis). Then I outline the design of the study, starting with a summary of who was interviewed, the processes of interviewing parents and key informants, through transcription and data analysis. Throughout I cite literature on the relevant methods selected, and the rationale for the approach taken.

Institutional Ethnography

The study follows an ethnographic method that draws substantially, although not exclusively, on Dorothy Smith's Institutional Ethnography (IE) (1989, 2005) and its elaboration through other ethnographic and textual analyses (e.g., Daniel, 2008; De Montigny, 1995; Hicks, 2009, 2011; Ng, 1996; Titchkosky, 2007). The initial data collection framework, starting in the everyday world of LGBTQ parents of children with identified differences, is premised on Smith's concept of "the everyday world as problematic" (1987, title). Thus, it is through the as-yet-unknown details of the "everyday" of parents' experiences that the topic is approached, rather than through more abstracted measures such as a model to test, a quantitative survey question (e.g., how many hours per month do you attend appointments with your child?), or an isolated document (e.g., an organizational non-discrimination statement).

Institutional ethnography or 'IE' holds great potential as a method for social work research. It is rooted in an expressly "social" investigation and challenges the researcher to ground research activities and findings in people's activities (Smith, 1999). The researcher starts from the assumption that the participants are knowledgeable about their everyday activities and that learning from them about these activities can provide crucial information on how institutional/ structural processes actually happen. Rooted in Marxist materialism, sociological and linguistic theory, and late twentieth-century American feminist politics, institutional ethnography offers insights into large-scale characteristics of "the ruling relations" by starting with the "everyday/everynight" material conditions of people's lives (Smith, 1987, 2005).[6]

For social work, Smith's work offers a theoretical and methodological resource that refuses any hard divisions between "micro", "mezzo", and "macro" levels of practice and

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[6] Smith's work has centred upon the foundation and development of "institutional ethnography". I slip between attributions to "IE" and to "Smith" when I address theoretical and methodological constructs that are almost uniformly accepted across "IE" writers, most of whom cite Smith extensively. Where Smith is making a more specific or less widely-endorsed assertion, however, I designate this as her own rather than as a tenet of "IE".

research. Drawing from both Marxist class analyses and feminist arguments against a public/private split, Smith instead insists that such divisions are conceptual artifacts of observers in dominant social positions. Indeed, she argues that the obfuscation of connections between large-scale, generalized processes and individuals' everyday activities serves the interests of those individuals with the greatest decision-making power in current social relations. In contrast, IE works to show that any "macro" processes must always be reducible to and observable in everyday/everynight activities of people, particularly those embodied processes that are taken for granted and dismissed under terms such as "women's work" (Smith, 2005). IE therefore moves from the specific/embodied to the general/ abstract rather than the more common reversal of that ordering in social science research. In Smith's words, IE proceeds from

> Whatever is produced/ accomplished by people 'at work,' that is, active, thinking, intending, feeling, in the actual local settings of their living and in relationships that are fundamentally among particular others -- even though the categories of ruling produce particular others as expressions of its order. (Smith, 1999, p. 75).

Smith's "ontology of the social" offers a valuable approach for social work research.[7] In Smith's work, human experience is always socially organized, and 'the social' needs to be observable in human activities rather than in abstract concepts. Instead of starting from a defined theoretical model that the researcher wants to test, Smith insists that research must begin with "actualities", defined as "always more than can be described, named, or categorized" (2005, 223). Rather than investigating concepts such as "stigma", "acculturation", or "resistance", a researcher following Smith's approach starts by examining how people in a particular social role (such as service providers or parents) and within particular organizational frameworks (such as schools or medical clinics) feel, speak, think, and act. In particular, Smith urges us to examine moments where there is a "disjuncture", where some aspect of embodied knowledge is in

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[7] See Smith, 2005, Chapters Three and Four for more on the "ontology of the social" and its contrast with "blob ontology" of other sociological traditions.

conflict with other received (e.g., textual, "official") accounts. This disjuncture can then be developed into a "problematic" or domain of investigation, as the researcher moves to examine how interactions or experiences of many individuals are coordinated across moments and locations, often in ways that might not be visible to the people involved. It is this approach to disjuncture that I used in Chapter 1 as I discussed the original impetus for the current study.

In contrast with other common forms of social work research then, the goal of Smith's institutional ethnography is to explicate how people's activities are coordinated or "organized" within a framework of power relations. The researcher's objective is not to identify, quantify, or typologize the specifics of individuals' experiences: "It is the aspects of the institutions relevant to the people's experience, not the people themselves, that constitute the object of inquiry" (Smith, 2005, p. 38).

In Smith's writing, "institutions" can be broadly interpreted, not bounded exclusively within single organizational, legal, or physical structures, but "complexes embedded in the ruling relations that are organized around a distinctive function, such as education, health care, and so on" (Smith, 2005, p, 225). Systems for children with 'special needs' cross multiple organizational and professional boundaries. This blurring can be seen when educational or recreational services depend upon and intersect with health systems, such as a community social group designated by diagnosis. At the same time, there are functional "complexes" that can be seen to coordinate the work done by many individuals, and in institutional ethnography, the initial focus on such everyday activities can be used to ground a project. It is not necessary, in Smith's interpretation, to delimit the field of research to a single organization (although this approach can also be taken if it fits with the mandate of the project). Such an approach also befits social work, where domains of knowledge and practice are less tightly bound within

single organizations than in many other professions, and, indeed, professional practice often engages directly with navigating multiple organizational frameworks.

Smith's definition of "institutions" is intimately connected to "ruling relations" or "the relations of ruling": "objectified forms of consciousness and organization, constituted externally to particular people and places, creating and relying on textually based realities" (Smith, 2005, p. 227). It is important to note that the concept of "ruling relations" is, in Smith's work, not to be reified as a "thing" but to be seen as a constantly reproduced coordination of people's activities. It is through the coordination of practices across individuals, moments, and locations that the operation of larger "ruling relations" can be seen in operation by an ethnographer.

These "translocal" practices are often transmitted through texts, defined broadly to include all recorded media: visual images, websites, intake forms, movies, and so forth (Smith, 2005, 2006). What unites all these "textual" forms is that they comprise important tools in coordinating relations between individuals across time and space. For example, pieces of human rights and educational legislation that require the funding of particular resources for "exceptional" students, activated as particular people produce other texts such as budgets, can coordinate the work done by teachers across different classes, schools, and school boards as they complete forms to designate their students' "exceptionalities" to match up with the legislated categories (see Daniel, 2008). Some individual teachers may agree with, object to, or resent the forms they fill out. Some may fill them out "better" and some "worse". Some may have extensive experience with the forms and some may be new to the process. Some teachers' forms will have "successful" outcomes in resources allocated, and some will not. Teachers will be variably influenced by a range of available discourses such as those on disability, race, gender, class, and the responsibilities of educators. However an institutionalized nexus of "ruling relations" can be traced as an *organizer* of all of the teachers' practices, while not displacing

their real diversity of experiences and the embodied and temporal variability of their interactions with the texts.

Throughout her work, Smith conceptualizes texts always as part of people's activities. Texts follow from and precede people's activities, and IE is particularly attentive to what it is that texts do: how texts are created and "activated" by those who read them, including how their activation obscures many of the embodied and social activities that contributed to their own creation (D. Smith 2005, 101-122; D. Smith, 2006; see also McCoy, 1995; Titchkosky, 2007). Any analysis of texts in IE is thus a part of a larger investigation of how "ruling relations" organize what people do.

Smith's shift of the researcher's focus from individuals, experiences, or even ideas toward investigating the institutionalized, textually-mediated practices that organize people's everyday activities suggests a particular understanding of why a given topic would be worth exploring. Instead of demonstrating that a given set of people or experiences are numerous, common, or particularly in need of theoretical explication, researchers are asked to consider the likelihood that these experiences will provide **a valuable perspective from which to examine larger, institutionalized processes** that affect everyone in a given social context. This focus on "keeping the institution in view" (McCoy, 2006) is intimately connected to the objectives of Smith and others using IE theory and methods.

For the topic under consideration in this paper, then, this would mean that any "ruling relations" evident from the starting standpoint of LGBTQ parents of children with identified differences will affect far more than those in this admittedly specific group. Instead, the knowledge held by these parents of their everyday lives promises to reveal aspects of social processes that will likely be hidden if analysis proceeds from more "mainstream", or institutionally-supported perspectives. The point is certainly not to exoticize LGBTQ parents or

parents of children with identified differences as "special knowers" but to proceed under the assumption that their embodied knowledge has not provided the central impetus of existing documents and research. Thus, 'disjunctures' also open institutionalized practices to greater scrutiny that will have implications for *all* affected by the "ruling relations".

Further, the goal of IE research is to obtain and analyze information on the specific operations of ruling relations in order to join with people in marginalized social locations to challenge institutional practices that restrict their access to decision-making power and resources (see e.g., Frampton et al., 2006). While IE is certainly not the only research approach that has a stated commitment to social change, IE's focus on institutionalized practices in everyday life makes it particularly useful for advocates and activists. As George Smith, institutional ethnographer and activist wrote: "Grass-roots organizing is better based on a sociology committed to describing how society actually works" (1995, 33). Most researchers using IE assert that "traditional sociology" has worked against social transformation through its "objectification" of people, and particularly those on social margins (Smith 1987). By shifting the research gaze from marginalized people to institutions, Smith and IE have significantly changed both the processes and the goals of research practice. Such commitments to social justice and applicability make Smith's work particularly suitable for social work research.

Smith's analysis rests upon a rejection of universalizing systems of knowledge such as post-Enlightenment, Euro-American positivism. In so doing, Smith calls upon a methodological and theoretical tool of "standpoint", advocating that researchers discern, in advance, an angle or social location they will use in mapping the social relations of their topic area. Again bringing together strands of feminist and Marxist theories, Smith uses standpoint out of the belief that the organization of social relations will be differentially visible depending on the observer's social vantage point (Smith, 1987; 2005). She does not, however, follow some interpretations of

standpoint theory that insist that certain standpoints are inherently "privileged" and thus better

places from which to view "reality" (see Harding, 2004; Hekman, 2004). Indeed, she argues

against the reification of "feminist standpoint theory" stating that this label, applied initially by

Sandra Harding, brings together a number of writers who were not working together as a

coordinated group. She writes "I am not proposing a *feminist standpoint* at all; taking up

women's standpoint as I have developed it is not at all the same thing and has nothing to do with

justifying feminist knowledge" (D. Smith, 2004, p. 264, original emphasis). Instead, Smith's

standpoint is primarily methodological, a technique for focusing the field of inquiry in

acknowledgement that the knowledge gained will be necessarily partial, reliant on the angle

relations are viewed from. For example, Smith defines her use of "women's standpoint" as

methodological:

> Women's standpoint. A methodological starting point in the local particularities of bodily
> existence. Designed to establish a subject position from which to begin research -- a site
> that is open to anyone -- it furnishes an alternative starting point to the objectified subject
> of knowledge of social scientific discourse. (2005, 228)

In Smith's definition, then, this term is used in such a way that the researcher's identity or social

location does not predetermine the standpoint that s/he selects. Indeed, anyone can start with

"women's standpoint", not only people who are themselves women or who focus on a standpoint

that includes women. For example, Gary Kinsman (1995) and George Smith (1995) have both

taken up Dorothy Smith's ideas in their work as gay men within gay and HIV-positive

communities.

Thus, IE approaches any investigation from a particular "standpoint" from which

institutionalized relations and power arrangements will be viewed. By starting from the

everyday experiences of LGBTQ parents of children with 'special needs', I am not asserting that

this is an unproblematic grouping of people with a common identity and experience, nor am I

relying on my own potential categorization as part of this group. Similarly, in selecting this

standpoint, this study is not looking for a unified experience of LGBTQ parents of children with 'special needs' or asserting that people in this grouping hold a privileged position as knowers above all others. Rather, this study investigates how diverse people experience and make meaning of being designated as LGBTQ parents of children with 'special needs' in their institutionalized relations with others, and why such designations have material consequences at all.

In other words, what is it about the ways in which special needs service systems and dominant discourses operate that makes it matter whether someone is an LGBTQ parent of a child with 'special needs' or not? What other aspects of the parent's or child's social categorization/ identity can also have material effects? This line of questioning effectively shifts from a psychological focus -- such as on how and why parents "cope" or "suffer" -- and instead looks at how institutional processes shape parents' experiences according to how they and their family members are socially categorized. In other words, how is "sexuality", "gender", "parent", "identity", "family structure", "class", "race", or "disability" made to matter in everyday encounters with special needs systems?

Perhaps unsurprisingly, Smith's methodological interpretation of standpoint has been controversial. Some object to a perceived privileging of unitary concepts of "women", seeing particular standpoints as more "real" or "truthful", or asserting that only certain researchers may address a given topic (Hekman & Jagger 2004, Smith 2004). Smith's responses to such critiques have not always been successful, particularly due to institutional ethnography's intermittently-acknowledged grounding in white, Euro-American philosophical and political traditions. Smith's narrative of her creation of institutional ethnography is intertwined with her experiences in a "women's movement" as a white sociologist in Berkeley, California in the mid- to late-twentieth century (Smith, 2005). Even as she has changed IE's designation from "a sociology for women"

(Smith 1987) to "a sociology for people" (Smith 2005), Smith's writing continues to privilege gender as a fundamental and relatively unitary form of "difference", one that will override all others. Many writers have convincingly argued that terms such as "women's standpoint" or "women's experience" are unstable or even irresponsible in that they obscure the many ways in which "women" are differentiated: by race, by nationality, by class, by (dis) ability, by sexuality, by religion, by profession, and so forth. Some, Judith Butler notable among them, have insisted that the very determination of "gender" needs to be troubled rather than taken for granted (e.g., Butler, 1999 [1990]; Namaste, 2000). Others, including many who have theorized and used "standpoint" in feminist work, have worked to challenge the exclusion of many (indeed most) women in feminist texts and the advancement of neo-liberalism and/or neocolonialism under an unqualified and under-theorized "womanhood" (e.g., Collins, 2000; Combahee River Collective, 1977; Davis, 1981; Mohanty, 1991). Further, Smith's idea of standpoint as something that can be methodologically taken up rather than being embodied or lived, contrasts with much other feminist writing on standpoint, in particular, work from women of colour and Black feminist traditions (see Collins, 2000; Hong, 2006; hooks, 1981, 1992, 2004). Smith's use of standpoint as something that can be assumed and then, presumably, discarded, can lead to practices of "speaking for" other "oppressed" people, and particularly racialized women; such "speaking for" practices have often perpetuated racist, ableist, heterosexist, classist, and colonialist activities under a feminist banner (Alexander, 2005; Mohanty, 1991). Similar objections might also be made to the ways that Marxist traditions have privileged a "working-class" standpoint (Hartsock, 1983; Smith, 1987). There is a danger that when certain people are grouped together as unquestionably "working class" it forecloses an examination of how class status is asserted and produced in people's activities.[8] While scholars such as Roxana Ng (1995, 1996) and

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[8] For a worthy exception to this trend in IE, see Roxana Ng's consideration of how immigrant women are produced as "working class" through policies and practices used in employment agencies (Ng, 1996).

Himani Bannerjee (2005) have worked on expanding IE's engagement with race and nationality/colonization, it is fair to say that Smith's work has continued to be far less attentive to issues of race, nationality/colonization, disability, sexuality, or to the intersections of multiple forms of marginalization than it is to class and/or gender.

Despite these important objections to Smith's particular definition and application of the concept, standpoint *as a method* can usefully help researchers examine how institutionalized practices explicitly position individuals in particular categories. For example, a wide range of contemporary, Canadian, institutional processes rely upon a construct of "parents" across multiple domains; these can be seen in people's everyday interactions, texts, and activities. An individual may be positioned as a "parent" in a particular setting and/or text, and as something else entirely elsewhere: a teacher, a patient, a customer, a policy maker, and so forth. Where the sorting of "parent" is difficult, uncertain, or contested, as in the case of LGBTQ parents (see Chapter 1), these institutional processes may become visible in particular ways. It is the institutional and discursive organization of categories and relations that brings particular bodies and experiences under the often ill-fitting rubric of "LGBTQ parents".

In expanding upon Smith's work, it is important to consider that standpoint is increasingly complicated but also crucial in situations involving disclosure or the incomplete and fallible communication of "difference". Issues of disclosure and uncertain interpretation of potentially salient identities and relations arise frequently in many social interactions surrounding sexual orientation, gender identity, kinship structures, and disability. Many LGBTQ-identified parents may not disclose their sexual or gender identities or kin relations across institutional interactions, or these identities and relations may be denied or otherwise unrecognized by those with whom they interact (Allen, 2007; Bergen, Suter & Daas, 2006). Additionally, their children's identified differences may also be undisclosed, disputed, or

uncertain across many of the same interactions (Farrugia, 2009; Goodley & Thegaskis, 2006; Landsman, 2009). In such a context, it is particularly important for the researcher to determine the starting standpoint of the research, as we could expect a different range of available responses from professionals, or from these parents' children, than from parents themselves. This is not to say that these other responses would be inadequate, or that we would not also benefit from talking to these other individuals as part of an investigation from the parents' standpoint.

Due to the IE's close ties to advocacy and activism and its particular attentiveness to both people's everyday lives and larger power relations, a number of researchers have used IE methods and theory in their work with various groups of disenfranchised people including groups that overlap with LGBTQ parents: transgender/transsexual people (Namaste, 2006), gay men (Kinsman, 1995), lesbian students (Khayatt, 1995), LGBTQ homeless youth (Abramovitch, 2013), mothers of school-age children (Griffith, 1995, 2006; Griffith & Smith, 2005), immigrant women seeking employment (Ng, 1996), and gay and lesbian foster carers/ adoptive parents (Hicks, 2009, 2011). Other researchers have also used IE methods and concepts to investigate the service systems that define and surround disability and children with 'special needs'. While not explicitly calling upon disability studies perspectives, a number of well-known IE researchers have investigated health care institutions and texts from the perspectives of patients/residents/service users and front-line workers (e.g., Campbell, 2008; Diamond, 1992; Mykhalovskiy, 2002; Mykhalovskiy & McCoy, 2002; G. Smith, 1995; Smith, Mykhalovskiy & Weatherbee, 2006). This body of research fundamentally challenges both the primacy of health administrators' perspectives and the invisibility of service users' and front-line workers' work (Mykhalovskiy & McCoy 2002; Rankin & Campbell, 2009). A growing list of researchers have used IE methods to investigate the ways that disability has been institutionally and textually

produced, and how this institutional arrangement shapes people's everyday experiences (e.g., Arndt, 2008; Barken 2013; Church 2007, 2010; Corman, 2008; Daniel, 2008; Deveau, 2011; Traustadottir, 2008). Additionally, Smith's approach to texts as integral to people's activities and embodied relations has influenced disability studies scholars such as Tanya Titchkosky (2007), and suggests useful methods for investigating "texts" as they rub against and through "experience", and vice versa.

IE holds particular relevance for social workers given their professional operations within and across multiple institutional organizational systems. Social workers' scope of professional practice is both restricted by and acutely attentive to the ways that people's activities are coordinated across individuals, organizations, and locations. Additionally, as described in-depth by Gerald de Montigny (1995), much of the work done by social workers relies on the production of texts (e.g., assessments, session notes, court reports) through interactions (e.g., interviews, home visits, counseling sessions) as coordinated with other texts (e.g., child maltreatment legislation, job description, organizational forms), with evident material consequences (e.g., the allocation or removal of child custody, financial resources, housing). Smith's attentiveness to how texts work to coordinate people's activities, and how people's activities coordinate the production of texts has direct applications for many domains of social work practice. As Stephen Hicks has effectively argued in his social work IE study on lesbian and gay foster care and adoption in the UK, Dorothy Smith's work is also particularly helpful in examining what social workers (and other professionals) actually do that perpetuates the construction of familial 'difference'(Hicks, 2009, 2011).

The theoretical contributions of Dorothy Smith have been wide-ranging and substantial and, as outlined in this chapter, hold great promise for their applicability in an examination of the 'ruling relations' that shape the everyday experiences of LGBTQ parents of children with

identified differences. At the same time, Smith's work has several weaknesses that might hamper such an investigation. First, Smith's work has, as mentioned, often privileged gender as a form of social difference that, while worthy of investigation in its institutionalized effects, is taken for granted in its designation and presumed stability. In Smith's work, 'women's standpoint' presumes that the unitary category of 'women' is both delineated and meaningful, even if a diversity of 'women's experiences' might be anticipated and even as the term has been applied to those other than 'women'. The grouping of "LGBTQ parents" does not fit within a restricted and cohesive notion of gender and, as Hicks has ably demonstrated, such assumptions about gender are at the core of many difficulties queer parents encounter with service providers (Hicks, 2008b, 2013). Further, Smith's orientation as a sociologist precludes any in-depth considerations of psychological processes and effects, always bringing the focus back to 'the social' as it can be directly observed. While such a framework usefully grounds research activities in materialities, what might such an approach miss in terms of the connections between the institutional/discursive and the embodied/experiential?

Additionally, as Kevin Walby has asserted, IE has not been sufficiently attentive to the ways that it might perpetuate power imbalances in "the social relations of research" (2007). In its production of a single, unified account of ruling relations from a particular standpoint, Smith's approach does not give sufficient room for alternate "stories" that participants/ informants might contribute (Gibson, 2012b; see Chapter 1). Further, Smith's writing presumes that IE studies can be fit together to produce a larger story of these ruling relations (e.g., see 2005, Chapter 10). Her understanding of IE findings is thus premised on a stability of relations and their interpretation across researchers, moments, sites, and projects.

Discourse Analysis and Performativity

There is not always a clear and clean line between institutional ethnographic method and discourse analysis, particularly since institutional ethnography has long paid attention to how discourse coordinates and shapes everyday practices. Indeed, IE investigations of texts in hierarchical text-work sequences will attend to the "shells", in Dorothy Smith's term, through which certain categories of response are required in order to make a text "actionable" (2005, 2006). For example, only certain types of responses to questions about a child's traits or behaviours will fill the necessary criteria for a particular program, as presented on a form or in an intake interview. IE also attends to the institutional purposes to which discourse can be put, such that dominant discourses make it almost impossible to identify let alone challenge the ways that institutionalized relations are organized. For example, unless the dominant "motherhood discourse" Griffiths and Smith (2005) identified has been brought out of the background assumptions of researchers and participants alike, researchers are likely to see the way that schools operate as unavoidable and unfortunate, rather than as a site for further investigation. However IE theory is clear that the language of individual participants is not to become an "object" of research, but rather that participants' descriptions of their experiences are to be used only to clarify the ways that ruling relations operate. The interpretive processes of the participants themselves, therefore, are outside of the analytic frame of institutional ethnography, for fear of objectifying these participants as topics of knowledge.

Under a strictly-interpreted IE approach, then, the interpretive work that participants do cannot be investigated. I have argued elsewhere that this prohibition against investigating participant narratives as interpretive material has the effect of instituting the researcher's storytelling – about their own research process, and about the ways that ruling relations operate in their field of study – as the only story told (Gibson 2012c). Indeed, this story can become too

tidy to permit any alternatives, including those from the participants themselves, and is often

told using terminology that can distance IE discourse from that of other interested parties

including participants and other researchers.

It is to address this "single story" approach to IE through the consideration of parents'

narrative strategies that discourse analysis methods were introduced in the current study. The

question of how notions of desirable reproduction are reproduced and resisted is not only to be

seen at the level of institutional interactions, but is also evident in the interpretive realm of

emotions and relationships -- of what goes beyond the story of institutional practices but

provides the interpretive background that may be essential to their functioning. When other

institutional ethnographers have incorporated participant narratives as a way to ground their

work and promote participatory methods, they have not called attention to the potential conflict

this can pose with classic IE theory.

The research tasks involved in discourse analysis can be quite distinctive from those in

institutional ethnography. IE looks primarily at how different data (e.g., passages in different

interview transcripts) "hook in" to ruling relations that operate extra-locally. Discourse analysis

instead encourages looking in depth at particular passages as a way to illuminate larger

interpretive strategies and resources – what is assumed and thus made possible on an individual

level is seen as both a response to and an indicator of available discursive resources. Thus while

the institutional ethnography questions are quite clearly bounded in pulling out particular

themes/ participant observations across settings and interviews and asking how they connect

across settings (e.g., what "ruling relations" organize all of these responses or practices?),

discourse analysis asks what the language, structure, and silences of a particular piece of

discourse – in this case, passage of parent narrative – reveals about the social context that

produced it (Gee, 2009; Riessman, 2008; van Dijk, 1993, 2001). The dynamics between

participants and the researcher must also be considered, as well as the order in which participants explain their experiences, the storytelling strategies they use (e.g., metaphors, repetition of particular words or phrases), and the ways that they shift discursive registries or draw upon specialist discourses (e.g., when and where diagnostic language is adopted).

The terms and methods of "discourse analysis" are used by writers from different epistemological assumptions and different strategic approaches. It is necessary to specify further. The approaches used here draw upon work by narrative approaches using the questions for analysis posed by James Gee (2005, 2009) as informed by the explicit attention to narrative and the interviewer/interviewee interaction in work by Catherine Riessman (2008), and the political commitment to investigating the ways that power relations infuse people's discursive options and strategies informed by work by Teun A. van Dijk (1993, 2001). While Foucault's scholarship provides background support for attending to how "expert" categorization regulates embodiment and sexuality, this work has not been given primacy in the methods selected (Foucault 1990; 1995; O'Brien, 1999). In its attention to intersectionality as shifting, relational, and contextual, the way discourse analysis has been applied in this study is most indebted to Black feminist, post-structuralist critiques which reject categories of identity or difference as "givens" and consider instead how these "intersect" in everyday life in ways that produce material differences and create subjective identities (Bowleg, 2008; Crenshaw 1989, 1991; Davis, 1981; Davis, 2008; Gibson, 2013; Hulko, 2009; Lorde, 1984; Luft & Ward, 2008; McCall, 2005; Mehrotra, 2010; Moraga & Alzaldua, 1983; Nash, 2008; Puar, 2008; Roberts, 1998).

The dominant influence on this approach to how difference is "reproduced" in both language and materiality comes from the work of philosopher Judith Butler and her use of "performativity". Butler first discussed performativity at the very end of her 1990 book *Gender*

Trouble: Feminism and the Subversion of Identity. In *Gender Trouble*, Butler argues for a rethinking of gender proceeding from the radically different assumption that socially-produced gender does not just reference or signal to an already established and embodied sex, but that the very production of sex is reliant upon and constitutive of social activities labeled "gender". Indeed, "the body" is integral to the construction of these social meanings as it "performs" acts that, through their discursive resonance, constitute "male/masculine" and/or "female/feminine". Butler writes:

> Gender ought not to be construed as a stable identity or locus of agency from which various acts follow; rather, gender is an identity tenuously constituted in time, instituted in an exterior space through a *stylized repetition of acts*. The effect of gender is produced through the stylization of the body and, hence, must be understood as the mundane way in which bodily gestures, movements, and styles of various kinds constitute the illusion of an abiding gendered self. This formulation moves the conception of gender off the ground of a substantial model of identity to one that requires a conception of gender as a constituted *social temporality*. (Butler, 2006 [1990], p. 191, emphasis in the original)

In her subsequent writing on performativity, Butler has emphasized that she does not believe gender to be a voluntary and free performance but a tightly regulated and obligatory accumulation of everyday and embodied acts that cite available discursive meanings to (re)produce a "gendered" subject (1993). At the same time, in highlighting "social temporality" in the production of identity and the subject, Butler shows that existing discourses are constantly vulnerable to transformation.

Butler's training in both hermeneutic phenomenology and the work of Michel Foucault (among others) are particularly evident in attention to minute, taken-for-granted, temporal, and embodied practices as productive of and restricted by available meanings or discursive power (Allen, 2006; Borgerson, 2005; Butler, 1999[1990], 1993, 1997, 2004, 2005). Butler's analysis can helpfully address a weakness in some other streams of feminist scholarship, such as that of Dorothy Smith, which takes the division of gender for granted as a completed fact, rather than a

constantly asserted production. Meanwhile, the social and embodied processes that underlie a performative theory of gender complement Smith's ontology of the social and her attentiveness to how discourses are observable in people's material, embodied, everyday activities. Butler's subsequent work on "ungrievable" lives and what is excluded in notions of the human expand the application of such performativity beyond gender to other domains of human categorization or identity and the fundamentally social reproduction of the self (Butler 1997, 1997, 2005; Featherstone & Green, 2009; Powell & Gilbert, 2007).

Butler's contributions add useful complexity to Smith's understanding of discourse, experience, and standpoint.[9] While in Smith's work researchers are to differentiate "institutional discourse" from "experience" to avoid "institutional capture" (2005, p. 225), Butler muddies the waters. As she addresses throughout her work but elucidates most extensively in *Giving an account of oneself* (2005) and *The psychic life of power* (1997), Butler follows Foucault (1995) on the assumption that no account of embodied experience, or even unspoken understanding of one's embodied "self", can escape from larger discourse, including its institutional forms. While she acknowledges that there are undeniable, material bodies, she argues, following hermeneutic tradition, that they cannot be accessed without recourse to interpretive, discursive practice. What's more, people simultaneously experience their subjugation under restrictive and unavoidable categories (e.g., "special needs", "queer") while also being reliant upon these same discursive elements for material resources, community, identity, resistance/ redefinition, and, more fundamentally, recognition:

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[9] It is important to note that Dorothy Smith has used Butler's 'performativity' as a primary example of how "postmodern" writing perpetuates a disembodied abstraction that is founded upon an "individuated subject" (1999). Smith argued that such "postmodern" discussions of "discourse" removed people, embodiment, agency, and the political will to institute change. Despite such critiques, I understand Butler's work, particularly as she has elaborated upon it in recent years, as showing the extremely high stakes for people and their material bodies in the repeated re-enactment of difference and identity (Featherstone & Green, 2009; Loizidou, 2008). Indeed, in her more recent writing (2004) Butler has taken up language also used by Smith to explore how people live and become subjects as they are "acting in concert".

> Performativity describes this relation of being implicated in that which one opposes, this turning of power against itself to produce alternative modalities of power, to establish a kind of political contestation that is not a 'pure' opposition, a 'transcendence' of contemporary relations of power, but a difficult labor of forging a future from resources inevitably impure. (Butler, 1993, p. 241)

Butler's attentiveness to the fundamentally historical, social, and embodied processes of interpretation/representation which constitute identity complicates any conception of "standpoint". If we extend Butler's understanding of performativity beyond gender to sexuality to consider any social category that is inextricably linked to social recognition, performativity encourages us to consider how the rules of any grouping such as "LGBTQ parents" or "special needs" are not only institutionally framed in ways that leave gaps and inequities of access, but they also penetrate the embodied actions and core beliefs of those who are so designated (Logie & Gibson, 2013). What's more, the very possibility of community and change will rely on both questioning and working with these categories, these "resources inevitably impure", as they are (re)produced in the everyday.[10]

While Dorothy Smith's work is part of a tradition that Judith Butler has critiqued in its fundamental acceptance of gender/sex difference (Butler, 1999), and Butler is part of a "postmodern" cadre Smith has critiqued for its inattentiveness to the material and the social (Smith, 1999), there is a useful synergy between the two. Butler's largely conceptual analysis would benefit from the material grounding in people's everyday "work" that Smith's methods and theory can provide, where development and dependency, and their multiple interpretations, occur in the present tense rather than as precursors to subject-formation. Smith's approach would benefit from Butler's attentiveness to the production of 'identity', and her scrutiny of how

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[10] Butler's thought has been centrally applied in a number of social work research projects. Most often these projects have addressed marginalized sexualities (Featherstone & Green, 2009; Hough, 2005; Logie & Gibson, 2013; Lessa, 2006; O'Brien 1999; Willis 2007). In queer and disability studies, Robert McRuer (2006) has invoked Butler's notion of performativity to indicate how it might depict the precariousness of both heteronormative gender and able-bodied identity-production and suggest opportunities for resistance. Others within disability studies have drawn upon Butler's work regarding discourse and embodiment (Samuels, 2002; Stocker, 2001; White, 2003).

'experience' and 'discourse' are bound together in materially and symbolically inextricable ways. It is for this reason that both scholarly approaches were used in this study.[11]

In the current study, applying the concept of performativity to an analysis of how desirable reproduction discourses may influence parents' narratives meant that I asked questions about identity and relationships in the interview guide and then probed for expanded answers about **the ways that particular types of social 'difference' were made relevant or irrelevant in everyday experience** (see Appendix G). In this sense, the notion of performativity was methodologically applied beyond gendered practices. Instead of typologizing parents' narratives by their children's diagnoses or behaviours, such an approach encourages attending to the many ways that parents may call upon diagnostic language for ends that may reproduce dominant discourses, but which may also, in each iteration, do something more besides. Thus any sharp division between "institutional" and "experiential" language becomes impossible, and the subjectivity of participants (and all social actors) is seen as constantly reproduced rather than finite and static. Thus, the methods and theories of Butler and Smith supported different components of the current project: Smith brought attention to the everyday work people do and how it is shaped by textually-mediated institutional (material) practices, and Butler highlighted the discursive restrictions and possibilities for relationship and personhood that such institutional frameworks rely on and produce.

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[11]Given that the work of Judith Butler has rarely been brought into conversation with that of Dorothy Smith, Stephen Hicks' social work research on lesbian and gay foster and adoptive parents in the UK stands out as a notable exception. While Hicks conducted his research within an IE framework and wrote about his use of Smith's methods and constructs, he also cited Butler's work in examining how certain genders and family structures were "performed" and reconsidering gender and family relations through a queer theory critique (Hicks, 2005, 2008a, 2009, 2011, 2013). Tanya Titchkosky's work on texts and disability (2007) also draws upon concepts and strategies from both Butler and Smith.

Ethics and Confidentiality

The study design was approved by the University of Toronto Health Sciences Research Ethics Board on November 18, 2013, then extended for another year on November 17, 2014 (See Appendices A and B). Following the approved protocol, informed consent was sought and questions about the protocol were solicited from potential participants prior to screenings and interviews (see Appendices A and D). I emailed copies of the approved consent forms prior to all interviews and brought printed copies for participants/ key informants to review and discuss in person, then sign prior to audiorecording (Appendix E). All identifying information has been removed during the transcription stage with pseudonyms substituted for names and generic agency descriptors substituted for agency names (e.g., autism service organization, public school board). Audiorecordings were deleted following transcription.

There was a $30 honorarium offered per interview, in addition to reimbursing any childcare or transportation costs, which were as high as $40. In couple interviews, the honorarium remained $30. Key informants also received honoraria. One key informant and one parent refused to take payment for their participation.

Consistent with broader standards of ethical practice and the approved ethics protocol, and in light of the potentially interconnected and small community participants come from, participant confidentiality has been a key concern throughout the research process. Only the information that was deemed relevant to the purposive sampling process is listed in the summary of who was interviewed (Figure 1). Additional information, such as the gender of any additional children who are not the focus of discussion, profession or employment status of the participant, or in what area of the GTA they reside, are not outlined here. While this more detailed information was collected as a part of understanding each parent's experiences, displaying such details may make participants identifiable.

Throughout the writing of this thesis, only the demographic or diagnostic information that is directly relevant to that interviewee's cited perspective on a particular topic is listed, and a number of quotations have been presented without even a pseudonym listed. While pseudonyms were consistently used in the transcription process, and at times they are used in the thesis text, I avoided consistently linking all of a participant's observations and experiences to a single pseudonym because of the risk of making them identifiable. For a totally fictionalized example, if 'Jose' is listed one place as a carpenter, elsewhere as a father of four children, somewhere else as bisexual, and in another chapter as having a son diagnosed with epilepsy, it is increasingly likely that Jose could be identified, even if none of the individual descriptors might themselves be identifying, Jose is a pseudonym, and each piece of descriptive information was necessary to contextualize the experiences or quotations presented. Instead, I would sometimes use the pseudonym ('Jose'), and sometimes just state the descriptive information: "According to a parent of four children". Similarly, while I took field notes on the settings of the interviews, I have not used them in the text of the thesis except when the interviews took place at the Factor-Inwentash Faculty of Social Work. Finally, key informants are not presented in terms of their identities at all, but rather in terms of the particular topic area for which I sought them out. The field of researchers and advocates on these topics is too small to add demographic or other descriptive information and still hope interviewees would remain anonymous.

Interviews

Parent Participants and Key Informants

The primary material used in answering all questions, and using all methods, was ethnographic interviews with parent participants. I completed 12 interviews with a total of 15 people identified as LGBTQ parents of children with disabilities or 'special needs'. Figure 1 describes the parent participants, highlighting the information that was used in purposive

sampling: gender; LGBTQ identity; family structure and creation history; racialization experience. Information is presented in aggregate form to preserve confidentiality (see above). The demographic information that was requested from participants can be found on Appendix D and Appendix G, the parent screening form and interview guide. In it, the "identified child" refers to the child they primarily discussed regarding their interactions with 'special needs' and related systems.

Gender and LGBTQ identity were identified and discussed by the participants and presented according to their self-description. Similarly, parents were asked to describe who was in their family (see chapters 5 and 7 for further analysis of this part of the interview). Racialization was broadly determined. Participants were asked about their own race and ethnicity and those in their families. They were considered "racialized" if they listed anything other than "white/ Caucasian" as their race/ethnicity. Of the parents identified as "racialized", two identified as Black, of Caribbean heritage, and one identified as multiracial, also of Caribbean heritage. The identified children discussed by these three parents were described as Black (one), biracial (one), and multiracial but often read as white (one). Two families had white parents and racialized children: one of these children was described as Black, and the other was described as Aboriginal.

The socioeconomic status of participants was assessed through a conversation about their highest level of education, their profession/ type of work, and employment status (part-time/ full-time, permanent/ casual). Attention was paid throughout interviewing to parents' financial resources, particularly as they affected service decisions and experiences. While highest level of education ranged from high school diploma through graduate degrees, the level of education did not directly map onto current financial resources. Changes in family structure sometimes correlated with shifts in financial resources. For example, two mothers who had separated from

their children's fathers talked about having reduced access to financial resources and

employment benefits in the ex-husband's name. None of the participants talked about precarious

housing or income levels that precluded meeting everyday necessities.

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Parents Interviewed

15 parents in 12 interviews (3 couple interviews)

1 bi-gender/ trans, 3 cisgender men, 11 cisgender women

6 lesbian, 3 gay, 1 bisexual/lesbian, 2 bisexual, 1 queer/trans/bi-gender), 1 queer, 1

queer/lesbian

4 parents were not currently partnered ('single') although of these 3 had co-parents

7 parents had adopted the identified child[12]

3 parents had the identified child from a previous heterosexual relationship

4 parents had the identified child through alternative insemination: 2 of self, 2 of partner

1 had the identified child with a current heterosexual partner

3 racialized parents

5 racialized children discussed in terms of 'special needs' (2 with non-racialized parents)

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Figure 1. Parents interviewed.

Of the four parents who identified at times as "single parents", one mother co-parented with a friend in addition to having shared legal custody with her ex-husband, two mothers had separated from female ex-partners and had primary custody of their children without formal legal arrangements, and one man had adopted as a single parent. It is important to note that of the currently partnered parents I spoke with, two other mothers had conceived their children and then separated from and negotiated custody with male ex-partners.

The children that parent participants were discussing in terms of their 'special needs' ranged in age from 3 to 30, but most of the children of parents interviewed were at the young end of this range. Only one of the children discussed was over the age of 18, two were between

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[12] Parents might use more than one means of forming a family (e.g. for different children) but these figures are only for how the child they primarily discussed came into their families.

the ages of 13 and 18, four were between the ages of 6 and 12, and five were 5 years old or younger. Several of the parents also had other children in other age ranges that were not the primary child discussed in terms of their interactions with special needs services. Of the twelve families that participated, five had only one child, five had two children, one had three, and one had four. These numbers include all children that the parents indicated that they parented, not only those for whom they had legally-recognized parent/guardian status.

The diagnoses that children received were discussed throughout the interview. These were not used as screening criteria however this information was important in understanding and analyzing the data, and particularly the responses parents received from others, including service providers. Several of the children discussed had multiple diagnoses, and some had received other diagnoses previously (previous, rejected diagnoses are not listed here). Also, in one family the parent discussed one main child in terms of 'special needs' but had another child who had received a mental health diagnosis which the parent touched on in terms of their other systems experiences. The list of diagnoses discussed were as follows: Apraxia (speech), intellectual disability (unspecified), Attention deficit hyperactivity disorder (ADHD), Attention Deficit Disorder (ADD), Oppositional Defiance Disorder (ODD), Down's Syndrome, brain injury, Leukemia, speech delay, Autism Spectrum Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Asperger's Syndrome, Developmental Coordination Disorder, Anxiety Disorder, Tourette's Syndrome, Obsessive Compulsive Disorder, Motor-Oral Planning Disorder, Learning Disability, Alcohol-related Neurodevelopmental Disorder (considered part of the fetal alcohol disorder spectrum).

Key informants were approached directly by email because of their knowledge and community expertise on a particular aspect of the topic (see Appendix C). Most key informants had experience as service providers with parents; several were also parents themselves. All had

been involved in research on the selected topic. All had engaged in activism and/or community work on the selected topic. They were not asked about their own experiences, however most brought some "personal" experiences into the interviews in addition to their commentary about the larger community and services. No demographic data were asked or recorded on key informants except as they particularly referenced their identities in the audiotaped interviews. See Figure 2 for a summary of the key informants interviewed. Information is presented in aggregate form and no details are offered due to the high likelihood that key informants would be identifiable.

Key Informants Interviewed
4 interviewed regarding knowledge of LGBTQ parents: 1 particularly with LBQ mothers, 1 particularly with GBQ fathers, 2 particularly with trans parents
2 interviewed regarding knowledge of parents of children with 'special needs': 1 with particular knowledge re. racialized parents' experiences

Figure 2. Key informants interviewed.

Parent Recruitment

Parent participants were recruited primarily through email via a range of individual and organizational contacts, primarily through email listserves. Social services that had a particular focus on children with disabilities or 'special needs' or on LGBTQ parents and communities were the focus of this recruiting effort. Autism Ontario, the Rainbow Health Network, the LGBT Parenting Network (affiliated with the 519 Community Centre and Sherbourne Health Centre), and the Redpath Centre all agreed to list information about the study in their newsletters and/or websites during some or all of the recruitment period. Information about the study was sent through many organizational and individual email networks in the Greater

Toronto Area. These included the Central Toronto Community Health Centres, the Sherbourne Health Centre, the Redpath Centre, Women's Health In Women's Hands Community Health Centre, Community Living Toronto, the Griffin Centre, the University of Toronto Institute for Women and Gender Studies, Re:searching for LGBTQ Health (Centre for Addiction and Mental Health), The Empowerment Council (Centre for Addiction and Mental Health), Bloorview Macmillan Rehabilitation Hospitals, LGBTTTSIQ Therapist listserv, the Toronto District School Board's Gender Based Violence Prevention Program, Sick Children's Hospital, the Rare Disease Foundation (Toronto chapter), the 519 Community Centre Parenting Program, and contacts from my own networks particularly of researchers and LGBTQ community members. Individual researchers, service providers, and community members who knew about the study also contacted others through word of mouth, sometimes even if they themselves did not participate. Some key informants passed the study information along to parents who became participants. The most common way that participants reported they had found out about the study was through the LGBTQ Parenting Network. Several participants identified that they had heard about the study through more than one means. See Appendix C and Appendix E for the recruiting emails and the invitation letter and consent form that I sent to potential participants. Recruiting lasted from November 18, 2013 until June 1, 2014. Email was the means chosen by all potential participants who contacted me except two who contacted me directly by telephone. These two did not end up becoming participants.

The diversity of parents that I interviewed was an important consideration from the outset of the study since its intersectionality framework demanded that I pay analytical attention to many socially-salient ways in which individuals and families were categorized in institutional encounters (Crenshaw, 1989, 1991). Ethno-racial identity is broadly recognized as a significant factor in how institutions respond to people and their claims in North American and other

Eurocentric, post-colonial contexts (Björnsdóttir & Traustadóttir, 2008; Collins, 2000; Crenshaw, 1991; Davis, 1981; Logie & Rwigema, 2014; Lorde, 1984; Pitner & Sakamoto, 2005; Roberts, 1998; Thobani, 2007). Similarly, gender is also well established as a significant organizational category in establishing social privilege within state institutions and neoliberal discourses, particularly around caring labour (Krane, 2003; Mosher, 2000, 2010; Namaste, 2000; Neysmith, 2000; Neysmith et al., 2012; Swift, 1995, 2010). Further, given the focus on LGBTQ experiences in this study, the different ways families had been formed and were likely to be 'read' in terms of institutional responses and discourses of desirable reproductions were also considered in deciding who should be interviewed (R. Epstein, 2014; Ross et al, 2009a; Ross, Steele, & Epstein, 2006).

I initially received the most responses to recruiting announcements from white, cisgender women who had not used any gamete donors (ie., they had not used a known or unknown egg or sperm donor) to create the child identified with 'special needs'. In order to preserve interview slots for others, I stopped interviewing people who had this background in February, 2014, after I had already scheduled or completed 8 interviews (7 with cisgender women including one couple, 1 with a cisgender man). I started recruiting parents of colour and/or trans parents specifically in March, 2014. At this stage I adjusted the recruiting email to reflect the change in focus and re-sent it to organization and individual contacts who had particular connections in these communities (see Appendix C). The final four interviews were selected to address the identified gaps in the interviews and resulted in the aggregated demographic totals listed in Figure 1. This brought the total number of interviews to 12, the anticipated maximum of the proposal and approved ethics protocol.

Parent Participant Screening

In order to be eligible for the study, parents needed to meet the following criteria:

a) Identify themselves as lesbian, gay, bisexual, transgender, queer, two spirit, genderqueer, transsexual, or other non-heteronormative or non-cisnormative gender and sexual identity terms.

b) Identify themselves as parents. This term was open to include adoptive, foster, biological, non-biological parents as well as stepparents, and was not be dependent on particular family formations, legal recognition, or custody arrangements.

c) State that they have been engaged in some way with professionals and/or systems in regard to one or more perceived 'special needs' pertaining to at least one of their children. Such 'special needs' could include a potential or identified disability (developmental, intellectual, learning, psychiatric, physical, sensory); behavioural, educational, and/or emotional concerns; or chronic/ significant health conditions. Parents would be eligible whether or not this engagement with professionals/systems had led to a formal or ongoing diagnosis or related categorization. Additionally, parents and/or involved professionals might disagree with the identification of their child as having "special needs". Professionals might include specialists employed within narrowly-defined 'special needs' service organizations (e.g., children's rehabilitation program workers), or might include adoption workers, teachers, family doctors, or others.

d) Live and/or receive services within the Greater Toronto Area (GTA). This restriction was due to the resources of the researcher to meet with participants and also because parents in a given geographic region may have similar services and interlocking institutional arrangements available to them.

Some parents did not contact me again after their initial email and we did not proceed to the screening telephone call. In one case, I did the screening entirely by email rather than telephone because of participant preference. For couple interviews I screened one parent on the telephone and asked for some brief demographic information about other family members (i.e., religion, gender, race, ethnicity, citizenship); then I confirmed or added demographic

information at the opening of the interview. I started each screening with a statement about informed consent and asked for the parent's verbal consent to continue (see Appendix D).

There were a number of reasons why parents were screened out from participation, either over email or on the telephone. The most common reason was that the interviewing period had ended or I had stopped interviewing the demographic group to which they belonged (white, cisgender women). Several people contacted me who lived and received special needs services outside the GTA, particularly trans parents. I heard from three parents who had children with 'special needs' but the parents were not LGBTQ-identified. I also screened one couple out of the study because their child had 'special needs' solely due to being identified as 'gifted'. In this case, I determined that the systems, resources and discourses that would influence these parents' experiences would be too different from the vast majority of 'special needs' categories. I did interview one parent who had moved outside the GTA but who discussed many years of experiences with GTA special needs services systems on behalf of their child.

Following the screening guide (Appendix D), I filled out the screening form for each parent and we scheduled an interview time and location at the close of the screening conversation. Only one person who completed the screening ended up not participating. The data from the screening was then destroyed and not included in any further analysis.

At the end of the parent screening, I also discussed the selection of a document that the parent would bring to the interview (see guide). Parents were asked to bring a document that had been "significant in their interactions with service providers". I explained that "significant" could be positive or negative or mixed, and that "document" could mean forms, emails, certificates, letters, and anything else that had an enduring written or pictorial form, whether on a screen or on paper. We discussed possible documents that the parents were considering, and several parents emailed back to check that the document they were planning to bring was

appropriate. I never had to turn down a suggested document. Every parent remembered to bring

at least one document, although almost half brought more than one along. In one case the

interview focused on two documents. In all other cases, the parent(s) selected one document to

talk about in the interview (see Chapter 5 for more on the documents selected). I did not keep

copies of the documents selected.

Key Informant Recruitment

Key informants were all recruited through email. They had been purposively sampled for

particular knowledge and experience for which they had been well-known in the research or

activist community, or recommended through my research and community networks. One

person I approached about becoming a key informant regarding special education systems and

LGBTQ parents declined to be interviewed. Key informants were not screened and no

demographic information was recorded about them since they were specifically selected for

their research/activist expertise on a particular aspect of the subject area. They were not asked to

bring in and talk about a document although they were asked in the interview to talk about forms

or policies that they thought might shape parents' experiences.

Interview Procedures

Parents were interviewed either at the Factor-Inwentash Faculty of Social Work or at a

community location that was private and chosen by them. Five parents chose to be interviewed

at the university, four interviews took place at workplaces, and the rest were at family homes.

Key informants had a similar choice of interview location. Four of the six chose to be

interviewed at the university. Two others chose to be interviewed at workplaces.

After the participant had signed informed consent forms allowing for audiorecording, the

interviews were audiorecorded. Participants usually talked more after the recorder had been

turned off at the end and this content was sometimes noted in field notes but not presented in the

thesis. Parents were given their honorarium, and other reimbursements we had arranged, and a handout on local resources (see Appendix F) at the outset of the interview.

The interview guide for parents or key informants were used in a semi-structured manner (see Appendix G). All questions were addressed with all participants, although sometimes the order in which the central questions were asked could vary (e.g., if the participant started talking about something that led to a different research question). Probes were used to elicit longer narratives and examples of particular incidents or encounters, although most participants talked at length without many probes being required. Participants were encouraged to bring up stories or thoughts they felt to be important even if they did not immediately address the question I had asked.

Interviews lasted from between 1 and 2.5 hours. Most lasted 1.5 hours. The two interviews that lasted longer than 2 hours were both with couples.

Transcription and Coding

I transcribed the interviews from the audiorecording, creating complete transcripts for all parent interviews. I completed partial (highlighted) transcripts for the key informant interviews which complimented my field notes of these interviews. As stated in the informed consent documents and approved ethics protocol, I conducted all transcriptions myself. Because I knew I would be doing a detailed discourse analysis on some sections of transcript I included repeated words, overlapping talk, and non-verbal communication such as sighing or laughing. I followed transcription suggestions from Riessman (2008) to create a transcript that would be useful for narrative analysis. When I used quotations for the ethnographic analysis and related presentations, however, repeated words and hesitation noises or words (e.g., "like", "um") were often edited out. I did not include all of my verbal nodding ("Mmhmm") if to do so would

interrupt the parent narrative. I included such interviewer verbal nodding when interviewees paused while I responded in this way.

Transcripts from parent interviews were entered into NVivo 10 data management software for coding and storage. I started with line-by-line coding, and proceeded through collapsing and editing codes into tentative hierarchies. I then moved to highlighting both thematic topics relevant to the research questions (e.g., encounters with professionals, references to different types of documents, reflections on LGBTQ identity) and narratives that would be important to consider for discourse analysis (see below).

Key informant transcripts were not coded and analyzed in this way, but the topics highlighted by informants informed the questions and the analysis of parent interviews. For example, when key informants highlighted the importance of school experiences for many parents of children with special needs and/or LGBTQ parents, I noted this for my questioning of other parents and analysis of parent interviews. Thus the focus of the analysis was always on the parent interviews, but the key informants helped me to "notice" what parents might have to say. I did find that parent interviews and key informant interviews supported the same ethnographic findings, in general, however key informant interviews presented fewer suggestions of how special needs systems might be differently organized. Since key informants were not usually engaged in the everyday work of navigating these systems, it was not surprising that their reflections were usually more abstract than experiential. It is important to note that the key informants also had overlapping identities with the groups discussed: all were either parents of children with special needs, LGBTQ parents, or offspring of LGBTQ parents. Many brought up examples from their own lives or those of people they knew in these communities as a part of illustrating their understanding of the issues. Overall, these interviews also helped to heighten

my awareness of possible avenues to explore in my interviews with parents and in the subsequent analysis.

<u>Analysis and Writing</u>

For the ethnographic analysis I followed the methods outlined in the institutional ethnography sources cited above. In particular, I focused on what parents were doing and what institutional and discursive arrangements explained the need for and significance of these doings. Thus my analysis did not follow thematic codes exactly, but started by wondering why certain themes came up as important in the first place. For example, why did parents talk about the need to advocate? Why did they describe the importance of getting an assessment done? How are institutions organized such that differences between parents matter at all? Thus I used the codes from my initial coding process to find passages to consider on various topics, but the findings emerged from an engagement with the data that often went beyond itemizing what was said. This approach follows institutional ethnography methods.

For the discourse analysis section (see Chapter 6 in particular), I focused on passages from the interview transcripts that I found to be entirely distinctive from "quotes" that I used as concise examples for the analyses on systemwork or parents' experiences of texts. The longer narratives were selected for what they reveal about possible interpretive responses to institutional and discursive pressures surroundings LGBTQ parenting and parents of children with 'special needs' in contemporary urban Canadian contexts. I started by considering interview transcript excerpts *in which parents narrated shifting or internally contradictory ways of interpreting their experiences*, where more than one interpretive framework was evident not only in what parents described, but also in how they expressed it. I considered the ways narratives emerged in interaction with me (as the interviewer) and each other in the case of couple interviews (see chapter 6).

The process of data analysis was thus intertwined with the writing of this dissertation. Writing was also informed by my experiences presenting emerging findings (see Gibson 2014b, 2014d, 2014g) and through further conversations with my committee, colleagues, and other community members, and additional readings. Thinking further about the data, and reflecting on the connections between different findings throughout the analysis and writing process, led to an entirely different understanding of the study than what I had started with. Indeed, it led to a different interpretation than I would have presented right after I had completed the interviews, or even after completing NVivo coding. Writing has been similarly iterative in that the relative importance of findings shifted across drafts as each chapter influenced the next through rounds of re-thinking and revision.

Researcher Positionality and Reflexivity

Because both the recruiting email and the informed consent forms identified me as a member of LGBTQ communities and a parent of a child with 'special needs', most parent participants talked about our experiences in terms of commonality at some points in the interview. Most but not all asked about my child with a 'special need' in terms of age, gender, and diagnosis. Since all this information is already quite publicly available from my community presentations and publications, answering these questions felt personally non-threatening. More importantly, answering questions about my own experience and family structure influenced the research process in useful ways. First of all, it was important for establishing a sense of trust given the common experiences of marginalization and even discrimination faced by LGBTQ parents and parents of children with 'special needs'. In feminist and community-based research methods, this sharing of common experiences and identities is a part of reducing power imbalances between researcher and research participant. It also informed my analysis as I used these exchanges reflexively. For example, as I discuss further in Chapter 4, when participants

interacted with me as a similarly situated parent, some gave me new information they thought might be helpful or asked for ideas and resources that I knew of; this sharing of resources was an example of what participants reported they did with other parents (see Chapters 3, 4, and 6). In other instances, I shared my understanding of institutions and procedures based on my emerging findings or personal experiences as it seemed useful in clearing up questions or confusion they were experiencing. I often followed up interviews with further information and resources by email, in addition to the list of resources that I gave all participants during the interview (see Appendix F). Further, participants and I often discussed community members that we both knew – a not uncommon experience in a small community. I did establish a professional boundary when one participant asked if I could become their clinician after our interview. I referred them to another provider with relevant community experience instead.

In addition, participants sometimes highlighted that they did not like sharing certain information with people who were not LGBTQ-identified, and so my analysis of our interview conversations took into account how my presence as the participant's expected audience might have influenced the exchange. Some conversations were only possible because the participants saw me as a member of the LGBTQ community and a parent. Other times, my role as "researcher" and "social worker" put me in a position that was separate from the participant, as in when they discussed what could and could not be said in front of social workers and other professionals. My role was therefore one of what Linda Tuwahi Smith has called "insider/outsider" in this study (L. T. Smith, 2008, pp. 137-140). I was seen as both similar to and apart from the participants and their community.

In sum instead of seeing such overlapping and shared experiences as a "problem" for the research, I found that acknowledging shared and differing experiences created an opportunity for participants to exchange certain kinds of knowledge with me. It altered but did not erase the

hierarchy and separation imposed by differences in experience and role between me and

individual parent participants.

Chapter 3

Systemwork: Securing Resources

In this chapter, I outline the ethnographic findings from this study on how existing institutional arrangements require that parents devote time, money and energy to accessing resources for their children in special needs service systems. First, following Dorothy Smith's institutional ethnography as method and epistemology, I recount what we learn about how special needs services systems are organized from the standpoint of parents' everyday systemwork. Next, I discuss what the strategies and levers that parents use in navigating these systems tell us about the ways these systems respond to parents' intersectional social resources and vulnerabilities. Finally, I revisit the meanings and limitations of parent "advocacy".

Throughout the interviews and in the analysis, I inquired about and noted the "systemwork" that parents reported doing: the intentional labour requiring time and effort that parents did to learn about, work with, and secure resources for their children and themselves through special needs service systems. This systemwork took many forms, and I asked interviewees to elaborate, not only on the type of "work" that might be recognizable to others, such as meeting with professionals and taking children to appointments, but also on activities such as making decisions, researching systems, coping with emotions that interacting with systems provoked, and communicating or negotiating about these options, emotions, and implications with other people involved in their children's lives such as co-parents.

Parents that I spoke with all had plenty of systemwork activities to report to me, and discussed at length the extent of their involvement with different services. While some of their interactions with service providers and special needs systems were certainly positive in parents' assessment, a larger picture emerged in which parents reported that, overall, services for children with 'special needs' are scarce, often inadequate, and poorly coordinated. As a result of

this context of inadequate resources, parents of children with special needs reported seeking out, fighting for, coordinating, and plugging the gaps of special needs services. Several parents had gone to quite extraordinary lengths to develop their skills and knowledge as "advocates" and even service providers for their children.

Following institutional ethnography methods, this chapter works through the experiences of parents so as to uncover the "ruling relations" of special needs services and related institutions (Campbell & Gregor, 2008; D. Smith, 1987, 2005). What this particular group of parents recounted from their everyday lives is not, in and of itself, the object of this line of analysis. Rather, these accounts and experiences point to the institutional and social arrangements that shape or "organize" them (D. Smith, 2005). The perspectives of LGBTQ parents provide one starting place for investigating and understanding how power and structural arrangements operate in "special needs services" more generally.

The findings, therefore, are relevant to policy makers, service providers, and service users far beyond the grouping of "LGBTQ parents of children with 'special needs'". Indeed, many parents identified ways that their experiences were interrelated with the experiences of service providers and administrators, children, and other parents who are not "LGBTQ", since all were shaped through the same institutions, albeit from different standpoints. Some parents and key informants reflected upon how these institutional arrangements are themselves influenced by broader legislative and economic trends and limitations, such as "cutbacks" across the public sector, and the increasing assumption that parents should fill in the resulting gaps.

A key term throughout the interviews and analysis was "advocacy". In this chapter I consider how advocacy language and practice assumes the primacy of "private" or kinship responsibilities for children's needs, and for disabled children's needs in particular. This emphasis on "private" responsibility for navigating systems often masks the absence or limits of

systemic and "public" responsibilities. This emphasis on addressing people's collective resource/service needs through "private" (unpaid) means to be supplemented by consumer activity rather than "public" programs funded by government is a central component of what is often termed "neoliberalism" (see Chapter One).

At the same time as parents' private responsibility is highlighted through advocacy discourse, professional expertise and discourse are also given dominance, such that in order to advocate, parents are required to both i) become "experts" on their children's diagnoses, interventions, and services, and ii) submit to the language and professional authority of professional "experts" (Douglas 2013; Gibson 2014f). In order to fulfill their "advocate" role, parents are required to subscribe to particular "expert" frameworks regarding their children and available accommodations without expecting that "experts" such as administrators and professionals will take on the full costs and ultimate responsibilities for assessing, understanding, or responding to their children's needs, or indeed their own.

In other words, parents' strategies indicate an "idealized" parent in special needs systems and are one means of documenting what is at stake in parents' "advocacy". The findings in this chapter may have come from LGBTQ-identified parents, but the systems they describe shape experiences of all parents of children with 'special needs', as well as the experiences of children themselves. Thus the findings in this chapter are considered as a commentary on how parents, LGBTQ and not, are asked to perform certain types of "advocacy" within special needs service systems in response to institutional and systemic factors; parents' variable resources and social locations substantially influence the outcomes of their efforts.

Squeaky Wheels and Scavenger Hunts

> I think what sometimes makes me a little bit sad about this is you, so your family and you as parents have your own process of whatever, denial and grief and celebration and this and that and whatever, post-partum depression, and have another baby, and marital issues, or whatever, work problems. And then it's like, "Oh fuck, now we've got to do

this [meeting] thing with the school" right? So, you know, partly then I have grief about the fact that I didn't do whatever earlier. Because I had my own denial issue, or that we've been on a waiting list for [a special needs program] for six years. {*laughing*}

Parents encounter a bewildering range of demands on their time, knowledge, emotions, and energy as they approach and engage with special needs service systems. At the same time, they do not lose all the other responsibilities of parenting when additional appointments, concepts, and activities are added to their schedules. Thus the everyday "process" this participant described is one in which feelings, relationships, and struggles cross work, family, and service sectors that extend across and beyond those designated for "children with special needs". Her struggles with everyday parenting demands were, however, intertwined with her experiences of special needs institutions and institutional barriers, whether long-term (a multi-year waitlist) or short-term (a contentious school meeting about special education allocations). This parent's feeling that she should have done "whatever earlier" is simultaneously an acknowledgement that systems will respond slowly to her doing, if at all, through such waitlists and gatekeeping.

This tension between parents and institutions in this participant's description flags a larger struggle to navigate special needs service systems that was widely expressed across the parent interviews and underlined by the key informant interviews. Parents I spoke with clearly identified an **underlying scarcity of publicly-funded special needs services as the context that makes parent systemwork or "advocacy" both necessary and challenging**. For example, one parent said, "I think you have to advocate for services. I think that, you know, it's a rare situation where someone's going to say, oh this would be perfect for your child. Particularly as your kid gets older." Parents talked about the need to be a "squeaky wheel" as required of any parent encountering the special needs services, but possibly in particular for those who may face discrimination. As Elizabeth described:

Being a squeaky wheel is a really important piece. It's difficult if you are not confident with that. Then find someone who can speak on your behalf. If you have a queer friend or someone within queer services who can come with you when you have to negotiate things within the system, bring them with you. Somebody that's mouthy? Go for it. Because otherwise you will be ignored. You will be shuffled to the side. But I would say that to anybody, regardless of their orientation. Bring someone with you if you need support. But I think in particular for queer parents, I think it's important.

Another participant, Nora, offered a related suggestion:

I guess one of my recommendations would be to go out and do the research on the policies of the service providers. Because I've seen that they won't always tell you what's available. That being the squeaky wheel does make a difference.

What might be required in the "squeaky wheel" role varies from parent to parent. Several parents described attending workshops on how to advocate for children with 'special needs' in the school systems. Some of these were free and some required a substantial fee as well as the time and energy required to attend and to study the related materials. Parents cited these workshops as they discussed the strategies they brought to their interactions with professionals, particularly within school systems. Several other parents talked about belonging to online and in-person support and information groups, sometimes sponsored by agencies where they were already receiving services or on waitlists. All the parents I spoke with described reading and researching and talking with other parents to get ideas on where to go for services, who to talk to, or what words to use. Some parents even described engaging in additional training, such as taking sign language courses, as a way to bridge gaps they had encountered in finding appropriate services for their children.

This search for and sifting through of information, services, and referrals demands extra time, knowledge, and energy from parents and forms a central piece of the systemwork they engage in. As one parent recounted, "Finding the right services -- it's like a scavenger hunt, man. It's not easy to do. Even when a service is out there." Almost every participant talked extensively about this type of "scavenger hunt", but one in which the list of services that are

"out there" is uncertain and changing. A theme emerged of "you don't know what you don't know", in which parents identified the work they were doing to gather information from a variety of sources, identifying services and how to access them. Throughout, parents expressed doubt in the quality and accuracy of the information and services they had encountered. Parents tied their expressions of "you don't know what you don't know" to a frustration at a perceived reluctance on the part of service providers to give them solid and complete information. This apparent withholding of information caused parents to feel suspicious about what they were and were not told, and sometime to attribute more and less innocent motives to the systemic omissions.

Overwhelmingly, parents said that they had found that schools, in particular, claimed to offer services that were in fact unavailable or very difficult to obtain. Parents who had children in school all talked about engaging repeatedly with educators and administrators to secure appropriate placements, challenge school practices such as suspensions or inadequate responses to bullying, and obtain appropriate resources and accommodations for their children within the educational system, such as technologies or special education classroom supports.[13] Even parents whose children were not yet in school described school as a focus of their concerns and systemwork strategies, particularly around the decision to have their child formally assessed and diagnosed (see Chapter 5). For example, one parent – who had professional training as a teacher -- explained her hopes for her daughter's formal speech disorder diagnosis.

> So I think this is something that is going to open doors for us to make sure that they don't just say "Oh well let's just see how she does." Because a lot of people, heading into school, heading into kindergarten, that's what you hear. Or at least that's what I've heard from friends who are advocating for support for their kids. That's what I've heard at a conference that I attended, is that there is a level of… of… I don't want to quite say

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[13] All of the parents I interviewed who had school-age and pre-school-age children were interacting exclusively with public school systems. One parent of an adult child described having left the public system and moving their child to a private school that focused on working with children who had different abilities but did not rely on a formal diagnoses.

apathy? But a desire to wait and see, even if that isn't the most proactive or the most effective remediation. Because it costs less money.

A parent who had also had their child professionally assessed described a conversation with the school principal about their child's entry into school in which they felt the principal needed to be persuaded to move past a "wait and see" approach.

> We presented also the letter from [the developmental pediatrician]. And because in the letter [the pediatrician] also spoke about [my child] being quite high-functioning, he also sort of was leaning, the school principal that is, was leaning to saying, 'He doesn't need to be assessed within the TDSB, right? Don't worry about an assessment, just bring him in. Come to the open house, and let him start school. And if he starts to struggle, then we'll do something.' Okay, well, from a parent perspective… that to me isn't an option. My kid is not a guinea pig for whether or not your school is going to be a good fit for him. We know already that he requires very particular supports to be okay.

Parents with children already in school also described a prevalent reluctance among administrators to commit to accommodations, particularly when these accommodations were costly. Another parent talked about how her previous experience with schools for her children without 'special needs' led her to do additional research for her younger children and directly ask principals how they accommodate children with disabilities.

> So, I have also come across like school after school, principal after principal that is just kind of like, oh my god. Who just want to do *nothing*. I'm overgeneralizing when I say 'do nothing', but you know. Do nothing for these kids [with special needs]. So yeah, [my kids are] going to go to school in September so I've spent a lot of time. I think I've toured every school, talked to every principal, and we finally got him into this, not the alternative school the [older kids] go to, a different one.

Parents who had more financial resources, sense of confidence or assertiveness, and knowledge of the systems had more options when negotiating with school systems. For example, Steve described his experience of "not taking no for an answer" with schools:

> S: …[My child] transferred to a new school for grade seven and it wasn't as good a fit with the teacher… So that's when I had to find a solution, right? So when they [school administrators] say, well, you know, he doesn't qualify for an MID [mild intellectual disability], or, we can't get that together in the next however many months to make that happen for September. And I'd say, well what are the barriers? …Well, you know, there's a three years wait for a psych assessment with the board, or whatever it is, I might be exaggerating. Or, we don't have the, we couldn't get the report ready to get an IPRC

[Individual Placement and Review Committee] review -- do you know anything about the board of education?

M: A little bit. Yeah. [yeah] But spell out your experiences as well.

S: Okay. So I just said, okay, what if I get the report privately, so I'd write the cheque and pay for it. Which I think we talked a bit about on the phone, about how income makes a big difference I think. But, so if I could get a psych ed assessment, what date would you need it by to make it to that meeting? 'Well the meeting's this date.' So if I got it to you that date that's good enough? 'No, no, we'd need it', okay how far ahead would you need it so you could read it? So just backing it all up. … So in that instance, I just pulled out all the stops. It didn't just stop at the school board, I got, I found this great psychologist who, we agreed on all the time frames and everything, then her, her gatekeeper, her secretary was like, 'well that can't happen'. 'I don't know, Dr. M. said it could. You should talk to her.' And it did, right. So we just made it happen.

Parents described needing to access professionals, often outside of publicly-funded school resources, to obtain a diagnosis or other formal assessment of their child in order to challenge school practices. For example, one parent used a diagnosis to successfully challenge their child's suspensions and expunge them from the child's record (see Chapter 5). School systems were also described as having a great many confusing processes, meetings, and documents. Some of my interviews with parents focused almost entirely on parents' experiences with teachers, principals, school documents, administrators, and formal meetings such as Individual Placement and Review Committees (IPRCs). One couple, for example, talked about these meetings as openly hostile and confrontational:

Parent 1: …The [school board] has a really great pamphlet about disability and all of this shit, but really they're there to save money and kids with disabilities cost them money if they need individualized stuff. So you know, to have to feel like what you're doing is having to fight for your kid, and that, if you're going to an IPRC meeting that you're actually going to war. And you bloody well better not go in there alone and blah blah blah. So we don't go to any meetings
Parent 2: Unprepared.
P1: Individually.
P2: Noooo.
P1: It's definitely together.
P2: We're prepared.
P1: And it's like a war. And I don't, I never really feel badly unless I go to one of those meetings. And then, I feel terrible for my kid. I feel terrible for us.

Across the board, all of the parents I spoke with who had children who had been in school talked about having to "advocate" within school systems for their children. One had moved their child from one school board to another based on lack of accommodation and lack of response to bullying, and another had taken their child out of the public system altogether. One described waiting for "years and years" for a laptop for their child, and eventually got a doctor to write a letter that this was a required accommodation (see Chapter 5). All of them identified the barriers they met as a systemic feature and most recounted stories from other parents they knew who struggled to find adequate accommodation for their children in public schools.

Schools might have been the most commonly-discussed system where parents described having to "advocate" but they certainly were not the only ones. The scavenger hunt for information and referrals is an area of parental systemwork that remains unseen by most professionals. By the time that parents had come face to face with a special needs professional, they told me that they had already engaged in months or years of researching, thinking, deciding, and waiting. And the hunt did not end with engaging with a particular organization or professional since new needs or services might always be required. For example, when asked for her suggestions for other parents navigating special needs systems, Debbie described an ongoing and open-ended research process as an integral part of parenting and advocacy:

> Anyone I come into contact with I kind of pick their brain and just shelve that information because who knows, maybe in ten years I might need that information or, it might be useful… I like hearing other people's experiences. So I think becoming educated [is important], whatever that means for you. Because especially if I think about me, my kid is [young age], he can't really advocate for himself. I have got to advocate for him. For whatever he needs, he might need now or later, so I can't really do that unless I'm educated, I think.

This process of ongoing research often fell primarily to one parent within co-parenting families. Debbie acknowledged the extent of the work she had undertaken: "I have this whole binder of notes. My co-parent was like, she's like, just do your thing. I'm on this mission {*laughing*}".

Whether they were in a current romantic relationship with their co-parent or not, many parents also pointed out that both co-parents regularly attended appointments, in contrast to many (presumably) heterosexual parents they knew where only the mother attended (see Chapter 4). Of the parents in the study who had previous or current heterosexual partnerships with co-parents, all described the woman in the relationship doing more of the systemwork. Many of the parents described disagreements between co-parents about whether and how to engage with special needs services systems; working through these disagreements and decisions became a part of these parents' systemwork. Feeling alone and acting without the support of a partner/co-parent was a central part of the emotional labour that some parents described.

Sometimes there was additional work that needed to be done after co-parents separated, where disagreements between parents on diagnoses and services could be a part of court arrangements or everyday disputes, as described by one parent:

> As you were asking about all the thinking and the researching, I feel like in our family, that's always been one of my major roles. I've been the one who goes and finds all the information, consolidates it, and then presents a report to say "I think if would be best if we do x and this is why". It's something I'm good at, and something that I've discovered is different now that I'm not with their dad and we're making decisions separately. He's still expecting me to do all that research stuff and present my report *{laugh}* but now because there's a certain level of animosity, he doesn't always take the information I present at face value. So I feel often I do all that work, I present, and he just says, "no that doesn't make sense." And then I don't know what my next step is, because… it's not like he's providing much more than "no I don't want to do that." It feels like now, I'm doing everything that I was before, all of this planning, except I've got somebody else who can nix it that I don't really have that much power to influence.

Given that special needs services currently do not easily offer information and resources, parental uncertainty or disagreement about which course of action to "advocate" for left parents like this mother feeling stuck. She went on to explain that she would not be able to ask the school system for the accommodations she felt would be ideal for her daughter because she would have to take her ex-partner to court to get him to agree to such an arrangement in addition to combating the school board's resistance. She said that this use of

time and money was not feasible for her. In this instance we see how an institutional

framework that makes access to information and services largely dependent on parental

efforts and resources shapes the everyday experiences of parents, and, ultimately, of their

children as well.

Parents described devoting substantial amounts of time and energy to systemwork. One

parent said that they set aside half an hour each day for service coordination or advocacy

activities. All the parents I interviewed talked about decisions regarding place or hours of paid

employment that had been affected by systemwork and parenting considerations. Several talked

about reducing or not returning to their paid employment, or switching jobs based on the hours

or the flexibility that would allow them the time for special needs systemwork. The need to

move across and between different special needs agencies also increased the behind-the-scenes

systemwork that parents engaged in: researching, waiting, deciding, getting referrals, making

appointments, and filling out paperwork each time a new service was considered. When the

service did not end up being useful to their family, this led to substantial frustration, as one

parent recounted:

> And the other thing that kills me about the service coordination stuff is that whether,
> almost any service requires for me to show up during the business day, perhaps sit there
> in a waiting room. Most of the time pull [my kid] out of school for us to talk like I'm
> talking to you right now, with some professional, fill out a whole bunch of forms. [My
> kid] misses a half day of school, I miss a half day of work, and we may or may not get
> anything out of it. And that's the part that's just so maddening for me.

This mother went on to describe how she used up almost all of her personal days and vacation

days from work to make it to all of these appointments with her child, or to cover the days when

there was no school and therefore no accessible childcare. She highlighted that getting any

formal respite services had been difficult and expensive. She used all of the "respite" hours she

could afford for after-school care while she was at work, since the less-expensive, school-based

childcare was not prepared to support her child. On top of managing this day-to-day patchwork

of services, this mother had no vacation days left that she can take while her child is at school in order to rest and recharge. Here we can see that a range of institutional arrangements did not anticipate or respond to the needs of a single parent who had a disabled child and also a full-time job, and/or the needs of a full-time employee who also had institutionally-shaped constraints on her working hours related to parenting and special needs systemwork. Institutional definitions of "respite", "vacation", and "personal days" clearly did not correspond to this parent's everyday realities.

Waitlists were a dominant theme in the interviews, and their very existence pointed to the scarcity of services available for their children. For example, a parent of an adult child described years of trying to find supportive community housing for her daughter. Ultimately, the mother experienced a major medical crisis of her own, and a social worker prompted her to write a letter to the housing agency which finally got her daughter into supportive housing:

> When I went through the [GTA housing support organization], we were able to get her off the waitlist. She was 2500th on the waitlist but I had a [serious medical crisis with chronic effects] and they said, write a letter, and I did, and she got off the waitlist.

Waitlists pointed to the scarcity of available resources and to the stakes of any "failed" systemwork. For example, one couple had a adopted a child and been told that she was on a waitlist for a special needs preschool. When it turned out that this referral had been lost between multiple professionals, the parents no longer had the option of using that service. Waitlists not only indicate a scarcity of resources, they also leave very little margin for error.

At the same time, getting on a waitlist and getting through that list are not entirely passive activities. As Dorothy Smith has described, waiting is work, and it is a form of work that is rendered invisible within institutional discourses (2005, pp. 151-153). While service systems set waitlists up as a low-cost response to a demand that outpaces the supply of services, parents generated and enacted strategies to get on the right lists, anticipated needs to get on lists as early

as possible, and worked to move up the list faster. Some parents described very active waiting, including calling agencies almost daily to motivate providers to move them up the list. Other parents described waiting as a big part of services even before getting onto the waitlist. As mentioned above, many talked about having to anticipate and challenge a "wait and see" response when they asked to be put on the waitlist for resources, particularly in schools.

Beyond waitlists and the scarcity of services, parents talked about having to facilitate processes in-between institutions and professionals that otherwise had very little understanding of each other. Lisa described the challenge of also becoming a "toggle", in her case between a culturally-specific medical clinic, speech therapists, and public school teachers and administrators:

> I mean the school doesn't talk directly to the -- we're constantly in the translation role. And that's the other piece. There's one thing to be able to advocate for your kid, and to be able discover a good kind of research mind for the services and where to find them. But acting as the sort of toggle between the services, and the translator between those services and institutions? That is very, you know, it's hard, it's very hard. And not everybody can do that.

Lisa emerged wondering whether the solution to the struggles that she and other parents are facing may be less about "more resources" and more in this realm of coordination between systems. Another participant showed me a written document that they made about their child in order to "translate" the many professionally-written documents for everyday use across different services and trainings (see Chapter 5). Some parents reported disagreements and difficulty communicating across "silos" of different professional training, as in one example where a parent and child would go back and forth between speech therapists and instructors of American Sign Language.

Parents also described "hidden gems" in encounters with providers a bit outside of "special needs services". They expressed that these individuals or programs "understood" them and their children, often without even needing a diagnosis or requiring much systemwork of the

parent. One parent described a gym daycare as one of the most successful programs for her child.

> I've also found a couple of like totally hidden gems in the whole situation. …Believe it or not, there's a gym near our house which is a women-only [company name]. It's a crappy gym, and it's a crappy group of equipment… But the childcare is fantastic. And they love [my kid] and [my kid] loves them, and they totally get [my child]. And I'm like, okay, you've got my business.

In contrast with the many special needs services this parent had interacted with, this program seemed to understand this particular child. Another parent talked about finding some of the best resources for her child with the school kitchen staff.

> Last year… the [school] kitchen staff noticed [my child] liked to be helpful so he brought out desserts. So he was able to be with another child one-on-one and ended up developing a friendship and got a cookie at the end of it. And avoided recess, which made him so happy. But such a sense of accomplishment, like, "today I cleared the plates". And I called the kitchen and I was like, thank you so much. Before that [my son] was going in to the office and saying, my tummy hurts. And nobody was bullying him, he was just terribly lonely. So it's, you know, it's that kind of thing. The kitchen staff did that, but the teachers could do that.

Such encounters highlight that the documentation requirements and the professional credentials of many providers and systems are not always directly connected to an improved relationship with the parent or the family, or a better understanding of their needs.

While most parents described considerable frustration and systemic gaps, one couple I spoke with had a noticeably different perspective. Marvin and Allan did not describe scarce services, waiting lists, withheld information, or poor coordination of services after their child received a cancer diagnosis. While this child had previously been on waitlists for other disability-related services, with a cancer diagnosis they were given coordinated services and supports including a binder full of information on resources, definitions, and the standardized treatment protocol. When their child's needs intensified temporarily, a home care nurse was immediately assigned through a community care case manager. They described this as a harrowing experience, but one in which they had confidence that they could get the supports and

information they needed from available professionals in a timely fashion through a central institution, in this case a hospital. The contrast between this experience and those of the other parents was dramatic.

What set this situation apart? How we define 'special needs' can certainly come under scrutiny, and perhaps cancer care is not a "special needs service" but a "health care service". Not all health care services would be seen as related to 'special needs' or 'disability', and possibly this child would be seen as more "normal" within institutions and discourses of 'desirable' reproduction. For example, the discrete "onset" and possible "cure" trajectory of the diagnosis stands in contrast with the other diagnoses of children whose parents participated in this study. While a number of other children in the study had significant medical concerns, they did not have primary diagnoses with such an established course of treatment and exclusively medical focus of care. Cancer is seen as a centrally medical concern in a way that these other diagnoses are not; indeed, many advocacy groups for people with disabilities or diagnoses on this list have in fact critiqued the medicalization of their experiences and their identities (e.g., http://www.cdss.ca).

Apart from the debatable social benefits of medicalized understanding for different experiences and needs, **institutionally** the medical recognition of a particular set of "needs" is often required in the form of a diagnosis. Having a diagnosis that is regarded as comprehensible and treatable through a medical institution and discourse seems to have particular systemic benefits. Indeed, a participant who had a child with an autism diagnosis even made the comparison between systemic responses to cancer and autism, particularly in the role ascribed to parents:

> Like, if we did autism like healthcare, so autism would be health, right? So if we did
> cancer, and you had breast cancer, and there's kind of all different kinds of breast cancer.
> If you had breast cancer and we sort of said, well, there's all kinds of things. Go ahead.
> You figure it out for yourself! {*laughing*} Can you imagine?!! That would be hilarious.

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But we do that with our kids and autism. You know, like, What?! You know, 'you're the experts' … I'm totally prepared to learn about this, but you know, that's what I find really frustrating.

It is important to note that other parents whose children had spent time in hospitals did feel that they encountered gaps in services and information. Indeed, a couple whose child had a developmental disability, a brain injury, and a variety of medical conditions that had required extensive hospitalization described a wish for "parent mentors" to help them navigate the system. In contrast, the parents whose child had a cancer diagnosis were indeed matched with other parents who had already been through a similar treatment process.

These findings suggest that the degree of coordination and responsibility assumed by institutions to address particular situations, such as cancer, outstrips institutional and material supports for others, such as intellectual or developmental disabilities. This may be a result of a variety of possible causes: differential social stigma/ ableist associations for particular diagnoses, targeted healthcare funding, the differential status afforded to medical as opposed to educational or other publically-funded expenditures, or most likely some combination of the above. What is clear from these findings, however, is that the particular diagnostic category that a child falls into has direct implications for how the institutional frameworks parents engage with will respond, ultimately determining how much, or how little, parental systemwork or "advocacy" will be required. Indeed, while other parents who used single-diagnosis clinics (one public, one private) for intellectual or developmental disabilities still reported more systemwork requirements than Marvin and Allan, they also described the "one-stop shopping" approach as very helpful. Parents who did not have access to such clinics but had heard about them also saw this as a potentially helpful approach. Other parents expressed a hope that school systems could take up this role, but this had not been their experience to date.

The "one-stop shopping" approach is unlikely to be available for all children, however. When children have multiple diagnoses or do not easily fit within the mandate of a particular organization or set of services, this lack of service coordination can be profound, again exacerbated by the shortage of services and waitlists at each step of the search. Parents end up having to learn the criteria used by each institution and develop creative strategies when they encounter service gaps. For example, Lenore described her daughter as a "gap kid" in that she did not meet service criteria of programs that offered services the family desperately needs, such as respite. Lenore illustrated "the gap" through a description of looking for respite services, explaining how engaging with one service or organization required and built upon additional encounters with many others, each one operating with its own gatekeeping criteria.

> [The staff from the respite agency] talked to me and got all the information, did an intake, that sort of stuff, and and then said, Sophie has a severe intellectual disability but she hasn't been identified as having a developmental disability. And I'm like, what's the difference? And they're like, well, it's not really that big of a difference except for developmental usually means more of like a broader range of issues and intellectual usually means… a hard time learning. And Sophie's psychologist and psychiatrist think that Sophie should have a diagnosis of developmental disability because she's got such a severe intellectual disability. And *they* think that the psychologist from the [school board] mislabeled her. And so that's why we are reopening things with [another organization on developmental and intellectual disabilities]. But the problem is, we're on the waitlist, it will take a while for the assessment, all that sort of stuff. And meanwhile, [the respite organization] is saying, yeah, until you get the word developmental? We can't touch you. That's the gap.

The scarcity of services and the abundant supply of potential agency clients mean that organizations become increasingly restrictive, while parents become increasingly desperate in their search for services.

Who Can Get Through? Parents and Levers

Parents described using a variety of strategies to navigate the systemic scarcities and gaps they encountered. Indeed, at the core of training for and developing skills in "advocacy", parents learned how to lean on whatever levers were available to them. These strategies show

that the existing institutional arrangement of special needs services is not equally accessible or effective for all parents. Strategies and resources varied based not only on the particular diagnosis or situation of the child, but also on characteristics of the parents themselves.

The most commonly cited means that parents might use to improve their results in the scavenger hunt for services was money. As seen in the example of Steve bypassing school board assessments through "writing a cheque" for a private psychologist, the option of "going private" substantially changed parents' experiences and outcomes with special needs services. While Steve was ultimately interested in and able to access "public" education resources for his child, his ability to access these "public" programs was directly linked to his ability to pay for "private" services. Several other parents talked about how they circumvented long waitlists by using cash or employment benefits plans to pay private service providers, and those who had not actually done so explicitly described considering it or determining that they would not be able to "go private".

Parents who reported "going private" continued to use as many public programs and services as they could, but supplemented services that were not available. For example, all of the parents who had interacted with speech and language therapy services remarked on the substantial waitlists in this sector. They also identified the common practice of approving the same number of sessions for every child before putting them back on the waitlist (see Chapter 5). Most of the parents that I talked with did manage to supplement these times on the waitlist with private services, but of these, several were unsure they would be able to afford to do so for long. Interestingly, some parents who had more money were also better able to secure public (no fee for service) resources than parents who had less money, often through negotiating arrangements through adoption agencies or using professional contacts to learn about programs and arrange reduced waiting times.

One parent who also worked as a special needs service provider within a publically

funded service described the differential outcomes based on parental income and often

corresponding differences in race:

> There's no cost [to the services where I work]. So there's always people who will find us
> because of that. "Oh, you're the only free service. Sign us up for that! I don't care if it's
> a two year waitlist. That's the service I want because it's free." Whereas families who
> have money may still put their kid on the waitlist, but while they're waiting they've
> accessed like all this. I've seen that. … I've seen white families that appear to be Mom,
> Dad, high-paying salaries, and yes, they're on our waitlist. But meanwhile. And
> sometimes it's a two year wait. In those two years they've accessed daycares, home
> workers, an OT, SLP, and like everything you can think of under the sun. And other
> families don't have that same thing, and I find often it's families of colour. I have seen
> that, where I work. I don't know if it's just where I work, but I've seen that. Definitely.

Meanwhile, parents who did not have enough benefits or income to "go private" described

having to devise other strategies, including more persistent calling and researching, drawing

upon people they knew to obtain lower-cost services, or re-arranging their own paid

employment. Often they were forced to wait while knowing that their children were not

receiving the services they needed:

> You know we've sort of looked into trying to access some of the programs that are out
> there. A lot of them you have to pay a lot of money to access. They're private, not
> necessarily, you know, uh, programs that are easy to access if you have cash flow issues.

Beyond financial resources, several parents I spoke with had relevant professional

training that they were able to use in navigating special needs systems. For example, after her

child was bullied extensively, Elyse, who was also a teacher, brought examples of forms from

the school where she worked along with photocopied educational legislation to a school

meeting:

> E: I even brought a form in from my school, because in my school they had a specific
> form that you would file, and I brought it in. And I said, "well, if you don't"… because
> some of the teachers would see some of the things that were happening to my son, and I
> said, "well did you report it, as per Bill 157?" So I brought in the paper and I was like,
> "well, would you like to photocopy this one?" Because it was just like, they didn't know
> how to deal with it, or, yeah.
> M: So this was like the incident report form?

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E: Yeah. It's just a form. But like a lot of times, if you put things in writing, it's the only thing.

Other parents reported asking colleagues for favours or describing their profession and where they worked in the hope of moving up waiting lists or receiving better services. Such strategies were, of course, only available to some parents.

In addition to professional know-how and financial resources, parents described developing whatever interpersonal strategies they thought could work. More than one parent talked about acting as a "poster child" or workshop presenter for adoption agencies as a means to gain leverage when asking for additional resources for their child. Several talked about consciously managing how they appeared to service providers in order to maximize their chances. In one father's case, he described crying as a way to get results: "I cried. It works. They don't like to see men cry." One couple talked about their "gift strategy" of giving more expensive and elaborate presents to teachers on behalf of their child. These often elaborate and individualized strategies were honed over time, but they also indicate that different "levers" were available for different parents, leading to different outcomes. Crying might lead to a different result for a man than for a woman, for example.

Race, education, and immigration experience particularly influenced the strategies that parents felt were available to them. A number of parents cited their own privilege across these domains. For example, one parent described using her ex-husband's class and professional status as a doctor (thus portraying herself as still married and heterosexual) to get her child a much-needed and long-delayed surgery. She attributed the results of her advocacy both to her skills and to the layers of privilege that she was able to either affect or rely on:

> I pulled out the doctor card. I did. And that, for me, sets me up with privilege. If I was a woman of colour, if I was a forever lesbian, the chances of me being able to convince them to do her surgery would have been nil. Absolutely none. So it was through privilege and having a lot of chutzpah, because of my good luck until then with where I worked and how I was received, that I felt confident to push.

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As discussed in the next chapter, some parents felt they were not visibly queer in all interactions and that they sometimes received better services as a result (see Chapter 4).

Racialized parents and parents of racialized children talked about how racism and white privilege influenced their interactions with special needs service systems and with other parents. For example, a White parent of an Aboriginal child described a concern that if people were to learn of his disability the resulting stigma may pile on to the racist messages he already faced.

> We were very worried, particularly because he's an Aboriginal boy who was, at that time, at risk for fetal alcohol syndrome. We just imagined the picture, the *path* that people imagined themselves. And we didn't want people's first impressions of Owen to be, "This kid's never going to finish high school. So why bother doing more for him? He's never going to be able to concentrate really. So why bother pushing him to excel? He's going to probably find himself in prison. So why bother teaching him to manage his anger?" Those were all of the, the moments of fear. And because that is not the complete lived experience of kids, of adults, with fetal alcohol spectrum disorder. But that's the narrative that we hear, that we see.

This parent described trying to consciously create a "new narrative" about fetal alcohol spectrum disorders and also drawing upon culturally specific, Aboriginal services for her son. A Black parent of a Black child talked about a similar concern that her son will be written off due to how others perceive the intersection of his gender, race, family structure, and disability.

> I mean, he's a child of two moms, he's a boy of colour, he has a special need. I just feel that people who are not necessarily educated, are not necessarily…. I mean not necessarily educated in [his diagnosis], educated in all the –isms of the world, that could take that and lump it all together and be like, "He's just a typical Black kid, and he's a write-off." Or, "It doesn't really matter because he's not going to amount to anything." Like, I'm really over-dramatizing, but people do, right?

As a result of her concerns about this intersecting marginalization of her child, and her previous experiences as a racialized parent in this school system, this mother spent many days researching different school options. She ultimately chose to send her son to a school that will require a long transit commute each way. This is an example of how racialized parents and parents of racialized children often have an even more substantial burden of systemwork. Such

everyday experiences point to institutional "ruling relations" – in this case in schools – that prioritize the needs and experiences of socially-dominant groups such as White, middle-class, heteronormative, cisnormative, able-bodied children and parents.

Parent Critiques of Advocacy

While parents described engaging with the activities and terminology of advocacy, and some conveyed a sense of pride in their advocacy skills and accomplishments, parents also talked openly about the limits of advocacy. For example, one parent talked about their own trouble with reading and, in so doing, identified differences in the skills that parents bring to their ability to "advocate". In this exchange, we referred back to a story of the principal who met with Andre and Beth (Andre's partner) but could not remember what the "IPRC" letters stood for and did not explain how an IPRC meeting would be helpful for their child.

> A: I guess [it's important] for parents to actually know, learn some stuff about what's going on with your kid. And I think that I am totally, uh, um, terrible with that. Because I'm not a great reader. So the way I learn is by Beth reads, we have a conversation, I take it all in. Um, I watch Steve Paikin on the Agenda, that's where I learn all my shit. I don't learn from reading stuff, right? So what I'm trying to say is parents need to equip themselves with as much knowledge as they can.
> But we need people to advocate for us. I don't think we can be the only advocates for our children. We need support with advocacy. Because even though you know stuff doesn't mean you know how to use it. So I could do all this reading, I don't know how to navigate the school board or the system. So, what's, you know?
> M: Well, and if the principal doesn't know what an IPRC stands for
> A: Exactly
> M: What are you going to do with that?
> A: Exactly. How am I going to use it to my advantage or my kid's advantage, to get the support or the services that I need? I can't do that.

Andre identified the conundrum of being told to "advocate" as a parent when institutional representatives are also obscuring information and preventing parents' access to information. Indeed, the system should be ultimately responsible for "advocating" for parents and children.

Andre's critique highlights the institutional motivation to support "advocacy" as a way to manage or defend the widespread cutbacks to public services. Neoliberal ideologies support

extensive cutbacks and gatekeeping within public services in order to encourage people to use resources in the "private sphere", whether through unpaid carework or though becoming "consumers" of market services (see Chapter 1). Even for those parents who are unable or unwilling to access for-fee services or take on additional unpaid labour, "advocacy" as a standard parental expectation pits parents in competition against other service users/ parents rather than putting pressure on systems to provide more comprehensive and available services. Service systems therefore attend only to the few who "advocate successfully" rather than anticipating and responding to the needs of all.

It is important to note that neoliberal ideologies and cuts to government funding affect service providers as well as service users. As Jennifer Wies (2013) has found in her research with domestic violence shelter workers, even non-profit organizations have shifted their focus under neoliberal pressures to ensure that there is an entrenched divide between "professionals" and "clients", while simultaneously giving the "professionals" low job security, reduced wages, and little agency in their everyday work. There are considerable pressures on providers to spend more time in "gatekeeping" roles than in helping users navigate service systems effectively, increasing the need for service users to learn and "advocate" on their own.

The experiences of parents in this study also highlight that only some, very specific types of parents will have the time, privilege, temperament, and environment for "advocacy" to work. This intersectional specificity can be seen in Steve's discussion of how he successfully "pushed" a number of professionals -- educators, a psychologist, and a secretary -- to meet his son's educational needs. Steve's advocacy strategy was shaped not only by financial resources but also by his social location; as a White, middle-class, professional, cisgender man, he receives a more privileged set of responses in institutional interactions. Other participants used humour to

highlight how only certain parents can "succeed" as advocates, using the example of the parent and child who were featured as a success story for the advocacy workshop they attended.

> Parent 1: And [the son] presented a really great talk, right? It's amazing. It's amazing. So. Just as a person who's been through the system and shows how it can work. Yeah.

> Parent 2: If you have a Mom who can do that full-time.

> P1: Full-time {*both laugh*}.

> P2: Who speaks English, who's White, who's really assertive, who's …

> P1: Who lives in an affluent neighbourhood.

> P2: Yes.

> P1: Like obviously. {*laughing*} Yeah.

In this exchange, the parents both endorsed the usefulness of what they learned about how to advocate for their child, and also acknowledged that the likely outcome of their advocacy work is determined by who they are, what they have, and where they live. Many parents highlighted the specificity of their options as advocates, explaining how what they could do was connected to who they already were. In contrast, the **need** to advocate, to do skilled and demanding work to learn about and navigate systems, was presented as a universal. Even the most privileged parent, in their account, still needed to work "full-time" as an advocate.

The findings presented throughout this chapter underscore that existing special needs service systems are difficult to navigate, and that the options available to parents vary depending on who they and their children are. In other words, while parents had all encountered the systemic and social expectation that they become "advocates", they also presented a critique of where this advocacy might lead and what it might cost. A number of parents voiced suspicions that performing the advocate role too effectively may in fact work against their own interests, and those of their child, since it could let professionals off the hook. This finding suggests that in promoting "advocacy" as a parent role, service systems may simultaneously be off-loading

responsibility for the tasks associated with research, referral, and hands-on strategizing onto parents. One mother explained her experience of being read as more knowledgeable than she felt she actually was:

> The other part that's negative to all of that is I think that I'm a good advocate, and very organized, and pull stuff together for [my child] and do a good job. But because …I present as a professional, and all of that, sometimes I think it would be to my benefit to be a little more stupid and needy, you know. Because I sometimes I don't get help. Because when I know stuff, I *think* I know stuff but sometimes there's a whole gap, like I know just enough to be dangerous on certain topics. I don't actually know as much as service providers or professionals know… That's the other side to being a verbal lesbian who is good at advocacy. People say, oh, she's in good hands. We'll move on to the next one.

Another parent discussed a similar feeling that service providers assumed they knew more than they did, an assessment that her partner pointed out was complicated by the institutional restrictions on what they could and could not do before their daughter's adoption was finalized.

> Samantha: It just kind of fell into this black hole of everyone always assumed that somebody else had done it. Like we were taken care of. And again, again, people kept saying like, "you're knowledgeable", like, "Oh, you're already on it." There was kind of like that blasé, like, "oh, you understand everything." And we were like, "Oh." And only when we realized that we needed it, that we were like, "Oh god, where do we get it? And why, why hasn't this just been part of it all along? Like, why are we now? Like Natalie's adoption has been finalized for well over a year... And we were like, why are we only doing the paperwork for funding, like government funding, now?" Like, this really should have been something we did

> Aurora: No, no, no, we weren't allowed [until the adoption was finalized].

> S: No, no, no, we weren't, for some of it, but for other, a lot of the other stuff, we don't need her social insurance number.

The common denominator in these experiences was parents' sense that providers are looking for any reason not to offer any more than they deem immediately necessary, and that there is an ongoing triage in which scarce resources are offered first to those who appear to be the most in need. For parents who are practiced in showcasing their competence -- as they may be required to do during an adoption process, or custody hearing, or as a part of responding to homophobic

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or racist beliefs about their parenting -- the requirement that they portray themselves as uncertain and "needy" to professionals could be especially fraught.

Not only do such experiences of being read as "too competent" mean that parents feel the need to think through and manage their appearance to professionals (thus adding to their systemwork), but they also indicate ways that professionals can reduce their own responsibilities, particularly when widespread cutbacks have increased employee workloads. The option of "moving on to the next one" must be tempting in an overloaded professional and institutional environment. The parents I talked with did not actually report that the most "needy" parents ended up receiving more or better services. Indeed, it seems instead that knowing more about what to ask for is an essential component of navigating these systems. What may be simultaneously true, however, is that professionals are quick to dismiss parental "need" of all kinds, either due to a parent seeming like "a good advocate" or because that parent did not know what to ask for.

This shifting of responsibility and labour from professionals to parents points to an overall offloading of "advocacy" responsibilities and service coordination tasks throughout special needs service systems, as seen through the everyday experiences of parents. When such offloading occurs in a framework of scarcity, privatization, and competition, differential parental resources (e.g., finances) and situations (e.g., diagnoses) lead to different parental systemwork requirements and, ultimately, to different material outcomes. Intersectional parent and child identities or experiences (e.g., race, class, family arrangement, diagnosis) are thus central components of how these systems respond, and what work they demand of parents. In the next chapter, I will consider how being an LGBTQ parent, in particular, can influence parental interactions with special needs systems.

Chapter 4

'We don't fit in': Navigating Categories

Although all parents who have children with 'special needs' or disabilities engage with the same overall service systems, differences between parents can significantly affect their experiences. The parents I interviewed talked about the ways that their LGBTQ sexuality and gender identity/ expression had influenced their experiences as parents navigating special needs systems. The impact of LGBTQ identities in parents' experiences resulted from an ongoing interaction between how parents felt about their own identities and communities, the available and institutionally significant categories that they saw available to them, and how they were (or thought they might be) interpersonally interpreted or "read" by others, including service providers and other parents. These effects were therefore contingent, uncertain, and complex; they varied from parent to parent, and even story to story.

These interview discussions of parental identities and experiences brought up the notion of "fit". Parents talked about fit both for themselves and for their children, as a way of understanding what may, or may not, smooth their passage through systemic interactions. In this chapter, I consider how parents discussed queerness, kinship, and disability in their experiences of "fitting" or "not fitting" into the available categories and social groupings of special needs service systems. Often, whether, how, and where parents felt they and their families "fit" was elusive and unsettled, so that parents were asked to anticipate how they may or may not fit, and the possible consequences, in order to ameliorate their experiences and outcomes.

In this chapter I consider the following: how LGBTQ families define themselves and how these definitions are constrained in institutional interactions; what LGBTQ parents report is required to "fit" institutional guidelines and expectations as parents, families, and service users within special needs service systems; how LGBTQ identity, child's diagnosis, and other

intersecting identities including race and gender, may influence parents' experience of "fit" in these systems; and the ways that parents reported LGBTQ experiences, worldviews, and communities that they value and draw upon as they navigate special needs systems.

Families and Institutions: Creativity and Containment

One of the first questions I asked parents in this study was "who is in your family?" There were a range of responses, although participants all mentioned their children and their partners, if they had one. Many mentioned members of their family of origin, ex-partners, and friends, sometimes explicitly using the term "chosen family" to identify the importance of people not related through legally-recognized bonds (Weston, 1991). Often this discussion led to a consideration of how long different people had been in the family, and how the family definition might be different for their child(ren) than for themselves. Adoptive parents often mentioned connections to the biological parents or other relatives of their child as part of their family definition. One participant, Nora, talked about a friend/co-parent with whom she had never had a sexual/ romantic relationship with and with whom she did not share a residence, but with whom she had created an intentional shared parenting arrangement after her separation from her ex-partner. Nora expressed a belief that in LGBTQ communities there was more room to be "creative" in how family was defined and structured.

> I think part of being part of the queer community has opened me up to different ideas of family and facilitated um because also, I parent [friend/co-parent's adopted child] , and I think if I wasn't queer, then it wouldn't have. Or certainly it doesn't seem to occur to people outside the queer community to partner cross-family in different ways. I think it's a little bit more blended and creative in our world.

Nora described the co-parenting/friend arrangement as central to her parenting experience, and said it was the relationship where she receives most of her parenting ideas and support. This

belief that family can, and should, be consciously created beyond biological/legal frameworks was found in family definitions of the other participants.[14]

At the same time, participants also defined their families with explicit reference to institutions. Some talked about having been married or divorced and often discussed court decisions around custody. Nora described about how she was not given (and had not sought) any legal recognition with regard to her friend's (legally) adopted child, and there was already extensive court involvement in the initial adoption and subsequent separation and custody arrangements between her co-parent and others. While Nora was not an official participant in these court processes, she highlighted their impact on her everyday parenting experiences. Adoptive parents I interviewed all talked at length about the ways in which their interactions with other people and services shifted after the finalization of the adoption, and described institutional influences on their decisions around whether and how to involve their children's biological families (see Chapter 5 on adoption certificates).

Thus while there was a lot of talk about how "creative" and "chosen" family could be, there was a concurrent recognition of how institutionalized family recognition was. Parents described having gained a great deal from moving beyond dominant institutional definitions in their own familial definitions and relationships, and yet they were very aware that they could not escape institutional process that would, or would not, allow them to "fit" in pre-existing notions of family.[15]

As parents talked more about their experiences with institutions, it became clear that "fit" was a struggle even for familial relationships that had been legally endorsed. LGBTQ

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[14] The only exception to this inclusion of non-marital/ biological relations in the description of family was from one parent who was generally not "out" as LGBTQ, was heterosexually married, and had their biological (non-adoptive) children through this marital relationship without having used any assisted reproduction services.
[15] See R. Epstein (2014) for another consideration of how LGBTQ relationships bump against institutional definitions with particular material consequences.

families' departures from "expected family" forms was evident in both institutional documents and interpersonal encounters. LGBTQ parents identified a range of reasons why they did not fit institutional or sociocultural expectations of who would be accessing special needs services. For example, Aurora and Samantha discussed a range of reasons they did not "fit in" with a parent support group at a special needs service agency:

> A: We definitely don't fit in though… Young people don't adopt. We were the gayest, for sure. Like no other homosexual couples. …Then we adopted a kid with special needs, and why would you do *that*.
> S: And we're lesbians who adopt…
> A: … And we chose [a child with a particular diagnosis] and the [particular diagnosis] people don't understand that… And so we don't really fit in anywhere.

In this exchange we learn that Aurora and Samantha did not feel they fit with other lesbian parents, other adoptive parents, or other parents whose children share their child's diagnosis or receive services at the same organization. Furthermore, Aurora talked about meeting strong resistance from service providers when they asserted that they did not fit in and expressed reluctance about attending a parent support group.

> [The provider said] "Everybody here is in the same boat. They all have kids with disabilities." And what they *don't* see is, yeah, they all have [kids with] disabilities but, like, they're straight, probably some of them are homophobic, so, you know, we're not *great* in that group. So, we *don't* fit in.

These parents expressed that they did not get anything positive from most groups they attended because their perspective and experiences were too different from others in the group; while they stated that they had not encountered homophobia, they described being treated as objects of curiosity by other group members. One other parent told Aurora in an awed voice, "I've **read** about people like you". The institutional understanding of "who fits", as asserted by the service provider, did not reflect either the parents' experience or the apparent perspective of other parents using the same services. This example indicates that an institutionalized insistence that "everyone fits" only underscores some parents' sense of exclusion since they then have to also

negotiate their disagreement with the service provider and/or spend time receiving ineffective services. As Aurora said of the provider, "They *argued* with us!" Such interactions also add to the time and energy parents must devote to navigating complex systems and professional relationships.

The potential consequences of institutionalized exclusion ("not fitting") within special needs services are greatest for parents with the fewest sources of material and social privilege to begin with. While Aurora and Samantha described having abundant supports from family and friends that would make up for the inadequacies of the support groups they attended, other parents who described themselves as socially isolated (e.g., having just moved to the area, single parents, parents living far from LGBTQ-specific services) expressed particular longing for more LGBTQ-inclusive parent support options through different agencies. Again, many parents described currently available services as officially "for everyone" including LGBTQ parents, but this did not reflect parents' own sense of where and how they fit. None of the parents I spoke with described parent support groups created through or sponsored by special needs service agencies as a primary source of support. They were more likely to talk about particular individuals they had met, LGBTQ parenting programs, or family and friends as the places where they found such support and sense of belonging.

Intersectional Effects of Fit

As seen in the support group example, the importance and impact of fitting institutional categories can vary for different LGBTQ parents. The range of reasons that parents may or may not experience belonging or "fit" within special needs services also reflects the intersection of many particular identities and experiences in institutional encounters, including but not limited to their LGBTQ identities and their children's 'special needs' designation. Within systems that have scarce resources, where service providers are often also required to perform gate-keeping

roles, the particular identities and resources of individual parents and families can have important effects what they and their children receive (See Chapter 3).

This means both that i) some LGBTQ parents "fit" more than others with institutional expectations, and ii) that the need to fit with a particular service's intake requirements may be more acute for parents with fewer resources. Parents with more financial resources and often self-described privilege (for example, through race, class, education, and/or gender), talked about being able to leave services and/or find other options in the private. One parent talked about taking their child to a private clinic which not only offered all services under one roof, but also had an openly-LGBTQ clinical director. Other parents with fewer privileges and resources had to wait for the first available provider within publicly-funded systems.

The parents I spoke with described uncertainty, not only about how service providers might respond to them as LGBTQ parents, but also about whether and when they were even identifiable to others as LGBTQ. Parents who were currently in heterosexual relationships or co-parenting with heterosexual exes were often read as "straight." For example, Sarah, who is bisexual, generally not "out", and married to a man, described her experience as largely unaffected by her LGBTQ identity:

> I think there is a certain privilege because I did marry a man, and so I generally, I don't have to be out about my status. So it makes going through the world, dealing with school systems, it makes everything more normal in a way, and less having to explain or worry about discrimination. And I can see going forward with institutions, that would be a concern of mine if I was out. I would just be nervous about being discriminated against.

Even though Sarah described herself as privileged by her heterosexual appearance, she nevertheless modified how she describes her relationship with her partner/husband to match the normative family structure she thinks service providers will most value:

> It's interesting, because in a lot of circumstances I'll say, "oh, my partner." Dealing with formal organizations, it's "my husband." It's just, I've kind of noticed that. And it's so funny because neither Derek nor I have ever been comfortable with "my wife", "my husband". We don't like those terms. And so we've kind of struggled and it's like,

"partner"? Okay. So I usually have to say, "This is Derek". {*laughs*} "You figure it out." Right, but yeah, I do find we tend to use very nuclear terms. "My husband." Yeah.

Another bisexual mother being read as "heterosexual" with regard to the children she had with her male ex-partner, and "queer" with regard to the child she co-parented with another woman.

> You know I think that's so difficult for me to speak to [suggestions for LGBTQ parents] because of my stealth level of being an LGBT parent. Because so few people see me in that light, I don't feel like I hit that barrier very often… I mean I can see how egregiously the world oversteps the rights of minorities, and I can see that partly because when I live in one world, I don't get hit by it, but when I live in another, suddenly, there it is.

Other participants often commented on the impact of being "out" in navigating systems. While Sarah, in particular, highlighted the risks of disclosing an LGBTQ identity within systems such as schools, other parents speculated about how difficult it would be to effectively challenge professionals if parents were "not out". In other words, these parents regarded being "not out" as a hindrance to effective parental systemwork. For example, one parent said:

> I mean I found the process of going through the adoption, in talking about how to be a parent, was like my own therapy. It brought up my own issues and baggage and concerns. I just keep doing that as [my child's] parent. It's like a living therapy. So I think there is something about being very self-aware, very self-reflective, and as comfortable as you can be in your own skin. Because there is so much that is uncomfortable that it's, I think I would find it very difficult to do that and not be open and out.

As addressed later in this chapter, many of these parents saw the skills they had developed through openly living as LGBTQ as directly contributing to their ability to challenge and work with systems and individuals around disability and accommodation.

Other intersectional identities or social categories such as race and gender also influenced how providers read and responded to parents.[16] For example, one Black mother talked about how she did not know if she was even seen as LGBTQ since people -- including

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[16] Following S. Bear Bergman, I use "being read by others" rather than "passing" as the central construct (Bergman, 2009, pp. 105-112). This approach is also consistent with the critical intersectional framework which highlights social encounters and dominant discourses rather than an intrapersonal focus on a stable identity.

educators and other professionals -- often assumed that she and her co-parent, who was also

Black, were sisters.

> I think people make assumptions about my sexuality or my gender… I think, in a couple
> of schools we went to… people thought we were sisters. People think we look alike. I
> don't think we look alike at all… So we get that a lot. 'Oh, it's nice that you brought
> your sister.' So they somehow see me as the parent, I don't know why. And they're like,
> 'Oh, it's so great you brought your sister for support.' And they think all [the] kids are
> mine. Like, 'That's so nice that you're a single mom and your sister is helping you with
> your kids.' And I'm like, {*laughing*} 'She's not my sister.' It's kind of weird.

In this example, race affected how providers read sexuality as they tried to 'fit' two women into

their understanding of family. Even though the parents themselves did not think they looked at

all alike, their race, when combined with heteronormativity, dominated how others categorized

their presumed relationship.[17] In a related example, when one bi-gender, multiracial parent and

their White, female, cisgender partner met with a White principal, race so dominated the

interaction the parent could not know exactly how the parent's gender, sexuality, and family

structure were interpreted.

> Parent: We introduced ourselves as [my child's] parents, but I was carrying the baby at
> the time. There were moments in that meeting where I felt, personally, 'Does this guy
> think I'm just the nanny?' I'm not really sure. Do you know what I mean? Because he
> didn't speak to me. He just spoke to [my partner].
> M: That's sort of telling, yeah.
> Parent: So I would say that race played a factor in that, right? So this idea that, you
> know, he speaks to the White person in the room. And so, you know, it wasn't, and at
> some point I speak up anyways. So I spoke up, and like I said, I didn't speak up until the
> end because he was having this conversation with [my partner]. So I just stood around
> with the baby going, 'Well, [my partner] is answering all the questions, so should I say
> anything?" You know?

Regardless of how, exactly, the principal interpreted the relationships and identities of the

people in front of him, there was a substantial impact: this parent was excluded from the

conversation and consequently unable to voice an opinion and be heard. Such examples show

that the intersection of race, gender, and sexuality, combined with a possible interpretation of

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[17] See Ahmed, 2006, p. 96 for another account of a queer girlfriend being read as a "sister" or a "husband". See also
Ahmed, 2014, on how race can operate in how relationships and identities are read as inherently questionable.

class (i.e., being seen as an employee rather than a partner) make institutional recognition, response, and fit particularly unreliable and high-stakes for non-cisgender and racialized parents.

Throughout the interviews a number of parents described the presence of openly LGBTQ-identified service providers as helpful since they believed that the LGBTQ providers' presence meant that the organization was more likely to recognize their family and respect all of its members. For example, one parent described a lesbian principal "taking [my child] under her wing" thus preventing the bullying toward the child that ensued once that principal left. Parents generally described a sense of relief when they encountered openly LGBTQ providers who would be able to work with their children, although the presence of one LGBTQ employee did not always guarantee that an entire institution would be LGBTQ-positive. For example, one parent talked about knowing that one teacher at her child's school was LGBTQ, but finding the principal to be homophobic and misogynist:

> [The principal] didn't smile. He was harsh in the way that he spoke to me. He asked me a number of questions about math. 'Do you understand this?' And he presented me with a math problem, in terms of the new curriculum. And I was totally lost... I may have a master's degree, but I failed grade 9 math. And I was so intimidated but I wanted [my child] to go there because beyond him it was a good place. …So we did not hit it off because he felt my antagonism back. 'You're giving me a hard time because I asked for there to be curriculum that was inclusive of lesbian and gay issues and families. Oh, and you think that it's really great that you've hired a lesbian, but is she out? No, she's not out in the program.' And she wasn't.

The parent did not have another appropriate school placement for her child and so she had to negotiate this hostile relationship throughout the remainder of her child's education.

Even within private systems, some parents described doing considerable work to avoid encounters in which their families would not be well-received. For example, one parent described having found that many of the speech and language therapists in their area were strongly religious in anti-LGBTQ ways. This parent then found a well-connected speech and

language therapy instructor who was willing to screen a list of possible providers. The parent described how her concern necessitated a thorough pre-screening:

> Because… my ex, is the person who took [my child] to most of her therapy appointments, especially speech therapy appointments, [my ex] presents as a very masculine, butch lesbian and would often encounter homophobia of all different sorts just instantly. Because it was gender phobia, not just homophobia. I was like, I need a speech therapist who is not only very skilled with [my child], but comfortable with [my child's] family... And [the instructor] said okay. Give me your list of names and I'll give you a yes or a no. {*laugh*}

This approach resulted in finding an excellent provider for the child, although ultimately the family was unable to retain this practitioner's service because their new respite provider could not transport the child to their appointments. This situation illustrates how a parent could engage in a considerable amount of work to find an LGBTQ-affirming practitioner who would not discriminate based on family structure or gender presentation, but other systemic arrangements might still curtail their options.

Religiously affiliated services concerned some other LGBTQ parents, and they also talked about having limited options. For example, one parent described how her adult child ultimately found supportive housing – an extremely challenging service to secure – through a Baptist (Christian) organization that received public funding:

> So, [the organization's] thing is that …they're getting a whole lot of money from CommSoc [the Ministry of Community and Social Services] now... At the interview I said, while we were at the table, I'm a lesbian, and I think that it's important that you know that. And they said, "Not a problem. If she wants to go out with girls we would support that completely." And I said, "No, *I'm* the lesbian. [My daughter] identifies as heterosexual. We do not *make* lesbians. My parents were straight, hey!" So, there are certainly quite a few myths that they believe in and they… would not hire an out lesbian or gay person. It's in their mandate or their by-laws. But they will accept children of any affiliation and also parents who are lesbian or gay.

As in this example, many parents said they were making the best they could out of potentially difficult situations because they wanted to find the best situation available for their child.

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The scarcity of resources meant that parents found it difficult or impossible to walk away from organizations that were hostile to them and their families. There were few other options. For example, one parent described both homophobia and misogyny as so prevalent two decades ago that it was unavoidable. Another parent talked about having struggled to find respite services that would cover her after-school childcare needs. When she wanted to list "must be okay with same-sex families" on the job description, the supervisor of the respite organization refused:

> He actually said, "We're here for the child. Not for your personal wishes." And [at] the words "personal wishes" I was like, what part of having a worker who is comfortable with our family is part of my "personal wishes"? I just wanted to kill, but I just realized. In fact, I would have totally disengaged from the service but they're the only game in town. I have no choice but to accept their blatant homophobia because I need their services.

There are often very limited options to appeal anti-LGBTQ decisions, especially when there are few organizations that offer a particular service.

In another example of "blatant homophobia", one father applied to adopt a second child through the public agency where he had adopted his first. When this application did not generate a response in the usual time-frame he finally spoke with someone who made an unfounded accusation based on nothing but the father's gay identity:

> Parent: Part of the thing that I left out about the [child welfare agency], why I really don't like them, is that they got anonymous call after [my child] and I became a family about a gay man who had adopted a child and "How could they have allowed that to happen?" And that the man was inappropriate with the child… And I was like… "What made you link that call to me?" "Oh well we don't know if it was you." "Okay, well then, investigate it." "Oh we can't investigate it, it was anonymous." Then why are you bringing it up, right?
>
> M: So they called you?
>
> Parent: {*loud, angry voice*} No, they didn't! They had gotten it in December, and when I went and said I want to know why I'm being treated the way I am, and that was like April, this is what they brought up. And it was like, "Well, when were you going to tell me this?"

Such allegations build upon long-standing assumptions that gay men, in particular, are sexually predatory and unsafe around children (Kinsman, 1987; Kinsman & Gibson, 2014). The agency knew they could not link this parent to the anonymous call and yet said they had held back his second adoption application as a result, a decision he had no means of appealing.

Most parents I spoke with had less clear-cut examples of how their LGBTQ identity had influenced their interactions with services and providers. Parents described a persistent awareness that heteronormative or homophobic beliefs might come up at any time. For example, one parent said,

> In every interaction through the hospital system, and the other supports that we've had, I'm very conscious that we're a gay family. Like I'm conscious that I'm almost a little sensitive to you know, like when people are really, don't even bat an eye and are really positive, and will refer to his other dad, I'm pleasantly surprised, happy about that.

This parent's experience suggests that, for some LGBTQ parents, the everyday work of navigating systems and parenting is influenced by a watchful awareness of the heteronormative environment. Indeed, an interracial gay couple talked about a recent encounter where a hospital doctor assumed the White father was their child's family doctor. Most parents had similar examples of having to correct -- or deciding not to correct – providers' false assumptions about their family make-up. Other parents also acknowledged that their "difference" from expected parents or families was a common theme in their experiences, even if they did not encounter explicit homophobia or overtly-expressed assumptions. Parents acknowledged that, even if they did not always know about it or agree with it, others may be viewing them primarily in terms of their sexual or gender identities. For example, one mother said,

> Like when we go into the meetings, I don't think of us as like a lesbian couple at the meeting. I think of us as a family at the meeting. They might see us as, like, "Oh this is the lesbian couple that raises a lot of noise." Right? But… so what? I just think of us as a family advocating for our child.

As this parent explained, LGBTQ parents may need to be aware that systems and individuals may see them through a lens of "difference", and proceed as if they "fit" nevertheless.

Parents talked about the question of "fit" as affecting many different families that do not conform to dominant understandings of what family means, including but not limited to LGBTQ families. For example, one participant who was also a special needs service provider explained that providers look at familial "difference" -- including separated or single parents, immigrant families, grandparent-led families, any family without a father, as well as LGBTQ parents -- as a way to account for children's disability or "behaviours". She advocated for a larger questioning of how systems and providers "fit" people into dominant notions of family:

> Sometimes I think how the professional interacts with the parent or guardian or whatever often stems from that assumption of that family make-up… I find that judgment there a lot. "You should look like *this*, and then when you don't, it's different, and that could account for some of the behaviours we are seeing in your kid. Because you don't have *that*." I mean, what is *that*? Like where did that come from? And why is *that* any better than anything else? I don't know, I see that a lot. They try to take whatever you have, and fit it into *that*.

> Not necessarily… to deal with my [child] and [their] diagnosis, but we've had in the professional realm. "Oh, you're the mom and you're the dad." Even though we're two women. They need to fit you into that. But, "No." But they have that need to, your family has to fit somehow into that picture. I don't know. I've had that experience with professionals where we've all been together and they really try and like fit you in.

This parent went on to talk about the ways that people have assumed she is "the mom" because she is the biological parent. Heteronormative, cultural, and gendered notions of how parenting occurs thus shape parents' interactions with service providers, and can add to the work parents feel they must do in order to get providers to recognize and respond to their family.

The fathers in the study identified times that they often did not fit institutional and social expectations because they were men doing work that was often done primarily by women. For example, two fathers described not fitting in because they were men caring for a child.

> Parent 1: I mean, 9 times out of 10, you're the only dad if you're at a generic, parent-child thing, parent-child drop-in.

Parent 2: It's usually moms or nannies.

P1: It's usually moms, or nannies. And you just have to, I didn't actually connect so much with other parents in the centres. I did somewhat, but it was hard.

P2: Like at the early years drop-ins.

P1: At the [provincially-run, public] Early Years Centres. I didn't quite connect with the other parents there.

They found that this experience of not fitting in or "connecting" with other parents also continued within special needs services. For example, the online parent support and information group associated with their main service provider was called "Mothers of [the treatment location]". For gay fathers, this moniker was a constant reminder that parenting and systemwork were considered female tasks, and that families that did not include a mother were not even considered. Another gay, adoptive father talked about how, while there was a "mother" in his child's life, as the birth parent she did not play the role other people would expect. For example, border guards sometimes asked if he had permission from "the mother" to travel with his child. He said he addressed the possibility of this question by having all his paperwork at the ready and disclosing both his adoptive status and his child's developmental disability diagnosis before guards started questioning the child on the mother's whereabouts. This preparation for how the family may be interpreted and regulated thus formed an additional layer of work, and shaped his decisions around disclosure (see Chapter 5 for more on border crossings).

Simultaneously, common social expectations that children "without a father" will have more life struggles also influenced some families. While parents who were read as "mothers" did not report as strong a sense that they did not fit on the basis of gender in settings where few fathers were physically present, there was nevertheless the possibility that providers and others would interpret their children's needs through the pathologized social category of "fatherless children". When combined with views that disability or gender-nonconforming behavior in a

child were a 'problem', the absence of a father could be blamed for the child's 'difference'. For example, on bi-gender parent recounted that their child's daycare provider -- who read this parent as a woman -- believed that the child behaved the way that he does because he doesn't have a "father":

> So [the caregiver's] assumption is, you are a woman, and your other parent is another woman, and your kid, basically he can't cope with change and he can't, you know, he cries when he's sad, right. That's because you guys, you guys are raising him, right? If he had a Dad, your kid would be more out there. He'd know how to ride a tricycle. My kid doesn't know how to ride a tricycle. I couldn't give a shit! I don't care. Who cares? For all I care, he can never learn how to ride a tricycle. What does that have to do with him as a human being?

In this example, the intersection of familial differences -- in sexuality/gender in the parent and disability in the child -- were seen by the caregiver as equally troubling and causally related.

The legal options available to parents have also been shaped by the priority given to fathers' involvement, particularly when the fathers are heterosexual and the mothers are not. LGBTQ parents' options were particularly restricted in the recent past. One participant had divorced her children's father – a doctor with considerable financial and legal resources – in the 1980s. She recounted that the legal environment of the time was particularly slanted against both lesbian parents and mothers more generally.

> [My ex] threatened me that he would fight me for the children. And with the OMA [Ontario Medical Association] behind him and their legal supports, he could, you know, take me to the cleaners, financially and emotionally and it would just be a horrible situation for the children. So I agreed to shared parenting. And at the time there was a part of me that thought it was the best option too. Because the children, because the research that I had read at that point… was that it was important for the kids to know both parents. And at that point, "both parents" were male and female. Not two women.

In such an environment, this mother agreed to joint custody which continued until their children were teenagers and the father hit their disabled child hard enough to cause injury. The mother described receiving advice from a lawyer at the time of the separation that, as a lesbian, she might lose all custody and possibly even have to pay her ex-husband alimony even though he

made a lot more money than she did. Other mothers who had separated from male partners more recently also described court involvement as highly unpleasant, but they did not recount the same level of fear that their LGBTQ identity would be used against them. The legal vulnerability of LGBTQ parents, particularly when they are non-biological parents or their ex-partners are heterosexual, continues to be a common community concern, and was noted by several key informants who work with LGBTQ parents. Participants who had separated or divorced expressed an eagerness to avoid court involvement if at all possible.

Almost all parents talked about the need for service providers and systems to re-examine institutional documents, since texts such as intake forms routinely showcased heteronormative and cisnormative institutional beliefs. One parent pointed out the gendered and cisnormative expectations that permeate systems' interactions with parents.

> So, so with the, this is the [School District] Developmental History form. So when you go to enroll your kid, they ask you to fill in all this stuff about who you are. And, I mean, I struggled with this form because on it, it has 'mother' and 'father'. And I'm thinking, we know your school has queer parents. Why haven't you changed this form? Like it's about time you changed the form! So I struggled mostly with how to talk about myself as a parent, and wondered, why can't it just be 'parent'? Why can't I just be a parent, why do I have to identify as mother or father? Like, I'm his other *parent*.

While all LGBTQ parents may encounter forms that do not reflect their families and their identities, the frequency with which parents of children with 'special needs' fill out forms makes the cumulative impact of this hetero- and cis-normativity more constant and profound.

> I fill out intake forms of all different sorts all the time. For *all* different sorts of things. From camp, to community recreation programs, to school stuff, to medical stuff, to whatever. And some of the forms are really great that say Parent and Parent and then you can leave a blank if you want. But how often does it also say Mother and Father? I always cross out Father and, you know, remake forms so that forms are okay.

Many parents expressed that service providers need to scrutinize their forms and change the ways that they reinforce heteronormativity and cisnormativity. Parents usually described correcting assumptions and 'remaking forms' as need be, but emphasized that the need to do

so highlighted dominant assumptions that they and their families did not fit with what other people and institutions believe 'family' to mean.

Parents also talked about having to monitor their appearance in interactions with special needs service providers in response to dominant beliefs about LGBTQ people. As in the statement from one parent that she and her partner may be seen as "the lesbian couple who raises a lot of noise", another parent explains that the demanding or "angry lesbian" stereotype influences how she behaves with professionals.

> I think some of the harder parts about [working with providers] is there's stereotypes around you know, angry lesbians. And I am definitely a person who can go right to that edge with a service provider if we need to for some reason. And I found that, um, that's frustrating for me to sometimes feel that I have to be a little extra nice or a little extra accommodating. {*fake voice*} "Oh, that's okay that you refer to my husband." {*normal voice*} or whatever. And have to turn it around again and not harbour any kind of resentment for some stupid thing that they just said.

Some parents talked about trying to use their LGBTQ status and its recognition as "different" from expected families – even exotic or "cool" -- to gain leverage in accessing services for their kids. Jan and Annette talked about being as the "pet lesbians" for their local school.

> Jan: And you know I think, Simon is liked at the school, well-liked, and it has to do with maybe because they like us. Who knows, right?
>
> Annette: Yeah, if anything I'd say we're like the, you know, little pet lesbians. …Which is great. Fine. They like us.
>
> Margaret: Say more about what you mean
>
> J & A together: The pet lesbians?
>
> M: Either of you can comment on this.
>
> A: I don't know, it's sort of like the lesbian chic phenomenon. We up the cool factor for them, I don't know, people like to…
>
> J: Maybe they don't know how to treat us or something.
>
> A: Or they just like to be known for being, you know

J: Positive

A: Positive and supportive. You know. Whatever.

J: Right.

A: I mean, I think we're very likeable anyhow.

As Annette and Jan explained what being "pet lesbians" might mean, they linked it to school staff "not knowing" how to respond to their family while trying to position themselves and their institution as being "positive" towards family diversity. For the parents themselves, they were willing to go along with being viewed through a "lesbian chic" lens if it got more for their son. However they did not identify with or endorse this reading of their lives, as shown through Annette's "Whatever" and the sarcasm of "pet lesbians". Other parents I spoke with talked about promoting services or participating in LGBTQ workshops or conferences for different agencies, in part to retain an institutional connection in case they needed extra leverage in their search for services:

> But also, and this could be where the gay part comes in to our advantage, because, we're so out there, we're like poster people for them… And we're just such… a huge success story for them. Even though the story is still being written in my opinion… it would look bad for them I think if they just cut us loose.

By trading on notions of gay respectability and promoting agency profiles, certain LGBTQ parents are able to gain additional influence as they navigate systems (Duggan, 2003; Ward, 2008).

Notions of expected or "normal" parents and "normal" children played out beyond the strictly institutional settings of special needs services. LGBTQ parents talked about feeling that their families did not easily "fit" across other settings for parents and children, or within larger families, cultures, and communities. As in the parent's account of the home childcare provider seeing a child's behavior as caused by the absence of a recognized "father", a number of parents

talked about how their own families of origin had often tried to link their children's

developmental "difference" to the ways in which they had become parents. Two families

reported that extended family members had asked if a child conceived through donor

insemination had acquired an autism spectrum diagnosis because of the donor. These parents

reported that they had refused this connection of their child's "difference" with something

outside of the known family, and had instead pointed to other people in their biological families

with similar traits or diagnoses (even if in one case the parents also suspected that the donor may

have autistic traits). One of these parents summarized: "Fits in perfectly fine with our family."

Some parents questioned whether they really fit with other parents, even including

parents in LGBTQ communities. One parent described feeling judged both by other LGBTQ

parents and by their family of origin due to the child-led approach they had to parenting.

This approach often meant they did not attend a lot of loud, crowded community events or

when they did that they kept their child on their lap for a lot of the time; this parent reported

that other people often suggested they should "push" their child to do things more

independently. The same parent also described the ways that their parenting did not "fit"

with their immigrant and racialized cultural norms as seen in their family of origin. They

highlighted that "not fitting" with gender training and parenting approaches that predominate

in their Caribbean culture actually felt like reclaiming the parenting approaches that had

been indigenous to that community and were damaged through colonization. Thus using

parenting approaches and beliefs that "don't fit" could be a site of conscious resistance to

oppressive structures and histories for some parents.

The parents that I interviewed had different levels of involvement with LGBTQ

communities. While some reported extensive social and political involvement with LGBTQ

communities and organizations, others explicitly questioned whether they would belong in

LGBTQ environments. For example, Aurora and Samantha returned to the theme of "we don't fit in" when discussing LGBTQ organizations and community:

> Samantha: But again, we go back to, we don't fit. And it's funny because somebody had, I had been recently talking about it, and they were like, '[LGBTQ organization] has a group for adoptive parents.' And I was like, 'We're too straight for that.' {*laughing*} We were laughing and I was like, 'We are the straightest gay people we know', like…
>
> Aurora: We have a minivan! ...
>
> S: We have a minivan, and, like, we live in the boonies. We are fully straight. We don't go out.
>
> A: My brother's fiancée said that when … we bought our house. 'Man, your sister is more straight than I am! She's married, has the kid, has a minivan, a home now.'
>
> S: And we haven't been to [gay-identified neighbourhood] like …I don't think I've ever been. {*laughs*} And we haven't been, like, that's not our scene…
>
> A: Like we don't do -- like we don't fit in.

In this excerpt, Aurora and Samantha highlighted certain attributes as "straight" even while they described themselves as fully "out" as lesbians. These attributes -- including where they lived and what they owned as well as having "a kid" – show that "straight" continues to summarize a certain normative or even aspirational lifestyle. This exchange also demonstrates the continuing tension between "parent" and "queer" in many people's identities, and could prevent parents such as these from exploring LGBTQ-specific services, even as they also express that services geared toward heteronormative families are inappropriate for them.

The search for community and belonging was affected by a range of interpersonal factors. Parents whose children behaved in ways that others found annoying or disruptive reported that they were feeling increasingly isolated, even among friends, and family members. Several parents also described feeling that there was a "competition" among parents of children with disabilities so that it was difficult for parents of children with

different diagnoses and abilities to empathize with and support each other. Several parents also talked about carefully deciding whether or not to disclose their child's disability to other parents and family members, often for fear that their child would be excluded or stigmatized if this were disclosed. Of course, some disabilities were more or less possible to hide from others, just as the LGBTQ identity of some parents was more or less possible to hide. The options available to each family were thus also different.

Finally, there were situations in which the parent's sexuality, the child's behavior, and other people's notions of "fit" combined in ways that were impossible to disentangle. For example, one parent talked about how her daughter does not wear dresses because she is uncomfortable with the feeling of tights and she would show her underwear to others if she wears a skirt or dress with no tights underneath. As a result, her parents decided to keep her in pants. In addition, this child finds it very uncomfortable to have her hair brushed, so her parents have cut her hair short. Because her daughter has short hair and does not wear dresses, extended family members have asked the parents, "How come she never wears any pretty dresses? How come [she] always looks like a little lesbian?" This example shows how loaded parenting decisions can become in a context of heternormativity, gender binarism, and ableism. Here we see a potent combination of gendered expectations that girls should wear certain clothes and that parents should enforce gendered dress; concerns about the consequences that girls, and perhaps particularly disabled girls, might face from showing their undergarments (including possible safety ramifications); and dominant beliefs that LGBTQ parents will impose gender and sexual "queerness" on their children -- and that this queerness would be a bad thing. Such examples show the intersectional complexity that LGBTQ parents of children with disabilities navigate in everyday interactions.

‘Outside the mainstream’: Alternatives to Fit

The parents that I interviewed expressed a range of concerns about notions of fit or belonging within existing systems and categories. Rather than primarily or exclusively expressing a concern that they were being excluded within dominant institutions and discourses, participants also questioned the value of fitting in. While they certainly objected to the marginalization of their families within service systems, most also expressed a larger critique of the values and practices of these systems. In other words, "not fitting in" – whether with institutional categories or other parents – had its own value in many parents' estimation. This value often linked to their politics around LGBTQ communities and disability.

For example, one parent recounted the importance of not trying to "blend in" as coming from her politicized notion of disability and her history of activist work within feminist, anti-poverty, and queer organizations:

> Many years ago I did some work with a group called the [disabled women's group] that was very active, very strong, and very involved in women's service coordination. And I really learned from a woman who is now deceased who was the chair of that, who was really clear and open about her advocacy needs, and about thinking systemically. And at the time she smacked me upside the head a few times metaphorically, and I learned a lot, learned a lot from this.

> And then as I became [my child's] mom I realized that we have the same ability to be able to be open and clear and proud about all of our advocacy needs. And there's nothing we need to hide about [my child] needing special services or accommodations or things like that. And that actually it's not to our benefit to even think that we're going to blend in or something like that, into the woodwork. Because we just *don't*.

In this parent's explanation, her insistence that both she and her daughter ("we") don't "blend in" was simultaneously activist and pragmatic. In the phrase "our advocacy needs", this parent positioned herself alongside her daughter and simultaneously asserted that both of them have needs. This stance differs substantially from dominant notions of "advocacy" as a role left entirely to the parent (see Chapter 3). Further, she explicitly connected the ways that their family did not "blend in" due to queerness to the ways that they did not "blend in" due to disability.

This critique of what constitutes "normal" also extended to the same parent's discussion of professionals asking about what "gender role models" her child has (see Hicks, 2008a).

> But I find that that sometimes it also… there's a little bit of added pressure that I think almost all queer parents have that 'I want to make sure that I'm providing healthy gender expression, in the broad sense.' You know, and that sort of thing. And that can be hard. I've also been asked by service providers who [my child's] positive male role models are and things like that. And I'm like, 'Do the transgender ones count in this conversation?' Is what I want to ask {*laughs*}… Because if you really want to have a meaningful conversation about gender, let's have it. But I realize, no, they're just wanting to tick boxes and write stuff down.

Her systemic analysis allows the parent to understand and give the answers that professionals require her to give for certain questions (in order to satisfy textual requirements of "ticking boxes"), while she also retains her own disagreement with these questions and the assumptions they contain.

Other parents also described their LGBTQ experience and politics as part of a larger societal critique that influenced how they also understood disability. For example, one parent directly connected their own struggles with school as a gender-nonconforming person with the struggle to find resources for their child:

> I mean, my experience in school wasn't a cakewalk. I didn't have a disability. I just was gender non-conforming. You know? So, my risk of suicide as a young person came from just not being accepted for who I was, right? So I can see that for my kid, or any other kid, who looks or acts differently from what's considered to be the norm, or normal, or what we teach – because really, it's what our, the majority of our world teaches other people to recognize as what's normal and valued and valuable.

For this parent, living as an LGBTQ person influenced how they viewed systemic discrimination, violence, and limited notions of the "normal"; they saw this worldview as central to their understanding of disability and the violence of ableism (Goodley & Runswick-Cole, 2011). Similarly, another parent connected her knowledge of being seen as 'different' with her understanding of her child's experiences in the world.

> I think that I know, both as a queer person and also my, my gender identity. I identify as a woman but I present myself in a very boyish way. So … I've always found that I stood

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out. .... So I have lived experience of being different and, and not always fitting in. And people looking at me funny… And oftentimes people find, I don't always fit neatly into the boxes for folks… So [my child's] experience of when he talks and he sounds a little funny, or when he behaves a little different… I empathize, because I have that experience as well, and that's very much related to my queerness. I think that that helps me, with empathy with [my son]. With being different.

Another parent, who was largely not "out", also talked about how her experiences of being LGBTQ contributed to her creation of her family's values:

[My identity] affects I guess my choice in partner. And then that affects the values that we have in the home. That we're on the same page with acceptance of difference. And that's actually been really important in terms of [one child's] differences and difficulties at times, and [the other child's] differences. Being very -- it's not, it's not a bad thing to be different. It's just different.

Even though this parent was not out to her children about her sexuality, she felt her sexuality influenced what she taught them, including what she and her partner taught them around disability.

The connections between parental identity and child identity were complex. For example, one parent described differences between the children of LGBTQ parents and children of non-LGBTQ parents as positive traits:

Well, I don't know, I just think that, in general, LGBT children are much more open-minded. You know. They're not {*long pause*} they don't feel as much that they have to conform to what it means to be, you know, male or female or that there's much more kind of openness to them. In general, about the world. So I think that, I've instilled that in [my child].

Another parent also connected his experiences of challenging institutional oppression as a gay man to his understanding of his adopted, disabled child's experience, and linked both to his willingness to challenge systems. When I asked if he thought his parenting and systemwork for his child was affected by his gay identity he replied strongly in the affirmative.

Yeah, yeah. I think it totally does. That you don't take, you don't take no for an answer. But not with a, sort of a -- this sounds judgmental -- not with a chip on your shoulder? If somebody says something can't be done or, you know, where there's right or wrong or yes or no, can't be done, always turn it into **how**. We didn't choose to be gay. My child

didn't choose to be adopted or [with a particular diagnosis]. Those just are the cards that you were dealt and you play them the way you need to.

Another parent described how her queer identity made her see different options with regard to accommodation or intervention than her heterosexual, cisgender, male ex-partner did. For example, she wanted to continue to develop her child's ability to communicate in American sign language – a more accessible mode of communication for her child – while also continuing the child's work in speech therapy. This mother said she was the primary signer and her ex viewed the use of sign language as "a fringe element to line up with my other fringe elements". She explained this as an ideological as well as an experiential difference:

It feels… it's sort of like, it's like because I have an experience of being outside of mainstream, I'm more comfortable with it… I'm more comfortable with looking for things that might fit with [my child] well, and yet be outside of typical, outside of mainstreaming. And [my child's] dad is not as comfortable with that. I think because as a straight white male…everything fits… like mainstream works for him very well. And so I'm starting to see a clash of ideologies, and that definitely it extends to [our child's] care.

This parent viewed her experiences as already being "outside the mainstream" as an opportunity to think of resources and approaches that "the mainstream" might not even consider.

Several parents explicitly linked their politicized understanding of "difference" through their LGBTQ and activist experiences to their work within special needs service systems. For example, Lisa explained how she has acquired useful analytical and strategic tools from past activism that contribute to her capacity to work on her child's behalf:

I came out in a very political way. I mean, I was very young, but you know, with a really strong sense of advocacy and activism. …I certainly have moments where I'm like, what? I thought I would be at every protest until I was in my eighties! {*gently laughing*} And I certainly am not. But I use all those advocacy skills and activism, on behalf of [my child].

Other LGBTQ parents who had 'come out' in this political way and been active in protest movements highlighted the importance of this perspective and skill set in reflecting on information and options that professionals and others offered.

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When I asked parents about whether and how their LGBTQ identity had influenced their experiences parenting and advocating for their children around disability, several parents responded that their LGBTQ identity influenced how they divided systemwork responsibilities with their co-parents (also see Chapter 3). For example, after initially questioning how their identities as LGBTQ might influence their parenting, Samantha and Aurora responded that the primary way their experience was different from heterosexual parents was that they were "two moms".

> S: Two maternal sides. I can see it [being different from heterosexual parents]. We're both very maternal. And so as opposed to having… Okay, so I was married, before, to a man. And I think of what that relationship would have been like with Natalie, sometimes. It would have been *me* doing the work.
> A: Yeah.
> S: As the mom. But here we're two moms
> A: We both do the work
> S: So we fight to do the work. *{laugh}*

These parents went on to reflect on the gendered division of parenting labour they had heard "straight women" complain about, particularly notions such as fathers "babysitting" their own children. Similarly, another couple pointed out how they engaged in systemwork and parenting "together", in contrast to most (presumably heterosexual) families where they saw "just the mom" doing this work:

> Parent 1: I would think that, um. Our response is more inclusive? Like together. Like, [my partner] and I are really together, with [our child]… we're trying to be on the same page as far as disability is concerned. And we're really together about this. And that's what I've noticed in comparison with other families with disabilities. Often you see just the one person.
>
> Parent 2: Yeah, when we're at the [disability organization], one parent would go to those workshops.
>
> P1: One parent. Even the [school disability] meeting we went to, the woman who was coming after us, it was just the mom.
>
> P2: Just the mom, yeah.

This involvement of both co-parents at meetings was endorsed by most participants in non-

heterosexual/non-cisgender relationships. While some of these parents reported less equal

divisions of labour, the parents who were co-parenting with a same-gender and/or LGBTQ co-

parent talked about exchanging roles between co-parents and consciously deciding who would

do the systemwork and everyday parenting responsibilities. Several parents in current or former

LGBTQ relationships reported that both co-parents had taken parental leave or reduced their

paid work responsibilities as a part of parenting.[18]

      Such arrangements stood in contrast with the parents I spoke with who were or had been

in relationships with heterosexual men, where the mothers I spoke with took primary

responsibility for all systemwork responsibilities.[19] For example, Sarah wondered about why she

had taken on most of the systemwork even once her male partner agreed it was necessary to

engage with special needs services.

> I think it's a personality thing between us and possibly a gender thing. Where I really
> saw it as my responsibility, as part of being a good mom, to get [my child] services. So,
> and because I was doing all that, [my partner] wasn't as concerned. He didn't have to step
> up to the plate with it. Yeah. Yeah, after we got married and after we had kids, our roles
> changed in ways that I wouldn't have imagined. But again, he's, he's pretty good. [My
> partner's] pretty good about seeing where I lose time and where he tries to give me time.

In Sarah's explanation she connected the responsibility for navigating systems with other

gendered parental responsibilities within heterosexual relationships that fall more heavily on

mothers.

      The historical context could also influence who was most visible and active in

systemwork. When I asked one parent who attended meetings, such as with teachers and

principals, in the 1980s and 1990s, she reported that she had always gone alone.

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[18] For more on parenting labour and roles among LGBTQ families, see Bennett, 2003; Bos, van Balen & van den Boom, 2004, 2007; Brown & Perlesz, 2007; Chan, Brooks, Raboy & Patterson, 1998; Ciano-Boyce & & Shelley-Sireci, 2002; Dozier, 2014; Gartrell, Rodas, Deck, Payser, & Banks, 2006; Goldberg, Downing & Sauck, 2008; Gibson, 2014g; Gurr, 2014; Hequembourg, 2007; Hicks, 2008a; Khanlou et al., 2014. For more on gendered labour and parents of children with disabilities, see Douglas, 2013; Gibson, 2012b; Home, 2004, 2008; Levine, 2008; Lewis, Kagan, & Heaton, 2000; Traustadottir, 1991.

[19] None of the male or bi-gender participants had been in heterosexual/ "non-queer" parenting arrangements.

[My female partner] was fabulous, but we had agreed that I would be the primary mover because I was the bio mom. And, it worked. I mean sure, it would have been great [to have her there], but it wouldn't have been realistic.

Even though this parent and her partner were "out" at a time when few LGBTQ parents were, given the extensive and virulent hostility toward LGBTQ families, it may not have been "realistic" to insist on having two parents at meetings, and might have caused more problems for the family.

Throughout the interviews, LGBTQ parents gave a wide range of responses to the question of whether and how their LGBTQ identities influenced their parenting beliefs, practices, and systemwork. In these discussions, parents described their everyday strategies and struggles to move beyond the restrictive notion of "fit" they found within systems and dominant community cultures, while simultaneously making systems and professionals see their families as enough of a "fit" with institutional categories that they could get the resources that their child needed. As discussed in the next chapter, this tension between using and questioning institutional categories often occurred through in the production, activation, and critique of texts.

Chapter 5

'This is real now because it's a piece of paper': Encountering Texts

Before each interview I asked participants to bring in a document that had been significant in their interactions with service providers (see Chapter 2). We discussed the types of documents that could be brought during the screening phone calls or emails and participants proposed at least one option in the screening exchange; they sometimes checked back with me over email in the time before the interview to be sure that their choice of document would work. All participants brought in these documents as requested, and in some cases they brought more than one option from which they selected during the interview itself.

The definition of a "document" varied widely. One couple showed me a binder full of papers. Another parent showed me an online pamphlet they often printed off for providers, but referred to on their laptop for the interview itself. Most parents brought in pieces of paper from one to ten pages long. In one case, a participant offered me a copy of the selected document, which they had written themselves, but usually I did not see the selected document directly. The text was, instead, a focus of discussion. In this discussion, we talked about how the document had been produced and for what reasons, who had created it, what the text had led to (or what they hoped or feared it would lead to), and how they felt about it. I was therefore not positioning the text itself as a focus of analysis, but instead investigating the ways in which this document operated in the parent's experiences. In other words, I was exploring how the parent and others (as reported by the parent) had "activated" the text (McCoy, 1995; Smith, 2006).

My approach to texts is rooted in institutional ethnography and the idea of "textually-mediated relations", based on the work of Dorothy Smith (1990, 1999, 2005, 2006). This analysis also sees texts as a central part of the way that disability is constructed and socially administered, based on the work of Tanya Titchkosky (2007). I draw upon disability studies,

institutional ethnography, and ample feminist scholarship in the recognition that the domain of "taken-for-granted" texts and bureaucratic processes regulate the ways that ideological groupings and social relationships are made manifest in everyday life.

However, in using the words of participants, rather than the documents themselves, as my interpretive point of origin, I differ in my method from many of these other projects. I situated my understanding of the documents not in their physical presence – since I did not even examine them directly – but rather in what their presence evoked and revealed about how institutional relations and discourses operate in parents' everyday lives. This line of inquiry addresses the central research question: what role do texts play in parents' interactions and experiences with special needs service systems? The findings help to explain how these systems structure parents' everyday work through, toward, and in spite of texts, showing a complex and fragmented relationship between institutional texts and parents' own narratives of their production and import.

This strategy is distinctive from IE methods in which the text itself is a primary document of analysis, since it extends the notion of "text-work sequences" to consider how people's everyday actualities continue to respond to and re-frame the texts that have been institutionally produced.[20] While I had initially considered asking for copies of the participants' documents as a part of the primary data for the study, the questions that I was asking did not ultimately require this strategy. Instead, since I was investigating how parents continued to work with and respond to the documents that they had selected, participants' accounts about the documents they selected (and about systemic documentation more generally) was far more helpful than any possible re-reading of the documents themselves that I might come up with.

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[20] See, for example, D. Smith's diagram of the relationship between "lived actuality" and "the factual account" of the text and its subsequent interpretation (1990, 72). My own approach to texts in this study extends beyond what is represented in this diagram and instead considers "lived actuality" in ongoing relation with (and possible critique and re-interpretation of) "the factual account".

The documents discussed varied across the parent interviews. Figure 3 summarizes the texts selected. One participant brought in two texts for comparison, thus over the twelve parent interviews, thirteen texts were chosen. Of course, other texts were also discussed throughout the interviews, and some of these supplementary texts are also considered in this chapter.

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Texts Selected by Parent Participants

2 adoption certificates

6 assessments by professionals: 1 by a speech and language pathologist, 3 by psychologists (one privately hired, one accessed through a public school, one accessed through a public child development clinic), 1 by a multidisciplinary team, 1 by a developmental pediatrician

1 letter written by a doctor (at a neurodevelopment clinic) addressed to a school

1 information sheet written by the parent to all professionals working with their child

1 information booklet about a diagnosis written by a Canadian research group

1 information binder with child's treatment plan/ records, including inserts of daily medication and treatment

1 school form on the student's developmental history

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Figure 3. Texts selected by parent participants.

In this chapter I consider what texts convey about the way special needs service systems operate from the standpoint of LGBTQ parents. First I consider the "gap" parents described between texts such as policies or advertised services or even recommendations of professional documents such as assessments, and parents' narrated experiences of what their families had been offered or received. This overall difference between "on paper" and "in real life" led to the method and analysis selected in this chapter. Further, this disjuncture[21] between what is claimed in and through institutional documents (such as policies or promotional brochures and

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[21] See Smith (2005) and Campbell and Gregor (2008) on disjunctures as an ethnographic starting point in institutional ethnography. See also Chapter 1.

assessments) and what parents describe as happening in the allocation of "real life" resources

indicates that this slippage may be more than haphazard and accidental. As I consider the

parents' thoughts, feelings, and stories about the texts, I look more deeply at these "particular"

responses and "personal" experiences. These experiences include parents' accounts of the work

surrounding the texts (such as what parents did to produce them and how they have used them

since) and also parents' thoughts and feelings about the texts and their impact. These parent

accounts were usually quite complex and ambiguous and show the struggle between how

parents would like to portray and view their children and their families, and the exigencies of

institutions themselves. I also explore some of how parents indicate that texts influence their

everyday parenting experiences and what they told me that such texts "miss" regarding these

relationships.

On Paper: Parents Recount Disjunctures

> What's kind of interesting is seeing the gap between [school] board policy and school
> level behaviour. Board policy says that if there is a demonstrated need, the school board
> has a responsibility to accommodate that need. What you hear from principals when you
> say "my child has a need" is they say things like, "I know but there are funding shortages
> and are there are kids with greater needs in this school". …It seems like often there's a
> gap between what the board values are and what the pragmatic values are. And I think
> what ends up happening is there is a small percentage of parents who both know the
> board values and have the resources to advocate for their kids and [they] end up jumping
> that gap, getting their kids what the board says they deserve.

This parent eloquently described an experience noted by many parents throughout the

interviews in which parents encountered a "gap" between what policies or other agency

documents state that they offer, and what parents actually encounter when they seek services for

their children. This slippage between what is "on paper" as a policy, agency mandate, or

professional recommendation, and what actually occurs "in practice" provides the framework

for this chapter. Indeed, due to these recurring comments from parents, my research approach

shifted away from considering a supplementary textual analysis of important policies to a

focused exploration of parents' experiences alongside or even in spite of the given policies. Parents told me, again and again, that the "policies" were fine, but that how they were or were not implemented was at the crux of their struggles.

This slippage -- between what policies or brochures claim is offered and what actually happens when parents try to access the services -- creates added work and confusion for parents. Beyond the "scavenger hunt" of searching for services (see Chapter 3), parents found they also needed to know what documents to obtain, keep track of, and marshal as a part of their response to the initial and insufficient responses they received within systems. Texts led to the need to acquire (and/or learn about) other texts, in text-work-text sequences such as those described by Dorothy Smith (2005, 2006).

Obtaining texts was not in and of itself the goal for parents. Parents explained that they worked to obtain documents because the documents were necessary precursors to accessing material resources: accommodations in school settings, funding for professional services such as speech therapy, access to services such as respite programs, and even relief from social censure of the ways that their parenting or their child's behavior departed from dominant expectations. Nevertheless, while documents are almost always required to start "advocating" for resources, parents also reported that documents alone are not, in and of themselves, sufficient, but require further systemwork on the part of parents and others. For parents, the piece of paper does not just appear without parents' participation and effort. Then, even if it is the "right" paper saying the "right" things, the text alone does not automatically produce the desired result. As this chapter delineates, the work that goes into producing, storing, retrieving, and using documents as a part of interacting with special needs service systems requires considerable time, knowledge, and effort.

Further, as the participant quoted above goes on to explain, the ongoing advertisement of services "on paper" raises questions about how systems use documentation requirements to back away from an implied promise. This parent proceeded to outline how the principals' arguments function as a means to reduce costs, while allowing the system to still appear to be benevolent or even generous.

> And the reason, I think, that they don't just present the board values at the school level is it save them a pile of money when there's a whole bunch of parents who either don't have the resources or the knowledge to know that their kids deserve and the board is required to provide more. So I think, in some ways, the principal, in particular, is a bit of a gatekeeper to the resources that the [school] board likes to *say* they provide, but doesn't actually provide unless you push for them.

Here, the parent noted generalized and systemic aspects of this gap: the problem was not that an individual principal refused to provide services, but that principals were required to be "gatekeepers" as a part of their jobs. This parent and others pointed out that the assertion that "other children have greater needs" is given to many parents as a gatekeeping and cost-saving rationale for little or no service provision. Parents must then, in this participant's words, "jump the gap" – while principals and others know that only some parents can and will do so.

As discussed in chapters 3 and 4, special needs systems make particular demands on parents such that parents with more "advocacy" resources and social privileges will be more likely to secure the services their children need. The ways that texts do, and do not, operate is an integral part of how special needs resources are distributed, and how they are provided inequitably based on intersectional parental 'differences'. **In other words, text-based institutional demands entrench the importance of parental difference and make it 'matter' in terms of the material resources that children receive.**

A number of parents observed that the availability of accommodations seemed to be directly tied to how expensive the requested resources were. For example, parents recounted that they were told by school administrators that individual educational assistants were "impossible"

to obtain within public systems, again often implying a competition among youth and their relative "needs":

> So [the principal] talked about, because what we asked, we asked if [our child] would get an individual EA [educational assistant]. So he said well, no, like there's probably no way that will happen because the school board just doesn't have enough EAs to go around. And so he said the best case scenario with the [special education placement meeting] is that we might get a sort of like a one point five EA, or something like that. For not just your kid, but that EA would be sort of parceled around different classrooms at different times depending on the needs of the other youth who are, children who are there requiring support.

Since parents cannot truly assess if other children have "greater needs" across the system or in the school, or even if there are more assistants or "EAs" available in the system -- especially since assistants are usually hired on short-term contracts based on "need" and their absolute numbers fluctuate --- this is an institutional response with little possibility of contradiction. This invocation of a resource person that is not actually there (the mythical or fragmented EA) is an example of how withholding parents find these service systems to be, as both gatekeeper and service provider functions come from the same professional points of contact.

Indeed, across a number of interviews the participants and I ended up filling in gaps for each other based on knowledge that exceeded or contradicted what each of us had initially been told and the documentation that each of us had encountered. Thus while more than one parent reported that individual supports are "impossible", I sometimes shared my own knowledge that these resources had been provided in particular situations, but that they are not easily or reliably available. In an interview in which a parent was new to school board acronyms and processes, I explained my understanding of the terms and different meetings, and followed up the interview with an email directing the participant to online information that I found reliable. In another interview in which I expressed that I was unaware of a new transit pass that allowed people accompanying children with special needs to ride for free, the participant explained where and how to apply and sent me an email afterward with the associated website. A key informant gave

me additional information about tax benefits forms. Participants clearly saw me, at times, as similarly positioned within these systems, and asked about and made reference to my own experiences as an LGBTQ parent who has a child with 'special needs' (see Chapters 1 and 2). In some situations, participants expressed a need for information or services that I was unable to provide, but asked that I let them know if I learned of it in the future. As mentioned in Chapter 3, parents had reported that they are constantly looking for and filing away information about possible resources or strategies. The interview encounter was no exception.

The time and energy involved in navigating systems added to the frustration and anger parents expressed when they encountered options "on paper" that did not represent their reality. For example, one parent had obtained an autism diagnosis for her child quite early outside of the school system, and had since been involved in many contentious meetings with school administrators trying to obtain accommodations and resources for her child. This parent then came across a school board pamphlet that claimed the board's response to children was substantively different:

> I've read a pamphlet this year. It's like, 'If you've got a kid pre-k [pre-kindergarten] and they're diagnosed [with autism], well, here's all the stuff we've got for you!' …Not one of [the school staff and administrators] mentioned anything to us. Right? And then you're trying to figure out what the fuck they have. And you know what, it's not my system. It's their system….It drives me crazy… You know, 'If your kid has got autism pre-k. Well! You just give us all their stuff and we have a program for them and lahdelahdelahde, and this is what we do.' And I'm like, HUH! Really?! Because nobody told us that.

Some parents hypothesized that this slippage between what was officially and actually available was due to people within the system (such as teachers) "not knowing" what the policies or advertised resources were. The parent who saw this pamphlet about autism in schools, however, saw this lack of "awareness" among special education administrators as serving a particular systemic function, and one that was rewarded.

I totally think they count the number of [special education placement meetings] there are and how many kids get special stuff and how many don't. And it wouldn't surprise me a bit if [the school administrator] got a bonus based on [saying no].

Regardless of the intent or rationale of service providers who do not offer the services advertised, such speculations from parents point to the lack of trust they have in special needs service systems. They also indicate that these systems operate with limited transparency such that parents are called upon to postulate what goes on behind the scenes.

Parents also described instances where they knew that particular policies existed and tried to get providers to implement them in ways that would benefit their children. A parent who was also a teacher described knowing about an anti-bullying policy that applied in her child's case even as she struggled to get her child's teachers and school staff to implement it. She described the teachers urging her child to "run into the school" to escape schoolyard violence, but doing little to prevent further incidents, which continued for years. This parent eventually brought a printed copy of the bill to her meetings with her child's teachers and other school staff and attached it to her other communication with the school system:

So I went into meetings and I would bring my, bring the bill. They passed a bill [against violence in schools] around that time. Where there was a procedure, if a teacher sees that happening, and it can just be verbal harassment, they have to file a report, and then it goes, you know it goes to the school report. And the kids [who did it] could be suspended. So I would email them, and I would cut and paste Bill 157 [the Keeping Our Kids Safe at School Act], and write, you know, my child has these rights, and you're not following… the bill that you've put out.

This parent reported that there continued to be little institutional response to stop the violence against her child (see Goodley & Runswick-Cole, 2011). Ultimately, she switched her child to a different school board to escape the peer violence and inadequate institutional response. Even though the bill was clear that school staff must recognize and stop violence, her child's experience demonstrated the limits of this policy-level response.

Some systems required particular documents, such as a professional assessment, but then offered services that were standardized regardless of what the document might say. A case in point is the publically-funded speech and language therapy system. While "on paper" (in the assessment required to qualify for service) it might appear that a particular child merited a certain number or frequency of speech therapy sessions, "in reality" every child with a documented speech therapy need received the same number and frequency of speech therapy appointments. I asked one parent why they took their child to two separate speech therapists each week, one session with a private practitioner and one with a publicly-funded practitioner.

M: Was the [public speech therapy agency] not willing to do twice a week or did you not…?

Parent: No, the way they do is it's always once a week. And how that program works is they have sessions. So when you come up on their list, and there's about a five month waiting period between sessions, and when you come up, you come up for between six and eight session blocks.

M: Oh, okay. That's pretty finite.

Parent: Yeah. And you do the block, and you go back on the list. And you do the next block, and you go back on the list.

M: And that's regardless of what the assessment says?

Parent: Yeah.

A number of parents reported on this same inflexibility of response and identified how, combined with waitlists, they struggled to meet the recommendations of the assessment. The parent who brought her child to two appointments per week talked about how financial concerns combined with difficult interactions with her ex-partner (whose benefits they used to fund private appointments) might mean that her child would not be able to continue with this frequency of appointments for much longer. Thus while the assessment and services may be identified as "for" or "about" an individual child, the resources that follow – particularly within the public system – are often highly standardized. Unless parents could draw on additional

resources (such as the ability to make and attend different appointments and convince co-parents of their necessity, as well as money to "go private") an assessment's recommendations might remain hypothetical or even aspirational. Similarly, some parents discussed almost surreal interactions where they found out that a given document meant their child "qualified" for programs or supports that did not actually exist, such as more hours of "resource" classroom time with a special education teacher than were actually available at the child's school.

In the words of Dorothy Smith, texts "coordinate" activities across times and places, restricting the range of possible actions for multiple actors in different institutional standpoints (D. Smith, 1990, 1999, 2005, 2006). This means that the integration of texts within special needs service systems coordinates the work of service providers and administrators as well as the work of parents. Indeed, the integration of texts makes it difficult for individual service providers to act in any way that is not in accordance with the larger scope of institutional practice, even if they may see benefits for particular children or parents. Parents talked about some individual professionals who offered services beyond the mandate of their program or agency, but who also expressed concerns about what would happen if their case files were audited.

> Well, [the case manager] though, they're like, 'we're not just going, like we'll continue until you go [to another program].' … So now, they've gone over a year. And our case manager said to me, like when [my child] was turning two and I had told her about all this stuff, like [a dropped referral] and all of that, she was like, 'Well, you know, unless someone starts poking around my files, we're just going to keep [your child] as long as we can.' … She could probably get into some trouble because this is like a year later and they did it anyway.

Parents were certainly appreciative of these gestures, but also aware that the systemic inadequacies meant they relied on individual service providers "going to bat" for them, in another parent's words. Further, parents will need to maintain this positive relationship and contribute to the secrecy that allows such activities to go undetected, likely also experiencing worry at what might happen to both the service provider and their own family if the tenuous

arrangement does not hold. A number of parents talked about their gratitude at the work many providers did while also expressing their frustration or anger that they were "supposed to" feel grateful when they managed to get resources to which they believed their children were entitled. This ambivalent emotional response also fit with the systemwork they described around presenting themselves as "likeable" while continuing to push providers to do more than they initially offered (see Chapter 3).

While the "gap" between what was on paper and what was beyond it created work for parents and often inhibited the material resources available to their families, the slippage between "text" and "experience" was also a space of possibility. As parents described their experiences of obtaining and working with documentation, they also retained some distance between their knowledge and experience of their children and the way that these documents described them. As discussed in the next section, much of the work that parents did to produce and use documents involved learning about, working with, and resisting institutional categories in order to present their interests and needs as intelligible and actionable.

Text Work: Producing and Using Documents

When parents brought out a document to discuss, I asked them how they had obtained this document. This question led to long narratives and descriptions, usually also relating several other documents along the way and infused with a range of emotional content. What these conversations also revealed was the extent to which interactions with special needs service systems both relied upon texts and exceeded them. As parents talked, they referenced not only the document in front of them, but also the feelings associated with deciding to get it, the hopes and fears it inspired, and the practical role it had played in accessing resources.

From our first interactions, some parents described their children very much in terms of their assessments and performance on standardized measures, occasionally citing percentiles. At

first I was put off by this tendency among parents, seeing it as a less respectful way to describe their children. However I came to see how parents' facility with percentiles and diagnostic terminology had been functional and important in other interactions with systems – and after all, in these interviews I was a social worker who might trade in similar currency. Many parents recounted how documentation including numbers could make huge difference in what material resources would, and would not, be available to them. Thus, for parents to learn and use terms that called upon professional assessments and diagnoses was strategic and beneficial in many contexts, even as it also restricted how the parents and others were able to talk about their children.

This way of talking about one's own child using diagnostic or professional assessment terminology may be considered a form of "institutional capture" in institutional ethnographic terms (Campbell & Gregor, Smith, 2005). However, the blend of discourses and strategies deployed by participants suggest that there is no "pure" experiential discourse that is not already shaped by the available historical and institutional context (see Chapters 1, 2, 6, and 7). Special needs systems appear to require and reward "institutional capture" in the way parents talk about their children. For example, one parent who works in the special needs service system used both their professional position and their familiarity with standardized test measures as a way to stand out and move their child up a long waitlist for a developmental assessment.

> Yeah, I was mentioning [my employer]. And depending on the conversation I was having, mentioning the director of the program that I work with that is very well known in the diagnosing circles and stuff like that. I think people, I mean, I can't say for sure, right, but I think that definitely played a role. And I knew who to ask for too. When you call it's just, put me on this random waitlist. I went in with specific doctors' names and what tests I wanted to have done on [my child], what I wanted to have run, and who I wanted to have seen, so I may have appeared… I kind of came with my own plan, so I don't know if that played a role.

This parent reported getting an assessment through the public system in less than six months, and acknowledged that this was probably half the time such a process usually takes. They

explained, "You kind of have to do what you need to do as a parent". An ability to use the terminology of assessments and refer to particular documents and measures, as well as to people and institutional affiliations, all formed part of a parental strategy to get their child resources in an environment of scarce public resources and gatekeeping.

At the same time, many parents expressed discomfort with this way of "labeling" or quantifying their children and what it might leave out. Indeed, the parent who requested particular "tests" for their child also described a fear that other people, especially teachers, would not see how "capable" the child was if they knew of the diagnosis, particularly within schools.

> I find that teachers don't really take the time to get to know the kid. All they know is *that* kid with [this diagnosis] could potentially be trouble in my class. Whatever trouble looks like for that parent, or that teacher. They don't really get to know 'Johnny'. Ever. They just know, oh, he has [this diagnosis]? Okay. He's that kid. I'll stick you over there. Or, you're the kid that's causing me more admin work.

Indeed, this parent felt that after a couple of years of work and growth, their child may no longer meet criteria for the same diagnosis, while the systemic impact of being seen through the lens of a particular diagnosis would be difficult to change if the parent disclosed it and the texts entered into the child's record. In this quote, we also see that the "admin work" particularly around texts such as individualized education plans and safety plans, may influence not only parents' workload, but also those of service providers such as teachers, who may resent the added documentation requirements for certain children. This parent went on to describe how overloaded teachers already are with large classes that often contain several children with 'special needs' for whom the system demands additional documentation.

The ways that parents talked about their children often reflected their mixed responses to particular documents and dominant documentation practices. How parents described their thoughts and feelings about the documents they brought to the interview drew upon a wide

range of stories and relationships as well as their beliefs about the meaning and value of difference. Different types of documents seemed to evoke different ranges of responses among participants and often engaged with different sectors and professionals within special needs service systems.

Adoption Certificates

For parents who discussed adoption certificates, their feelings about obtaining the document itself were primarily positive. They described it as both the culmination of many years of planning and striving to form a family, and a somewhat anti-climactic bureaucratic acknowledgement of the family that they had already become. Parents highlighted the restrictions they were subject to while they were living with their children in the months or year before the adoption was finalized, and the document represented the end of this bureaucratic scrutiny. For example, one couple reported the stress and work caused by the adoption worker's restrictions, including having to prepare to move their dog and then renovating their house to provide the right number and location of bedrooms. This couple recounted that their worker said that these measures would only need to be met until the adoption was finalized. However, for some requirements – such as renovations – the family would not easily be able to "change it back". In addition, workers would regularly visit with the families and monitor how things were going every month until the adoption was finalized. While most parents described having good relationships with their adoption workers, they also pronounced a sense of relief when this monitoring period ended. The arrival of the adoption certificate was immediately significant. As one parent said, "That paper [the adoption certificate] is pretty much like, at that point, we could live like a regular family."

Adoptive parents described feeling there were probably good reasons for the restrictions they encountered prior to the adoption being finalized, but also acknowledged that the

accumulated institutional history, along with a legalistic institutional environment, presented

concrete challenges in their everyday lives.

> Parent 1: Yeah. It's just sometimes it's a bit bureaucratically crazy. Which, and you
> know… rules are only in place because something happened. And you get that logically,
> but I'm like, oh, I hate the person who screwed up that rule.

> Parent 2: …Because nobody sits around the table and thinks, like, 'How can we make it
> harder for people to take children who have no homes?' I understand that. They don't sit
> around and do that, and they're not jerks, they're good nice people, they don't do that. But
> some fool, however long ago, did something stupid, and now we're paying the
> consequences for their dumbassness.

> Parent 1: …They don't want to get sued.

Thus, in contrast with parents' discussions of other systems, such as schools, adoptive parents

did not express the same belief that adoption systems had been deliberately concealing

information as they waited for the adoption to be finalized.[22]

 In interacting with special needs service systems, parents reported that the adoption

certificate fundamentally changes the ways that things happened. For example, until the

adoption is finalized by an adoption certificate, all of the child's medical procedures that are

designated "non-emergency" would require approval from the adoption worker. For children

with extensive medical needs and long hospital stays, this takes a significant amount of time and

energy, although parents generally reported that the hospital staff is well-practiced at making

these calls and the parents do not usually have to get involved directly. The uncertainty over

when and whether procedures would be approved, however, continued to be a source of worry

for parents until they had their adoption certificate. Across other systems, the adoption

certificate is essential for things like obtaining passports, but some families continue to

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[22] The one exception to this finding was in the account from Chapter 4 in which one adoptive applicant found his
application had stalled because of an anonymous call that had not been disclosed to him previously. However this
delay occurred at the application stage, rather than while the parent was living with the child and awaiting the
finalization of an adoption.

encounter administrative barriers even after the certificate has been obtained, as one father explained.

> So we're used to going in and out of the States all the time, but apparently there's another requirement in Mexico about getting consent to travel. So … there is no mother, we're not going to bring a letter, we're not going to bring a certified letter, which is what the travel agent is saying. {*fake voice*} "Well you've got to bring a certified letter from the mother." {*normal voice*} Like, mmhmm, mmhmm, mmhmm, mmhmm, like it doesn't exist. It's never going to happen. I can't even get [premier] Kathleen Wynne to do it because she's not the mother anymore, he's not a crown ward!

The expectation that there will be "a mother" for a father to get travel consent from permeates such encounters, demonstrating how the heterocentrism of institutional structures can influence parents' everyday experiences through and surrounding texts. In this case, the parent would likely have to get an additional document to explain the absence of an expected text (mother's consent), all because this family may not be perceived as "complete" in the eyes of a border official. Thus, added documentation and scrutiny does not always end with the finalized adoption; indeed, in this case there would have been a more institutionally recognized and established path for "a certified letter" when this child was still a "crown ward", as is hinted at in the parent's joke.

While adoption certificates themselves did not evoke many negative feelings among the parents I interviewed, there were ongoing questions from some parents about why and whether their families received different responses than non-adoptive families in service systems. Requests for additional documentation could be one sign of differential treatment. One parent recounted a sequence in which she discovered that her daughter, who had a number of medical needs and had already required more than one hospitalization, inexplicably had her health card suspended. She recounted that the process of getting her child's card reinstated required more documentation than she could understand, and that this difference seemed to be directly related to the fact that she was adopted.

> I needed the adoption papers, I had everything else, my birth certificate, her health card, my health card, right, **everything**, except that. So [the health card application officer] says, she calls and I guess the woman on the phone with her is like, well, do you have the adoption order there? No. Well then she says to me, well you need the adoption order. And I'm like, nobody told me that! Like, I don't live close to here!

Given that the child's card was in her adoptive name and matched the name on her post-adoption birth certificate, this parent could not understand why she needed to get additional documentation to renew her child's health card. She argued that this would not have been the case for a non-adoptive parent. The parent had to travel a considerable distance home and then return the next day, all with a young child who had limited mobility and required feeding equipment. This example highlights that adoption papers can be required at unpredictable moments throughout parents' everyday lives, and such requirements can have immediate and onerous consequences for parents, shaping their everyday systemwork.

Assessments and Other Diagnostic Materials

Another common text that parents brought in to discuss was a professional assessment (see Figure 1). Assessments evoked an especially broad range of responses among participants. A number of parents described having gone through a long process of deciding whether or not an assessment and/or diagnosis document was required. This was particularly the case for parents whose children had behavioural and developmental diagnoses that were not "obvious" to all, and who ultimately received diagnoses such as Autism, Asperger's syndrome, Attention Deficit Hyperactivity Disorder, Developmental Coordination Disorder, or Alcohol-related Neurodevelopmental Disorder (on the Fetal Alcohol Spectrum). Often parents who were co-parenting described a prior or continuing disagreement with their co-parents about the need for any professional assessment. Sometimes these disagreements lasted for years.

For some parents, their own experience and anticipation of "difference" played into their uncertainty about pursuing a professional assessment or diagnosis.

So, you know, I think perhaps my acute awareness of what it feels like to be different, and not necessarily be valued, does impact how I see or how I try to navigate his disability. And it could also possibly be part of my resistance [to a diagnosis]. It's like, oh my gosh… 'You already come from a family that's going to have its challenges in the mainstream system. We don't need one more thing.' You know? Which again is really unfair to him, because it's not one more thing. We don't see it as a disadvantage, but we know that the world sees it that way.

This parent and their co-parent struggled against the notion of a diagnosis until they decided it would be necessary for navigating the school system. All parents who brought assessments to discuss at the interview described concerns related to school systems as a central reason they decided to get an assessment done. At the same time, not all of these parents had, to date, disclosed their child's diagnosis to school systems, or had found this disclosure to be effective if they had.

Another parent summarized their discussions with their partner about whether or not to try to diagnose their child, who had been identified to be "at risk" for a diagnosis on the fetal alcohol spectrum:

What we kept saying is, we can't get the services. [Not diagnosing] would be fine if he could still get the support, the same level of support, especially with the school system. Or even the government didn't consider, like until we got that disability we were not eligible for the disability tax credit, right? Like until you get it… sign on the dotted line, in black and white.

So we found ourselves having to advocate for this potential stigmatizing of our child in order to get better and more easy access to the services. We kind of, for a number of years, did a patchwork. [We] relied on, we had some really… sympathetic teachers who were prepared to make some accommodations in the classroom and provide access to support… even without the diagnosis. So we could kind of do it on the side a little bit. But in time it became clear that in order to get him the really good support he needed to have that diagnosis.

This child was Aboriginal and the parents worried that receiving this diagnosis would create even more stigmatizing beliefs and resistance within the school system and broader community (see Salmon, 2007). However after the child had been suspended in school and they felt that other parents and teachers were singling him out as disruptive and "bad" for behaviours

connected to his disability, these parents decided to proceed with the diagnostic process (see Farruggia, 2009). While the work involved in getting the assessment was substantial for both the child and the parents, this parent reported that the impact of the diagnosis had been more beneficial than harmful, particularly since some additional learning disabilities had also been identified.

> And then it was like, {*slows down*} Okay. We got it now. And this is the form. We're going back to the school and this is the form. We got the suspensions removed from his record, because of that. We couldn't ever get, we had the [individualized education plan] but we couldn't, it was really hard for us to get anything from the IPRC, whatever the heck that stands for.

Here, the outcome of school meetings (such as IPRC, or individual placement and review committee meetings) and other interactions changed substantially based on "the form", to the extent that other institutional texts, such as suspensions, were made to disappear.

Once parents made the decision to seek an assessment, actually producing it required a substantial amount of time and work from the parents as well as their children. Most assessments required at least three different appointments with various professionals, with forms and/or interviews for the parents as well as the children.

> [The family doctor] referred us to [organization]. Then [the developmental services organization] did like, we saw an OT that looked at him, and then we saw a nurse practitioner that looked at him and did various assessments. And then as parents we filled out a ton of different questionnaires on different, on his social functioning, language, behavior, I mean they are all standardized questionnaires and tests. So we saw her maybe, I think we saw her three times for like the full day, like a full, kind of 9 [am] to 3 [pm]… when they did various things. But I think one of those, I think only two of those days he was there and I think one of those days we did all the parent questionnaires, they kind of walked us through and took notes. And then she took all that, compiled all that, and wrote a report, which is this.

Furthermore, the time required for the actual assessment itself was usually exceeded by the time spent waiting for an appointment, making and traveling to and preparing for appointments, and so forth. "Waiting" was a very active time for many parents (see Chapter 3); as one parent said,

"I called them like every day. I think they eventually said, Fine, come in this day and stop calling us. Literally. That's just my personality. I don't want to wait years and years and years."

Beyond this time investment, obtaining an assessment could require considerable amounts of money if it was obtained privately. Only two participants brought in a private assessment as their primary document, and in both cases their (straight, cisgender, male) ex-partners had paid for the assessments through employment benefits and/or their own income. One other participant made reference to having obtained and paid for a private assessment but got some of such costs reimbursed through an arrangement with the adoption worker. Private assessments could cost over $2000 and as much as $4000, representing a considerable and prohibitive cost that most participants stated they could not afford.

A number of parents described feeling some level of emotional distress at reading the assessment written about their children, even if the reports said exactly what they had expected or even needed them to say. One parent remembered back to when she first received her child's diagnostic report.

> I was in a state of shock almost. Even though I knew that was why we started this journey anyway. Yet to have someone tell you that that's actual… I remember sitting there and [the provider] was talking and talking and I was like going through the report, {*flipping pages*} and I was kind of like, Ohhh. {*laughs*} It was kind of a weird. This is real now because it's a piece of paper. … It was just a weird, a weird day. I remember that day.

This parent described having wanted this assessment to validate some of her own sense of how her child was developing: "I almost wanted someone else to say, no it's not just you. We see it too. Like someone who doesn't know him, like a third-party person." When she received the report agreeing with her own assessment, it was still difficult to absorb, since seeing it on paper made it "real now" in a way that her previous concerns had not been.

This parent also described feeling surprised at how her child's assessment included information on how he was conceived, using donor sperm and alternative insemination.

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Parent: [The insemination is] in the report! Which I find interesting. It's right at the top. How he was conceived, which I don't know, why that's important. I don't know if that is in anybody else's report, in a heterosexual family. That, "Mom and Dad had sex and the child was conceived." Yet it's in mine, right at the very, very beginning.

M: What does it say?

Parent: That he was conceived through donor sperm insemination. I don't see how that's relevant to anything. Like it's on the first page, right at the top. I don't know why that's important or relevant. But it is here, like I was surprised by that. That they put it in there.

Once the child is described "on paper", the text highlights and sorts what will be read and interpreted by multiple future audiences (Smith, 1990; Titchkosky, 2007). As this parent pointed out, LGBTQ parents and their families may be constructed and seen through a primary lens of difference in the way that assessments are structured. In this example, the text that made "real" the child's diagnostic "difference" proceeded to also "make real" and salient the parent's "difference", not only in family structure but in how the child was conceived. Given how this paper is required to be used across multiple systemic encounters and the dominant context of heterocentrism, this textual foregrounding of family creation histories could present particular risks for some LGBTQ parents.

Another parent described feeling very good about the assessment that a developmental pediatrician had written about their child because it reflected an understanding and a worldview that was closer to the parent's own. The parent had initially been very reluctant to seek a diagnosis for their child but was pleasantly surprised by the attitude of the developmental pediatrician and the way it translated into a "strengths-based" written assessment of their child.

So, why I think this [document] is different is because it does, it does focus on his strengths, right? It doesn't start off with, [this child] is a kid with Asperger's. And by Asperger's we mean that he has trouble with. Do you know what I mean? Just as an example, it starts off you know, talking about how *lovely* [my child] is. And what his strengths are. {*tearing up voice*} Which he has many. But which I fear will not be seen or valued. Or heard.

The same parent had brought in a school developmental history form to offer a contrast to the way that this doctor described their child. This form reinforced the parent's fears and political reservations about engaging with institutional categories such as diagnoses, and what they might leave out.

> It felt to us that [the school form] didn't really ask… what his strengths were. Because we're super sensitive to the fact that he has strengths. So when we talk about [the diagnosis], the questions are just like, well, what is he having trouble with? …But there's a complete absence, okay, of what's your kid good at? What sorts of things does he love to do, or he finds comfort in? And what strategies do you use if your child is anxious?...Which for me was kind of… how do you get to know my kid? You just get to know that he hits himself and lashes out if it's too loud. But there's nowhere there that says, yeah **but**, if you sort of tell him to plug his ears, everything is okay, nobody's in trouble, nobody's hurt and you encourage him to go someplace quieter, he completely calms down.

This school form was the parents' introduction to the school system for their child, and they received it when they went to register him and told the secretary they had a child "who may have some special needs". As this participant described, the secretary gave the parents "a little. a plastic bag with a bunch of stuff in it" and told them to "bring it back". For this parent, the way that the form asks parents to describe their children solidified the parent's concerns that the school system would not respond well to "difference", particularly around disability. They also learned quickly that disability is a textually-mediated category within this institution, and that filling out forms was a task parents would be expected to engage in. As described by many participants, forms and other "paperwork" were required forms of parental systemwork throughout special needs systems (see Chapters 3 and 4). When parents found that forms portrayed their children in ways that they objected to, this frequent task was overlaid with added, and potentially cumulative, sadness or anger.

Long after the decision-making and process surrounding obtaining a formal diagnosis, parents continue to hold apparently conflicted feelings towards assessment documents. As one parent stated, "Yeah. This is not my kid *{holding paper}*. He is more than these five pages or

whatever." Another co-parenting couple brought in a second school-based psychologist's assessment of their child's learning needs which added a learning disability to a pre-existing developmental disability diagnosis. In discussing the document, both parents moved back and forth between emotions including "hopeful", "sad", "bothered" (possibly angry) and feeling powerless ("out of our control"), all the while trying to retain a focus on their child's emotional experience and good qualities:

> M: So when you look at this document or when you think about this, what sorts of feelings come up?
>
> Parent 1: Oh, hopeful. I would say hopeful. I mean kind of…. I don't know that {long pause}. Like I wouldn't change anything.
>
> M: Like in the document?
>
> P1: No, the document is very descriptive, it's uh. {sigh} I mean, you read the document but in your head you keep telling yourself, what a great kid. Still. I mean, it sounds, it's tough to read but you still know, he's a wonderful, wonderful guy. I dunno. {sigh} It's sad.
>
> Parent 2: I just think it's got to be really hard to be him in this system. Like, I mean, it's hard for us to go to one frickin' meeting. And he's in that system for eight hours a day. And, you know, I think he's really well-liked and getting good supports. How much of that is on purpose and how much of that is random really bothers me. Right?
>
> P1: A lot is out of our control.

The document that was at the heart of this discussion was a school psychologist's updated assessment. They described being told by school administrators that they needed an additional assessment done now that their child is a bit older in order to have him "qualify" for more secure supports. Their child had to engage in three full days of testing at school in order to obtain it, with one of the parents present outside the room for most of this time, although they said they were lucky that they did not have to go outside of the school to get it done. As one parent noted, this assessment resulted in an additional "label", and a document that both parents felt failed to capture their "great kid" to such an extent that it was "hard to read". At the same

time, the text had a direct material impact that they felt was helpful to their child, since he was now able to go to a smaller classroom with more adult support for half of each school day.

Parents' conflicted feelings about documents were sometimes combined with their critiques of how the documents were, or were not, taken up. An additional frustration for the parents in this particular case was that the "professional" assessment was explicitly challenged by the administrator/ primary gatekeeper figure at the school meeting.

> And what else did [the psychologist] write in his assessment? "[This child] would benefit from one-on-one". And [the administrator of special education at the meeting] had a frickin' heart attack that the school psychologist would have written that. {*loud, screechy voice*} "He can't write that!"… But when does a corporate lunkhead get to dictate what a professional psychologist writes about a kid's diagnosis? Well, but they get to, right? So this poor psychologist, who has written his professional opinion, which is frankly everybody's opinion who has ever worked with [my child]. That he doesn't do anything unless it's one-on-one. 'But you can't write that because then the [school board] might have to supply it! And we have no intention of doing that even though we've got this really fabulous brochure.'

This particular encounter was a stark indicator of the way that institutional power structures influence what parts of texts are "allowed" to become "real" and result in resource allocation. Texts need to not only be produced but also institutionally activated in order to have a meaningful material impact. This example of the interpersonal, hierarchical, and simultaneously institutional regulation of both how texts may be written ("He can't say that!") illuminates how texts may be interpreted and implemented through a lens of reducing systemic costs and responsibilities in "real-life" situations, in contrast with co-existing brochures and policies. This described exchange also shows that "professional" evaluations are subject to (and must produce texts that are congruent with) institutional practices.

Such hierarchical, interpersonal encounters help to explain the disjuncture parents report between "on paper" and "in reality". The gatekeeping and managerial role of institutional administrators is coordinated through texts as well as exercised through its own textual residue. In this case, such residue would be found in the individual placement plan which resulted from

this meeting and the budgeting of additional special education classroom time but not "one on one" educational assistant support. Furthermore, we can postulate that the apparent "author" of the document, the school psychologist, will be less likely to include phrases such as "one on one" in future texts. The experience that many parents reported in which they were told that individual educational supports, or "one on one" requirements, are discouraged or "unavailable" across multiple settings and moments is given a possible mechanism through textual production, revision, and even censorship. Meanwhile, parents may follow all the textual requirements prescribed from previous school meetings, put time and effort into getting the "right" documentation of their child's needs, learn about the institutional policies and promotional materials (e.g., the "brochure"), and still the institutional bottom line of cost-control and cutbacks can prevail.

It is important to note that not all parents described struggling with the decision to engage in documentation of 'special needs' and related diagnoses. A number of parents adopted children who had already received diagnoses that were known to the parent before they even met the child. For these parents, the decision making and possible concerns about disability were most often connected with the "checklist" of possible traits they would consider in an adoptive child (see Chapter 6). Parents whose children had received speech disorder diagnoses did not seem to struggle with the decision to document or assess their children's speech, even as they may have expressed concern or uncertainty about other diagnoses for the same child. Similarly, parents of children who were treated for serious and life-threatening medical conditions did not express uncertainty about their decision to seek and receive diagnoses. Parents who described their children as "not blending in" to a considerable degree also did not describe the same reluctance to receiving professional documentation.

Elizabeth, whose child had been assessed numerous times over more than a decade described extremely different feelings associated with two professional assessments. While she described the psychologist who did her child's final assessment and diagnosis (in the early 2000s) in glowing terms and said "I kiss the ground she walks on", she also brought in an assessment from the 1990s that continued to evoke anger and strong negative feelings. Elizabeth's ex-husband's wife had initiated a third psychiatric assessment for Elizabeth's daughter with a practitioner that Elizabeth found biased and offensive.

> I very much was angry that she had [written], and so was [my partner] Karen because she had interviewed both of us, that she had written a report that referred to Amelia's father as "Dr. Hudson" rather than Amelia's father, Pete, and Amelia's mother, Elizabeth. So that was a problem for me. She did not mention that I was a lesbian, and I made it very clear that I was. And we both felt in the room when we were being interviewed that she was homophobic. It was pretty common, you know, and even more so in those days. We didn't have a loud enough voice.

The resulting report, Elizabeth felt, was "not useful" and deeply pathologizing of her daughter as well as her family structure. Indeed, it focused on "family conflict" as a central concern and had no treatment suggestions for her daughter. When asked how she felt looking at this document, Elizabeth said, "I feel a little sick to my stomach actually. I feel really betrayed. Yeah." At the same time, Elizabeth talked about the material benefits of having an accurate and helpful diagnosis for her daughter many years later, since this helped them understand her and find appropriate medical treatment and housing: "Getting an assessment. That's the biggest thing. Like getting an accurate assessment of your child is so key." Elizabeth also speculated that while her daughter had been assessed many times previously, the professionals involved had been "stuck on" particular diagnoses that were not accurate. This "stuck-ness" might reflect the reproduction of texts within texts, such that each assessment may draw upon what precedes it. Elizabeth's experiences suggest that assessments may be either pathologizing or liberating for

parents, and their varied effects connect to the encounters that produced them as well as what next steps they make possible.

When parents not only appreciated the function of the assessment but also felt that the person who had produced it represented their family and their child in an accurate and supportive way, they expressed positive feelings towards the document itself. For example, one parent had been impressed by the speech and language therapist's interactions with her child throughout the assessment meetings, and also felt heard and understood as she expressed her own opinions. As a result the document inspired positive emotions in the parent in spite of some of its "scary" predictions about her child's capabilities:

> I think I was appreciative of it because it reflected what I was seeing. And although some of what it said was scary, I think that not having a diagnosis and not having recommendations for programming would be scarier. So in that way I have a good relationship with this document {*small laugh*}. And I think that's partially too because I have a good relationship with [my child's] speech practitioner. [The speech therapist] is knowledgeable and she recognizes the valuable things that [my child] and I bring to the table. Yeah, I think the positive feeling that I have towards the document is part of the positive feelings I have towards the person who wrote it. Like, she **gets** us.

As this parent noted, the document helped her understand and act upon what she had already been concerned about with her child, and gave her a sense of what she could do as a parent.

Parents described reaching a place of pragmatism around documentation and assessments, where their reluctance to define their child in diagnostic and administrative terms was overcome by a sense that their child would suffer without these documents. As one parent summarized in response to her child's learning disability assessment, "It's sort of like a hoop that needs to be jumped through. I guess we're glad we have it because this is the language that the system speaks." Another parent summarized her bemused response to what her child's psycho-developmental assessment represented: "It kind of opens doors to things. It's weird because it's a random piece of {*holding and flipping page*} paper, really, that gets you stuff and

defines you in certain circles". Parents who discussed assessment documents described them as particularly powerful pieces of paper with ongoing repercussions.

Other Documents

While most parents selected forms that professionals had written about their child's diagnosis or adoption, several others brought in documents that had a different application or history. Perhaps most strikingly, one parent brought in a document that she had written to explain her child in a way that she felt was more supportive and more useful than the "professional" assessments and other forms she had filled out. This parent had already noted the time and effort required in filling out forms for all of the special needs systems she engaged with, but explained that it was worth creating an additional form that was more reflective of how she saw her child and more immediately useful. She did not deny the institutional necessity of the professional forms but doubted their everyday applicability. When I asked her why she had added to her pile of assessments and other paperwork in this way she explained:

> [The professional assessment] couldn't translate. It couldn't translate between what the document, anybody, even teachers, or whatever, couldn't translate. So I get this report and it says all these things and all this diagnosis and all this stuff. And each one of the reports is also always partial for different disabilities. What they couldn't translate would be, okay, so, how do I know if [this child] has to go to the bathroom? {*brief silence then laugh*}

This parent went on to explain that such "translation" work was particularly necessary because staffing across all special needs and children's services had such high turnover rates. She could not rely on providers having the time to get to know her child, nor did she have the time to explain her child for new people "every week". This finding suggests that low job security and variable training available to many people who work within special needs service systems shows up in parents' everyday experiences. It also suggests that parents understand texts to be an efficient way to navigate through the interpersonal requirements caused by systemic factors such

as high staffing turnover. In other words, this parent-produced text is designed to help "jump the gap" between what is available institutionally and what the parent believes is best for her child.

Two other parents brought in documents they used specifically within the school system to advocate for their children. One parent brought in a pamphlet-style document that had a general explanation of her child's diagnosis and suggestions on how best to work with children with this diagnosis. At the same time, it was not about her child specifically and had no actionable currency within the school forms and processes (or the "admin work" teachers were required to do around special needs and accommodations). The parent said that she hoped this form would be used by teachers within the school system, but had not found that teachers were generally able to integrate this information into their everyday practices. As a text that offers information but no institutional incentive (either as a part of the teacher's job description or the school board's budgeting of resources) the implementation of this document would require individual teachers taking the initiative and time to develop their own understanding and capacity, above and beyond their existing workload. It is perhaps unsurprising that it had not led to concrete action within the child's school, although the parent found it useful to inform in her own systemwork since it gave her additional terminology and credibility in such interactions.

Similarly, another parent brought in a copy of a letter she had asked her child's doctor at a neurology clinic to write, stating that her child required the school board to provide him with a laptop for school work. This parent said she believed this letter may have made a difference in what was a multi-year, ultimately successful struggle to get the school to provide this accommodation, but that success had not come for over a year after this doctor's letter was written and given to the school. A number of parents talked about how lengthy the usual waiting period was for school boards to provide any technological support, particularly if it was financially costly. This example supports the finding that systems such as school boards may

require additional documentation as part of slow and delayed responses. Asking for additional documentation would be one way of delaying the cost of accommodation, and perhaps testing to see if the parent will persist or give up.

Exceptional Texts

Not all parents noted a "gap" between what was written or advertised and what was actually provided. For one couple, the document they brought in was something that they referred to daily since it was their child's medical treatment protocol for a form of cancer. They described this binder as a "bible":

> So this, this this whole thing, this whole booklet is like a bible. There are descriptions here of all the different drugs that you take. There's advice here on mouth care. Um, in case they get sores in their mouth, right. So there's description of the drugs and their side-effects, the potential side-effects, you have to take. And there is also information on you know, different support for parents of kids with cancer, the summer camps.

For these parents, the binder was given to them by their health care providers upon their child's diagnosis. The documents in the binder exceeded what they had actually read or used, but they reported feeling better because they had them. They pointed out that parents of children across many different parts of the world were receiving similar documents explaining a common and standardized treatment scenario. As discussed previously (see Chapter 3), the cancer diagnosis seemed to hook these parents into a different and more coordinated systemic response than other parents I spoke with; this coordinated systemic response could be seen, at least in part, through the resource binder. For example, the more complex medical documents were also explained in a "user-friendly" version included in the binder. Professionals contributed to the upkeep of the documentation, and used the text to organize and coordinate the parents' daily routine.

> Marvin: So, this, the hospital pharmacist will give us a copy of this every couple of weeks. Which tells us, every day, what medicine we have to give him. So we have to follow this, we check it off, it saves our lives. Because I was like, did you give it, did you not give it, or whatever. Then we keep them all so we can tell the doctors afterwards, yes, we did everything….

Margaret: And do you have a certain routine in who gives what? To kind of keep track of that, or?

Allan: {*laughing*}

Marvin: Nope. Nope. We're, we're on a routine of

Allan: Did you do it? Did you do it?

Marvin: One does it and one asks.

Still, these parents reported that how parents used and viewed the binder varied between individuals, and even between the two co-parents I interviewed.

Allan: It's funny, some parents really use this a lot. And I… on a scale of 1 to 10 in terms of our intensity of using this binder, or being on top of it, I'd say I'm probably like maybe a, like 10 being really intense, I'm probably a 7, or maybe a 6. Right.

Marvin: Count me as a 3.

Allan: Yeah, you're probably a 3, yeah. But there are parents who are really, like I noticed this one woman, she was writing down every little thing, and I'm like, okay. I trust the doctors a lot. I'm not one to sort of, some parents… they memorize the protocol and they fight with the doctors around certain things. You should do this, or don't do this. I would never do that. I would never argue against the protocol… I trust the doctors at [the hospital] and I don't want to, I don't want to get into that headspace.

Again, these parents describe the connection between their use of a particular text and how much they trust the systems and professionals who are associated with it. For these particular parents, trusting the professionals and the service they provide was associated with spending less time reading and reviewing texts.

Conclusion: 'Jumping the Gap'

Parents' descriptions of the texts they used in their interactions with special needs services range widely, showing that the texts themselves operate across and through encounters and institutions. The gap that parents observe between what policies and brochures promise and what they actually deliver indicate that the textual demands that systems make on parents surrounding disability and "special needs" are not just influenced by gatekeeping, but actually

are a mode of gatekeeping in many circumstances. Further, ongoing hierarchies of the "ruling relations" within such institutions mean that the ways that texts are produced within systems, how or whether they are taken up and turned into material resources, and even when and how texts may be required to be shown or re-produced, create uncertainty and a perceived lack of control among many parents. Only parents who "choose" to engage with documentation in ways that are recognizeable and actionable within the particular institutional context will even get through the door. But not all parents are able or willing to make this choice. To reiterate the words of one participant, not all parents have the resources "jump the gap" from policies and advertised services to meaningful practices that help their families.

Parents' differential ability to "jump the gap" between policy and practice in order to secure resources for their children cannot be divorced from a context in which certain parents, and certain children, are seen as more or less deserving of attention and resources. The discourses of desirable reproduction which portray LGBTQ parents and children with particular diagnoses or ways of being as less worthy of institutional concern are thus an integral part of parents' experiences of engaging with special needs systems and their gatekeepers. In the next chapter, I consider how parent narratives illuminate the ways that such discourses of desirable reproduction are felt, responded to, made meaningful, and resisted in parents' everyday experiences.

Chapter 6

'It's not about a checklist': Relating What Matters

How do the narratives of LGBTQ parents of children with 'special needs' incorporate, respond to, modify, and challenge dominant social notions of "desirable reproduction"? In this chapter, I address this question through an analysis of three passages from my interviews with LGBTQ parents. In each excerpt, parents addressed how their experiences rub up against, fit with, or depart from normative stories and beliefs about parenting. Passages were selected in which more than one way of understanding a set of experiences is evident, as is more than one set of possible emotional responses. In each, the uneasy alignment of possible interpretations of "what matters" about a set of experiences can be traced in the way the parent(s) related the narrative, as well as in the content of the telling. I organize these passages under different modes of narrative orientation: When, Where, What. Clearly, each narrative excerpt also addresses the "other" headings, but parents' perspective on the slippages and insufficiencies in dominant notions of temporality (when), proximity (where), or relevance (what) form the basis of my analysis.

More generally, I analyze these excerpts in terms of how parents respond to, resist, incorporate, and modify dominant discourses of desirable reproduction in which disability is only and always a problem, and parents (particularly mothers) are responsible for preventing, monitoring, and working to reduce its impact with little regard to their own emotional well-being. I consider how the central narrative strategy of conditionality (e.g., it could have been, I would have) echoes and shapes the interpretations parents offer in these passages in which more than one "version" of events is conveyed, not only in disagreements between different narrators or characters, but also in different emotions that could be ascribed to the same events. I also explore how the parents discuss the work that they do in order to move across and between

storylines and their associated affective states, as parents talk about and also enact the effort, time, and energy required to navigate between different interpretive storylines.

The selected passages should not be seen as representative or exhibiting "types" of parental response that are indicative of the broader group of parents I interviewed, or of all LGBTQ parents of children with 'special needs'. In contrast to some narrative work on health (e.g Frank, 1995), I do not propose a set of common storylines into which parent narratives can be sorted. Instead, they are brought together to show particular parents' different ways of telling and making sense of their experiences alongside "expert" or otherwise "dominant" perspectives on desirable reproduction. I cite them in detail to encourage further reflection and questioning on the part of researchers and others, and to unsettle the notion of a "standard" narrative or counter-narrative.

In doing this work, I rely not only on critical theory but also on narrative methods of discursive analysis (see Chapter 3; Bridgens, 2009; Fisher & Goodley, 2007; Goodley & Thegaskis, 2006; Gee, 2005, 2009; Reissman, 2008). As such, I analyze extended exchanges rather than cutting and grouping sentences or words purely by content. In contrast with other chapters in this thesis, here I use the present tense to frame participants' words, in order to create a temporal immediacy that encourages the reader to attend to how the telling unfolds, moment by moment. In this process, the inconsistencies, uncertainties, pauses, gasps, sighs, laughs, and disagreements that participants integrate into the telling of their experiences become analytically valuable. Indeed, I argue that the affective element of their accounts offers an important critique of the supposed certainty and objectivity of institutional practices, and of dominant beliefs around lives, and what families, are not only "normal" but desirable.

When: 'We run on Natalie time'

One couple that I interviewed, Aurora and Samantha, talked about "developmental milestones" and "comparison" between children in the context of discourses of desirable reproduction. This narrative excerpt was introduced in the interview in the form of suggestions for other parents of children with 'special needs'. In this passage, the parents both describe the inescapability of dominant discourses about desired temporal development, and highlight the necessity of creating a different understanding and aspiration. The struggle to balance between interpretive framings is uncertainly tethered in a changeable web of emotional moments and possibilities.

Samantha and her partner, Aurora, have just talked about working with a professional, a pediatric physiotherapist, who they felt could not let go of the "checklist". They described their mounting frustration with this individual's constant dismissal of their daughter's accomplishments, as the therapist always returned to what their child "should" be able to do by a given age. They have described the difficulty they had in letting this therapist go even they knew there were no other therapists with the same credentials available as one of "trusting" themselves. If they declined this therapist's services, there would be no replacement available with similar skills and knowledge. They have gone on to describe their growing certainty that stopping this service was the right thing to do.

In the opening of the selected excerpt, Samantha offers a rejection of the totality of any medicalized or standardized understanding of an individual's well-being, quickly followed by Aurora's own guideline on what a good outcome could instead look like.

> Samantha: It's not about a checklist.
> Aurora: It's just, how they are. Like, if they, if she, every single day does something different, that's awesome!

In her statement of what positive or "awesome" development might be for their child, Aurora introduces a new form of temporality. Starting from "how they are", a reference to their earlier descriptions of their daughter's unhappiness when the physiotherapist visited, she moves to what the child does and when, but in a defiantly different way than a professional checklist. Instead of meeting the physiotherapist's predetermined timelines, she suggests that if "they", any child, or "she", their child, Natalie, "every single day does something different", then this is a good situation, even "awesome". This new standard is strict in some ways, in that "every single day" requires a particular outcome, but it also broadens what "something" could be, as long as it is "different". Thus, "different" becomes a new goal, rather than simply a diagnosis. Notably, however, we are still measuring "something". The need for a parent to monitor their child and look for change from day to day has not been escaped, even if the possible responses to this monitoring have broadened.

These mothers are grappling with the disciplinary regimes found in professional discourses of measurement and parenting discourses of intensive mothering. Post-Enlightenment Euro-American cultures have been increasingly organized around the assessment and promotion of standardized scales of how bodies should look, act, and change (Foucault, 1995). Under these processes, the role of "power" becomes less about the imposition of a particular moment of force directly from one source of authority upon a particular body than the diffuse, everyday, and often invisible practices that shape the thinking and action of every member of a society, their identity formation, and their relationship to and use of their bodies (Butler, 1997; Foucault, 1995). In recent decades, discourses that promote particular practices of development and 'self'-regulation have only increased, and professions have developed around them (Rose, 2007; Snyder & Mitchell, 2006). In addition, there has been an increasing trend in recent decades in North American society in which parents, and mothers in particular, are held responsible for an

almost limitless list of tasks and outcomes with regard to their children. Alison Griffith and Dorothy Smith have described this "mothering discourse" (Griffith, 1995, 2006; Griffith & Smith, 2005) as a dominant understanding in child development literature that children's development needs to be "shaped", and that mothers must do the work to make this development proceed as well (i.e., following expert models as closely) as possible. Motherhood studies scholars such as Sharon Hays (2007) have described the rise of "intensive mothering" that demands that mothers devote boundless time and energy to their children, particularly as a marker and promised promoter of class status in contemporary North America (see Fox, 2006).

The combination of these sociocultural forces has resulted in the belief that mothers (and other parents to a lesser extent) should be engaged in constant surveillance of their children's development, not only to ensure that they "know" if their children are not "meeting developmental milestones", but also to do whatever they can to promote an **idealized** development (Douglas, 2013; McGuire, 2013). In other words, mothers are to promote the most socially desirable forms of reproduction they can, in accordance with (but surpassing even the reach of) paid professionals (Landsman, 2009).

It is this potent combination of intensive, professionally-endorsed developmentalism that Samantha and Aurora address. After they have introduced the possibility of an alternative to the checklist through individualized timeline of "something different every day", they then shift to address "you", as probably a more general "you" but possibly also me, the interviewer and another parent of a child with 'special needs', and, by implication, parents of children with 'special needs' in general.

> S: Comparison will be the kill of you, like you can't compare to anything
> A: Like you can't. Absolutely not.
> S: Because every child, especially kids with special needs, are sooo different, and you just, you can't compare.

In this passage, Samantha and Aurora offer a central critique of a culture of both intensive mothering and developmentalism: "Comparison will be the kill of you." This is an unusual phrasing, since the usual expression that "[something] will be the death of you". Here, the expression blends noun with verb to make clear that the verb of comparing can also turn into the verb of killing. The cause and effect is highlighted, so that we know this "killing" is not inevitable, if only parents can avoid "comparison" – this strategy to preserve parental well-being stands in opposition to some other accounts of disability as causing parents' early deaths (see Gibson 2012b). But here it is engaging with the action of "comparison" that causes problems. At first, it is not clear what we are not to compare to, as parents, but the warning is absolute: "…you can't compare to anything". "Like you can't. Absolutely not." Comparison, instead of required or expected, becomes taboo.

This concern about comparison also puts the focus on a possible outcome for the parent, rather than just for the child. This shift highlights that it is not only a child's interests that we need to concern ourselves with, but also the parent's, in direct contradiction of intensive mothering discourses. Because, indeed, the interests of parent and child may, or may not, be in alignment. Again, there is a slippage in defining the "you", and it is unclear if it is okay for some parents to compare their children with others or not. Possibly comparison is only or particularly deadly for parents of children with disabilities, since while "every child" may be different, "especially kids with special needs" are "sooo different".

The question of how general the problem of "comparison" between children might be is further disputed between Aurora and Samantha in the next exchange. Aurora initially critiques the larger trend toward standardized developmental markers that takes place when parents and others are focusing on "milestones". As listeners, we know from other sociocultural knowledge of intensive mothering and the gendered construction of family labour that the parents who are

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asked to "be into" milestones, to report on them to professionals and others on the street, are primarily mothers (Landsman, 2009; Traustadottir, 1991). But Aurora highlights that this trend goes beyond parents of children with disability, beyond gender or even parent status. It involves "everyone". She shifts to quoting "everyone" prefacing each statement about what a child should do or be with a normative timeline. Here we can sense the echo of texts such as pediatric charts and parenting books, with sections identifying "proper" development for "everyone" to chart and mark and respond to.

> A: Everyone's so into milestones. Oh, at the eight month milestone, at the five month milestone.

But Samantha then disputes Aurora's implied critique of milestones, and we see a withdrawal from the more radical critique of parents being asked to measure development along predetermined, linear templates. Aurora indeed joins in with the rationale for milestones.

> S: Because typical children, that's what you look at.
> A: They follow.

"Typical children" are okay for milestones, Samantha clarifies. The children themselves don't get involved in the milestones, as we see in the shifting subject. That's what "you", as a parent or even as a professional, should indeed "look at" when you and your child fall under the rubric of the "typical". With "that" and "look at" we can almost feel the pointing: how does your day-to-day knowledge compare to "that" example over there, on a chart or in a book or across the playground? Comparison, at this point, is not necessarily troubling for "you" as a parent or a professional in the presence of "typical children", because, as Aurora adds, such children "follow". The milestones, expectations, and comparisons "lead" some parents and some children without incident. Professionals, parents, children, and timelines all line up in a predictable and non-deadly fashion for some "typical" cases.

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In Samantha's next statement, the meaning of "you" changes meanings once again, from the "typical" case or non-specific "you" back to the "you" of a parent of a child with disabilities, a child who is not "typical". Here she re-asserts the danger of the parent of a child with disabilities looking at milestones and comparing their child – with other children or with the non-specific archetype of normative child development.

> S: You look at milestones and so you have to stop that comparison right off the bat or you'll, {*overlap*} you'll go crazy.
> A: {*overlap*} You'll go crazy.

There is a renewed urgency, echoing "Comparison will be the kill of you" and culminating in a joint statement of a possible negative outcome for the parent if this comparison continues unchecked. Milestones are no longer a reasonable thing to "follow" but lead again to "comparison". "You" -- the parent of a disabled child -- "have to stop", "right off the bat". We learn that comparison may start of its own accord, or be started by others, but "you" have to stop it before it takes hold or goes too far. Again, the dangers listed are not to the child or to the broader society, but to the well-being of the parent. We hear a unanimous prediction from both Samantha and Aurora that, if "you" allow milestones and comparison to become a part of "your" experience in the context of a disabled child, "you'll go crazy". Indeed, with this outcome we see the possibility that under the standardized developmental framework and the mission of intensive mothering, the mother herself may face extreme distress, and even lose her own able-bodied/sane-minded status.

Samantha then offers a narrative example of feeling the pull of temporal comparison as well as its sting, which she presents as a funny anecdote, alerting us that this story is about "watching" and "we laughed". Aurora recedes into the background but periodically reinforces details and highlights the emotional messages of the story.

> S: It was, you know, watching, we laughed. My sister has two boys, and the youngest is significantly younger than Natalie, like a year and a half, two years younger than Natalie.

A: Two. About two.
S: He's eighteen months now. Yeah, he'll be two in February. Um, and for a while it was kind of nice because they were on the same level and we were like, this is great! But then Harry started walking and talking and whoa.

This story highlights the social inevitability of comparison, of a certain kind of "watching". Indeed, Samantha reports that when their daughter was "on the same level" as their nephew "we were like, this is great!" This moment of comparison, with its finding of similarity, brought along a feeling of positive emotion that is now phrased in the past tense. She explains that the growing awareness of difference between their child's developing skills and the nephew's then gave them pause and stopped the temporal moment of togetherness – "and whoa". "Walking and talking" are particularly prized developmental moments that are, currently, not ones their own child has experienced. Indeed, at another point in the interview, Aurora highlights her own belief that her child will indeed meet these "milestones", and the assertion has a particular vehemence and intensity.

In this excerpt, however, Samantha leaves it unstated that their daughter, Natalie, is not "walking and talking". She instead returns to "we laughed", the introductory phrase, with the time marker "now we laugh", as in after the "whoa". She then recounts a "game" of comparison, "well my kid", a form of boasting between these mothers and the other mother/ sister about what each kid can do. It starts from a place of parents together, "and we're just like…"

S: And now we laugh, and we're like, well my kid. And we're just like, well **my** kid still sleeps through the night.
A: Yeah that's true
S: Like and **your** kid is up seven times a day. Well **my** kid is walking. And we're like, well, shut up. {*laughing*} Like, this game not funny any more.

Samantha explains that they call a quick end to the "game" of comparison when the sister indicates a difference between the children appears that is too meaningful. "And we're like, well, shut up." There is no response and the best thing that can happen is for the parent of the "typical" child to also stop the comparisons. The moment of their child looking "better" because

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she "still sleeps through the night" has lost its gleam. "Still doing" may not be as good as "new doing", even if it is easier for the parents, since it indicates a lack of developmental progression through time. Again, stopping is required. For Samantha and Aurora, parents of a child who do not know if or when their child will walk with medically-endorsed certainty, for another parent to boast "Well my kid is walking" ends the "fun" of the "game" of boastful comparison.

Samantha is laughing as she says this last phrase, and "Like, this game not funny any more" engages with a comically-inflected near baby-talk by removing the verb "is". There is a stark contrast between "not funny" and the tone of how it is delivered and packaged in the story of "now we laugh". The "game" of comparing developmental milestones can no longer be as playful. Samantha ends the story of this experience and reflects again on the message of not comparing. She reinforces the conclusion that "you can't compare" in a new phrasing.

S: But that's it, you have to leave that comparison behind, really.

The change in phrasing highlights that comparison, in this social context, is not entirely avoidable. Again, it might not even be harmful in all circumstances. But for "you", a parent of a disabled child, your role is in stopping it and moving on -- "you have to leave that comparison behind".

Samantha then starts a not-quite-true story, a "could have been" account which parallels this "we laughed" account but without the laughter. Meanwhile, Aurora tries to head off the possibility of this "could have been" version as a place they don't even want to consider; she re-asserts the taboo of comparison and a tale of things being "upsetting" by appealing to its lack of functional utility. Aurora eventually shuts down Samantha's discussion of how "it could have been quite upsetting" to see another child meet more "milestones" more quickly than Natalie and eventually "surpass her".

S: It could have been quite upsetting to see a child who was just born…
A: Oh no, you'd go crazy.

S: … meet Natalie, be under Natalie's abilities, and surpass her, to the point where he's now taking care of her. Literally. We did a late Christmas like two days ago. And he scooped up some sweet potatoes and was trying to offer it to Natalie. He wanted to help Natalie, and I was like, oh, that's where we are {*subdued tone*}. **He's** taking care of her now.
A: But you can't -- you'll drive yourself nuts and there's no point.

Aurora's final admonition is more than a critique of comparison; here, the expression of any possible story of distress is disallowed as dangerous and pointless. Aurora is saying we can't even talk about the impact of comparison, the emotional difficulty of seeing it happen unbidden. Even if, or especially if, comparison is inevitable, talking about it (as in the "shut up" in Samantha's talk with her sister) makes it all the more dangerous. "You" in Aurora's interjections, is multipurpose: "we", "Samantha", "parents of children with disabilities", "me" (the interviewer and immediate audience). In even talking about this "you", or "we", will "go crazy" and maybe even drive ourselves "nuts", and nothing will be gained.

But Samantha's telling of the "could have been" also shows us an example of her own work in "stopping" the comparison, in "leaving it behind" when her child gets "surpassed" and left behind in developmental comparisons. In telling us "it could have been quite upsetting" she shows that she feels the sadness but then takes action to move her attention and emotional state in response. She tells us this to assert that it is possible to "leave that comparison behind", and that she has indeed done so. She is doing so in the retelling as well.

Aurora then brings her own preferred response to comparison and the possibility of sadness or upset by returning to an alternative temporal framework.[23] This framework is less restrictive and evaluative than the one she had suggested before ("if every day she does something different…"), and relinquishes the idea of predictable or even meaningful, linear,

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[23] See Ferris, 2010 and McGuire, 2013 for considerations of disability and temporality. See also Titchkosky, 2010, on the appearance of disability as "not yet" in the temporal registers of bureaucracy.

developmental progress. The subject of the action is once again Natalie, not the milestones or the parents or the professionals.

> A: Like, she's going to do stuff whenever the hell she's going to do stuff.

Samantha then joins in with the alternative framework while overlapping her partner's phrasing to propose a joining of the parent's temporal framework with the child's, in this case taking the "lead" away from milestones or other parents and children and giving it to their own, particular child.

> S: {*overlapping*} You've got to work on their time, yeah.
> A: And if you don't. If you are so interested in times and ages and all of that? You're going to…
> S: {*overlapping*} You're going to need to let it go.

Aurora and Samantha work together to explain that parents of children with disabilities need to move away from normative temporal measures such as "times and ages and all of that". You, the parent, need to "let it go". Comparison is perhaps something that you, the parent, are holding onto, rather than something that you can simply encounter and "leave behind". The level of implied parental control increases in the terms "letting go" of a possible "interest" in developmental markers – although, as we have also heard, comparison is everywhere as is the expectation that mothers must "do something" in response.

But as Aurora continues, she explains that this relinquishing of standardized markers does not mean that you give up on "pushing" your child to progress through time and ability. There is a return to focusing on "work" and "use", a return to a disciplinary mindset even as it is slightly removed from professional authority. Indeed, her next statement engages in fortunetelling to argue that parental comparison will actually hold the child's future progress back. Not "letting go" keeps the future from moving forward as far as it could for the parent and the child.

A: You're never going to … they're never going to get anywhere because you're focused so much on what they're **not** doing rather than what they **could** be doing, and what you can **push** them **to** be able to do. Like, and that's the problem, is that if you focus too much on soo negative? You're never going to see anything positive, like nothing. It's just all going to be.. bad. [*fake voice*] Oh she can't do this. She can't do that. Oh I wish she could do this. [*regular voice*} Well what's that going to get you? Nothing. Like, you're not going

S: Just frustration. And heartache, yeah.

In this passage, Aurora reinforces what Fisher and Goodley (2007) dub a future-oriented "challenging parent" narrative in which that parents need to work to get their child to work, with the common goal of the child achieving as many markers of "positive" development as possible. This storyline also reproduces an idea that parents have to/ can control their children's developmental accomplishment. Aurora asserts that this "positive" relies on parents not focusing "on soo negative", subsuming a part of the mothers' own emotional realities, as described by Rich (1995). There is a sequential interaction between parents not focusing on the negative in order to see the positive and push their child towards doing more "positive" things. Aurora even returns to Samantha's "it could have been" by mocking the "negative parent" voice with a fake whiney tone before returning to reassert the pointlessness of negative emotion and expectation. "Well what's that going to get you? Nothing." Samantha then joins in to point out that the "negative" story also has a particular emotional toll on the parent: frustration, heartache. Aurora and Samantha here bring the child's interests and the parent's interests back together, in that the frustration and heartache of the parent leads to an inability to "see anything positive" in the child and their abilities, and a subsequent inability to "push" for the child to "do more".

Aurora then agrees with Samantha in a series of phrases that start and stop and restart and themselves consider a possible present and future, a conditional "it would be". She explains that "It would be awful" for the parent to get stuck in "comparison", and reasserts what parents need: "to just watch her and to see her and to know her."

A: Well that's it! You're just going to actually go nuts. And like then you think, well what's the poi... It would be awful for you to be any sort of, like. Any comparison to anything? You just can't do it. So, to just watch her and to see her and to know her? That's all you need.

In recounting another narrative anecdote, Samantha then describes having to even "leave comparison behind" when visiting a group of parents and kids with the same primary diagnosis as their daughter. There is no safe space for comparison, either when staying still and watching, or in the retelling, as emotions come up again, even in settings where "disabled children" constitute the "norm".

S: We come back to that, because we, I knew, we sat. One of the first times we hung out with a group of kids, like, with the [Advocacy Organization] group, we were seeing kids the same age as Natalie. Who, again, even compared with kids with [same diagnosis], is verrrry developmentally delayed. And so sometimes you're just like, {*sigh, then whisper*} Man. Like… ohhh. {*normal voice*} It, but, it's hard but you have to bring yourself out of that, fast. Like, you can't let yourself wallow in that and be like… you have to..
A: No, you're not going to get anything

Samantha's "but it's hard but you have to bring yourself out of that, fast" shows us, once again, that parental efforts need to include marshalling willpower and energy to push aside the thoughts and feelings that you otherwise would "wallow in", to find a new volume and certainty in the telling. The subsumed and undesired comparison and sadness appears as a whisper and a sigh. As she talks at full volume again, Samantha again appears to be slowing, at risk of "wallowing" in muddy emotions that are both "hard" to feel and "hard" to bring yourself out of. Once again, Aurora intervenes and returns to outcome as the rationale for Samantha's "you can't let yourself wallow in that" begins to trail off. Aurora fills in, "you're not going to get anything" unless this comparison can be stopped, this wallowing ended, this sighing halted.

The two parents then conclude once again by revisiting the need and usefulness of an alternative temporality: "Natalie time". Natalie time is how they structure not only what they try to look at and what they do but also how they make meaning and identity as a family group.

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S: No, but again, it's the same thing, you have to remember, that. She's, we just say Natalie will do everything in Natalie time. And that's the definition of our life, is we run on Natalie time, like

Samantha offers "you have to remember", and says again and again, "Natalie will do everything in Natalie time." This belief in the hope and purpose of "Natalie time" becomes more than a coping strategy to form an identity: "And that's the definition of our life, is we run on Natalie time". Difference from other people or families becomes child-centred and temporal, and unites "our life" as a family.

In a brief coda to the narrative of questioning how development and progress is defined, Aurora interjects her assertion that Natalie will meet standardized measures of progress. Thus the importance of "milestones" comes back, but with a revised temporality and with the child's agency and volition -- and the parents' unwavering commitment to "pushing" and "believing" and "not wallowing" -- at its core.

A: {*overlap*} And she will, too. Like there's no question that…
S: {*overlap*} Oh, and she's done everything we've, we've yeah
A: She's going to walk, she's going to talk, like, she absolutely will.
S: {*overlap*} It's just has to happen when she wants it to happen. That's it.

In this exchange, the predictions of milestones met echoes professional frameworks and directionality, but without professional authority. The parents substitute their own belief and conviction, and the recounting of Natalie's past achievements, for professional credentials.

As the interviewer, I audibly mull over the idea of Natalie time, and the parents explain their alternative temporality as a move from standardized judgments and predictions.

M: On Natalie time.
A: And that's fine! And like… we got nothing but time.
S: Natalie will do it in Natalie time.
A: And that's it, and there's no...
S: Yeah.
A: …Right or wrong.

In talking about "Natalie time", Samantha and Aurora move from a narrative of restriction for parents as "you" -- you can't, you have to -- to a narrative of abundance for Natalie and for these particular parents: that's fine, we got nothing but time, Natalie will do it, that's it, there's no right or wrong.

In this exchange, Samantha and Aurora show the complexity of moving through dominant discourses of how parents should feel and behave when their child is identified as "different" when using expected temporal measures of progress and development (see Cohen, 2009). In their disagreements, their narrative examples, their use of "could have been" stories, their evaluation of certain gazes as damaging and pointless, and their creation of alternate ways of measuring and evaluating, this exchange shows that parents have no simple option of submitting to or denying dominant discourses of desirable reproduction. Instead, the very impossibility of a single storyline or set of emotions shows the chinks in the armour of these larger storylines when it comes to parents' emotional and practical realities. Samantha and Aurora are using narrative resources that are intelligible within dominant and expert-driven storylines, but using them to tell emerging, conditional, and incomplete stories. These stories, they hope, will help them combat totalizing and deadly modes of comparing and valuing people, including themselves and their daughter.

Where: Presence, Absence, and "Subtle Neglect"

Dominant discourses on disability and parenting do not only address developmental "whens", but also relational "wheres", as people are seen to be "close" or "distant", progressing "toward" or "away from" desirable outcomes (see McGuire, 2013). Following Sara Ahmed's queer phenomenological orientation of "bringing what is 'behind' to the front" (2006, p. 4), the interviews with parents offer opportunities to question the spaces and background in which professional encounters occur. While scenes described within the parent interviews varied

widely, many discussed places and encounters between parents and professionals, and the challenges of moving across the different professional expectations and environments.

An excerpt from an interview with Jan and Annette uses a particular scene to show how a professional encounter (in a particular time and place) highlights larger discursive beliefs about the spaces where disabled children and their parents should, and should not, be. Throughout, notions of proximity and contagion bring the parents' attention to the spaces in which difference may be seen and (re)produced, and to the ways that difference can be seen to "spread" within and across kinship relations. This encounter also demonstrates how parent narratives can repurpose the language of grief and trauma to actively challenge notions of "desirable reproduction".

Annette and Jan recount an encounter when their son, Simon, was at his second or third visit at a private occupational therapist's office to help him with his handwriting and other fine motor skills. Annette starts the telling by asking Jan, "Remember that time when we were at the occupational therapist's office?" She then describes the scene, accounting for each parent with each of their children, one (Jan) in the therapy room with the designated "patient", Simon, and the other parent (Annette) caring for the younger child, James, in the waiting area. Already we see that what happens in and around special needs service systems cannot be restricted to the formal encounter between patient and clinician in the designated clinical time and space, to what might be written up in an assessment or clinical note. This encounter takes place in a liminal zone, a "waiting area" where the one parent and sibling are not only waiting, but also playing. We see both parents also engaged in work of waiting and being with their children, although only one parent might appear in the clinical record of progress notes, if at all. We can assume these parents had already organized their individual and family activities to prepare and bring both children and both parents to the appointment, but until then they had assumed that only one

child, the child "in there", the realm of official therapeutic scrutiny, was going to be under the professional's gaze.

In other words, in the waiting area, Annette is not waiting to hear what the therapist has to say about her younger child. Annette describes the OT as addressing both parents, so we are to assume that Jan and possibly Simon have "come out" of the room with the therapist, where James is already (and other people might be) although the intended audience for the OT's statements is the "us" of the couple being interviewed.

> Annette: So, and we, we brought James in there, so he's playing with me in the waiting room and I think you [Jan] were in there. And [the occupational therapist] comes out, and she's like, oh you know, and she sees little James, and she says to us, basically, you have got to get that kid -- James -- into some programs. Preschool, daycare, anything. Because right now, his role model is an autistic older brother. And, like, he's going to, like he's not autistic, you can see that he's not autistic. And
>
> Jan: He's going to pick it up.
>
> A: He's gotta, like, get away from this kid. Pretty much. Was what I got. No, what else? And, yeah! That we subtly neglected James.
>
> J: 'It's called subtle neglect.'
>
> A: Was what she said. I was just like [gasping for air noise].
>
> M: In the waiting room!?

Annette alerts us that the occupational therapist (OT) offered unexpected and apparently unsolicited advice on how to parent their youngest child, James. She introduces this intrusion with several introductory phrases making the introduction of the topic seem laboured for the OT. "And she comes out, and she's like, oh, you know, and she sees little James, and she says to us, basically". Annette's tone makes the therapist sound as if she is speaking off the cuff, in a casual but calm tone, with no ill intent, just inspired by seeing "little James", in contrast with the devastating impact of her words.

The content and tone of their exchange with the OT draws directly from dominant, medical and educational notions of desirable reproduction. According to the occupational therapist, the presence of their eldest child, who has received an autism diagnosis, might reproduce his "autistic" (read: undesirable) traits and behaviours in his younger sibling, through his proximity and "role model" status. The therapist exhorts the parents to take on additional work and enlist more resources to prevent this reproduction of autism from occurring. She tells them to sign their younger child up for -- and we can assume find the financial resources to fund -- additional programs, such as preschool or daycare. Annette suggests that "anything" would do, but that there was a sense of urgency. They were being told they had to do something, and right away.

There is an uncertain division between the two children that Annette presents as troubling the therapist. As she explains what the therapist was saying, Annette tries out several phrases indicating that therapist saw a categorical difference between the two kids prefaced by an unfinished prediction of James' future: "And, like, he's going to, like he's not autistic, you can see that he's not autistic. And…" So the two children are placed in separate categories, one "autistic", one "not autistic", calling on either "you" the parents or the general/ omnipresent "you" to underscore the obvious visibility of this difference. These two children are not the same. Nevertheless, this divide, in Annette's telling, is framed by a looming uncertainty about James' future: "he's going to…".

Jan then picks up her partner's unfinished prediction: "He's going to pick it up". Continuing the syntactic structure of Annette's final series of phrases, "he" is still James, the child that (everyone can "see") is "not autistic". But "autistic" has changed from adjective to an implied noun. We had "an autistic older brother" and a "not autistic" younger brother. Now we have an "it" that is unnamed but immediately interpretable to all as the thing that makes non-

autistic more, or entirely, autistic. "It" is unclear in its exact identity, as either "autism" or "autistic behaviours" or "autistic traits", but unlike the framing of those who are or are not "autistic", now we have a possibility that James will "pick [something] up", and it will be to his detriment. "Pick it up" can be read as instructive ("he will pick the alphabet up when he goes to school"), social ("the things he picks up from his friends!"), or as contagious ("I worry he picked something up at school"). This ambiguity in the expression links it with both with the suggestion that James needs a different educational and social experience – preschool or daycare – and also with the medicalized setting of the waiting room and diagnostic categorization of James as "not autistic".

When Annette recounts that the therapist communicated, "He's gotta, like, get away from this kid" we once again move away from the "it" of autism/autistic traits or behaviours and back to the children. James continues as the assumed subject. To this point, Simon has been present as a threat, but not as an active agent. He has been linguistically left in the other room, and indeed we never learn how close he was to this encounter, nor whether he witnessed the exchange. Annette here brings him in again, still as the threatening object, but now as "this kid" rather than "an autistic brother" or the implied source of "it". "This kid", Simon, reflects the designation of James as "that kid", flipping around the associations of proximity so that Simon is represented as closer (this one) to the OT's perspective, and James as the more distant (that one), but, it seems, not distant enough. In voicing her understanding of the OT's statement, Annette highlights the imminent threat of contagion the OT sees in Simon's physical proximity to James. She uses a different social register in this statement from before, shifting from "you have got to get that kid" and "you can see that he's not autistic" to a more informal and adamant "He's gotta, like, get away from this kid." In this changed phrasing, and then in her subsequent phrases, Annette backs away from the certainty of her retelling. "Pretty much. Was what I got".

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She was there, as was Jan, but she flags that her words should not be interpreted as exact, or as objectively removed from her own memory and understanding. She offers me, the audience, the possibility that she may have "gotten" something wrong, and that this less formal and harsher summary was how the therapist's words were received but may not have followed the OT's wording or intent.

Annette then adds to her summary of the encounter. "No, what else? And yeah!" Here her phrasing shifts back to the more professional/ formal register: "That we subtly neglected James." Jan then supplements and supports this addition by apparently quoting the OT: "It's called subtle neglect". Annette endorses this quotation by finishing up "Was what she said". In the change between Annette's summarizing statement and Jan's quotation, the syntax becomes depersonalized and more diagnostic/ clinical. "That we subtly neglected James" puts Annette, Jan, and James in a particular type of relationship. "It's called subtle neglect" asserts a categorical statement from expert authorities beyond the room, about the types of relationships seen among certain abstracted parents and certain abstracted children. The OT is, in this phrasing, informing Annette and Jan that their behavior can be diagnosed in a professionally known, expected, and pathologized way, and that she, as a professional, has the authority and status to do so.

Proximity and space are implied in this unofficial diagnosis. "Neglect" identifies a lack of parental attention and presence, here toward James, in direct contrast to the presence of feared attention and proximity of Simon as an "autistic brother". In keeping James in the presence of Simon, and simultaneously in their own presence rather than at preschool or daycare, the OT claims that Annette and Jan are not truly present at all. "Neglect" is a category of child maltreatment that is broadly recognized as a form of extremely inadequate parenting that might even result in the removal of a child from parents' custody. "Subtle neglect" modifies the

accusation, suggesting that Annette and Jan did not likely intend this lapse in good parenting. It also suggests they, as non-professionals, would likely not recognize their own inadequacy. "Subtle neglect" in this case constructs a parental absence in *not* moving away from the rest of the family for at least part of the day. We have a "neglect" from too much attention, proximity, and togetherness.

Thus, we have moved from a statement about what Jan and Annette need to do differently in order to keep their younger child from "picking it up" to an accusation of their significant inadequacy as parents. And the threat, from this "subtle neglect", once again, is that their younger child might be too close to their older, and might become more like him. In positioning this feared proximity and similarity as a demonstration of parental "neglect", the OT reinforces a very harsh assessment of what traits, children, and parental behaviours are desirable, and which are so undesirable as to be harmful.

The emotional impact of this statement is clear in the interview. Annette recounts "I was just like" and then makes a loud and prolonged gasping noise. This gasping indicates not only emotion but a physical response to the OT's words, where she was temporarily unable to speak or do anything but try to breathe through the shock. I then asked, probably due to my own understanding of space, "In the waiting room?" This is an odd verbal clarification, in retrospect, but I remember feeling that this was an unprovoked and unanticipated attack by the professional in what is usually a more "public" space, and in front of their children, and that this could only add to the shock and the inability to speak back that Annette's gasp communicated. I was picturing myself as a parent, and also as a professional in this situation, and neither part of me would want such an exchange in a waiting room. Jan seems to endorse this focus on the space and timing of the exchange with a hearty "Yeah."

After coughing following her gasp, Annette comes back to words and offers a clarification: "Nice lady" to which Jan agreed, "Yeah". In listening to the recording, it is clear that these were not sarcastic dismissals of the professional, but suggestions that 'in spite of' this exchange she was still someone they valued and worked with – although, given the difficulties parents report in finding service providers, they might have been very motivated to find ways to work with this OT (see Chapter 3). The two parents then try to find other ways of reading the exchange, possibly attributing the OT's statement to a different cultural framework than their own, although Jan contradicts the cultural attribution Annette initially hazards.

> A: I don't know if it was just a [European country] thing, bit of an accent there, but she was blunt, right. And, 'best for everybody', right?
> J: [Other ethnicity], that's what she was.
> A: Ah, okay. But then I felt like we had to debrief that for like an hour!
> J: Yeah.

This shorter exchange can be read as a way Annette and Jan are explaining the interaction with the service provider, trying to move away, once again, from the idea that the OT could or should have known how hurtful that statement would be to them. Indeed, Annette suggests the OT thought the suggested parenting arrangement would be in "everybody's" best interests, rather than harmful to any of them. The parents' reference to the OT's accent and background may imply she received training elsewhere and be seen to introduce some questioning of her professional competency. Throughout, they are removing the OT's intent from the individual/professional to the cultural/contextual, but then reassert that the impact was very personal and, indeed, costly. "But then I felt like we had to debrief that for like an hour!" The larger discourse about what and who should be reproduced is not attributed entirely to this individual, but this does not dilute its effects.

As Annette and Jan invoke trauma discourse with this use of the word "debrief", their use of traumatic language is in direct contradiction with dominant 'taken-for-granted'

expectations of parents of children with disabilities. The trauma in such depictions is usually one in which parents are "upset" solely because of their child's diagnosis and disability itself, often requiring reassurance from a professional (see Gibson 2014f). While here we, once again, see trauma in an account of parents of a child with 'special needs', the trauma is not attributed to the child's diagnosis or disability. Instead, the trauma emerges from the suggestions and accusations of a professional within special needs service systems and the differential valuation of their two children, their parenting, and their family as a whole. The narrative content of dominant discourse is repurposed to critique the very system from which is emerges.

In this passage we also see Annette emphasizing the time and energy that is required, not only in getting the family to places and talking to people and making decisions, but also in dealing with the feelings that remain after these encounters. The conversation in the waiting room was brief, as we hear it recounted, but it required extra time and "debriefing" from already busy parents before they could move on with their other activities. Again, throughout the recounting, we see the time and energy and emotion that contending with one dominant storyline/ interpretation of their family and parenting "costs" them. Moving away or back from or through this story takes joint effort, in addition to and lasting long after the actual encounter.

Importantly, however, it is also through this work and effort that Annette and Jan do not stay in the language of trauma and debriefing. After a further invocation of the trauma – "It just killed me" -- there is a marked shift as Annette pushes away the notions of desirable and undesirable reproduction evident in the OT's account. She "comes back" to her particular children and away from diagnostic categories and professional opinions, in language that suggests awakening from unconsciousness or arriving in a new place.

> A: It just killed me. And then I finally came to -- Simon's a great older brother! A great older brother. And, you know, James chews his clothes and chews shit like Simon does, and I don't know if it's because James is anxious or because he's

copying him. I think it's because he's copying him. And that's kind of unfortunate,
because it's gross. But he's a great older brother.
J: Yeah.

When Annette explains that at first the experience "just killed me", she states the deadly impact
of certain moments where children – and in this case, their parents – "don't measure up" within
dominant and expert-driven value systems, echoing Samantha's assertion in the previous
excerpt: "Comparison will be the kill of you". Annette describes how this assessment of her
family was unliveable for her, as a parent, until she could snap out of it or move away from it
"And then I finally came to…."

With the repetition of "Simon's a great older brother. A great older brother," Annette
reasserts her own knowledge of her family and their relations beyond the OT's assessment, and
in the process reasserts Simon's personhood and value. Simon has a name for the first time in
the account, and he is the subject of the repeated phrase. Annette does not reify the division
between her children, and even states that James may, indeed, have learned to act like his
brother, but that this is not a reason to keep the children apart or take away the "great older
brother" status. The possibility that something positive could be "learned" from an autistic
brother is opened up.

To be sure that I understand her perspective on this event and on her children, more
generally, Annette clarifies "You know what I mean?" She does know, as does Jan, that I also
have two children, one of them with an autism diagnosis. This knowledge may have facilitated
the entire narrative, the expectation that I would know what she means, and be able to identify
with the strong emotions the story recounted and evoked for these parents. Annette then clarifies
her own stance:

A: You know what I mean? So I don't care if it's about autism or anyway, I did say. But.
Uhhhh. That was really
J: That was hard. Yeah.
A: That was a really hard moment. And she didn't mean it that way.

J: But we sort of took it, like, hard. Yeah.
A: That was like, ohhhhhh.
J: Yeah, subtle neglect.

As Annette trails off in explaining her verbal response to the OT in that moment, I learn that this immediate and verbal response is not the important part of the story for her and for Jan. They are back with the emotional upset, the impact of the OT's words in that moment and as they retell it, regardless of the OT's intent or their own beliefs about their children. They move away from blaming the individual professional, once again clarifying that "she didn't mean it that way", but the impact is the same, and almost beyond words. As a conclusion to the longer narrative, Jan reintroduces the OT's term "subtle neglect" as central to how, and why, they "took it, like, hard". Even if, as Annette says, "I don't care if it's about autism or anyway", the impact of others who **do** care about if behaviours can be categorized as "autistic" is very real.

In a coda to this narrative, however, Annette and Jan move back to a critique of their own accusation, and a normalization of their parental inadequacies and their children's differential treatment. This time they cite an encounter with a different professional.

A: And I'm telling my therapist and she's like, {*whisper*} Every second child is subtly neglected. {*J and M laugh*} That's what she does. She normalizes everything for me. Every kid is like that! It's all fine.
J: And wait until you get the third one. The third one is not subtly neglected. {*all laugh*}. Explicit neglect!
A: {*coughing/laughing*} Outwardly!

This passage moves quickly from almost inarticulate pain to riotous and communal laughter. In changing the meaning of "neglect" into something that can be laughed about, the OT's traumatic accusation is transformed into a joke among the three of us, leaving us all laughing at the impossibility of meeting dominant standards of what parents should and should not do. Children are no longer presented as just "autistic" and "not autistic" but as children in the context of a family that, inevitably, has limited resources and differential treatment. The pathology of the accusation, and the pain of the response, are both diffused.

What: 'Yuckiness' and Unwanted Conversations

What is relevant in a discussion of disability? Throughout the interviews, parents struggled to explain their experiences to me in ways that would reinforce particular lines of relevance and show me why certain stories or topics were or were not important. I turn here to examining a passage in which a topic is presented as difficult to explain, risky to address, and costly to tell. This parent makes sure that I understand enough about her own history of "being asked" in order to contextualize her not wanting to tell, or only wanting to tell if it will be understood in a particular way. **What** parents share as important in their experiences of parenting disabled children as LGBTQ individuals is often shaped in anticipation of the particular exclusions and harmful interpretations common to dominant beliefs about "desirable" parents and "desirable" children. The emotional impact of telling when only certain questions are asked, or only certain answers are understood, comes across in how the parent shapes her narrative of not wanting to tell.

Common to many dominant discussions about "burden" in parenting a disabled child is the belief that a child's disability strains parents' couple relationships. In many presentations of this discourse, parents' relational dissatisfaction or dissolution can be listed as further evidence of the 'problem' of disability and its inevitable, negative impact on caregivers, an impact that is seen as unconnected to any systemic or socio-cultural factors. Indeed, a number of parents I spoke with addressed ways in which their couple relationships – both same-gender and different-gender or "heterosexual" relationships – have been negatively affected or stressed in the process of parenting and interacting with special needs service systems.

In the context of more evidently "queer" relationships, such strain or separation can have particular connections to larger discourses about the instability (read: undesirability) of LGBTQ relationships, and as fodder for an argument against queer parenting (Gibson, 2010, 2013,

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2014a; Riggle et al., 2010; Riggs, 2007). In this section I consider an excerpt from one recently

separated parent, Lenore. Lenore talks about the dissolution of her lesbian/queer marriage and

couple relationship as both something that is directly connected to parenting a child and

something that is tricky and risky to discuss, even though (or particularly because) service

providers often ask that she do so.

This conversation occurred after I had asked Leonore who was in her family and

clarified what legal custody arrangements they had. Here, I start to qualify the reasons behind

my question, probably because I sense Lenore's reluctance on the topic and did not want to

appear to be pathologizing or prying. In this rationale, I cite the curiosity of "others" and "legal

status" as (in retrospect, rather unsatisfactory) reasons behind my own questions. Lenore then

picks up on my mention that "people want to know" and goes to recount her struggle in talking

about the dissolution of this relationship with a range of providers/ questioners.

> M: I'm just sort of thinking of all those interactions with service providers and some of
> the texts that we talked about, sometimes people want to know what the legal status of
> all those legal arrangements are.
>
> Lenore: Yeah. Probably one of my least favourite things to discuss. Because I think that
> one of the. I don't know if you want me to answer anything about the service provider
> piece, but when. For example, uh, at the school, or Sophie has a psychiatrist/
> psychologist team, and she has a speech therapist, and she has a, our pediatrician, and
> she has occupational therapy at school, and she has all different sorts of the respite
> workers, respite services, things like that.

Here we see Lenore starting to make an explicit connection between "one of my least favourite

things to discuss" and "Because" but the explanation is suspended. She apparently shifts back to

clarifying the scope of my own interest, and then, reassured (nonverbally) that I do want her to

"answer anything about the service provider piece", she begins to list examples of providers that

she and her daughter, Sophie, interact with. As she outlines the frequency and number of her

interactions with service providers, the relevance of this list to why she does not like to discuss

her separation is still tentative, but we do get a sense of how often she is asked to answer questions and explain things. We also sense that, perhaps, I am another person asking questions and trying to make easily summarized connections between her child's disability and the dissolution of her relationship – and that I was not telling her anything new by explaining "other people's" curiosity about the timing and legality of family changes.

Lenore then explains further, about "one of the really big challenges is," and as the audience I might anticipate more of the reason why this is a difficult topic, but the causal connection is still hesitant and unclear. Here Lenore brings to the foreground the interpretation that the "breakdown" of her marriage was connected to "the stress" of co-parenting a child with disabilities. This explanation is initially framed in terms of a shared opinion between co-parents, but then she suggests it is possibly just the "soon to be ex-partner's" perspective, since her ex was the one who decided to end the marriage.

> One of the really big challenges is, we -- at least my soon to be ex-partner -- attribute the breakdown of our marriage to the stress of disability parenting. Like, that is what she says. She says that is the reason she had to leave. She could not cope living with a child with such serious disabilities. And having no time, ever, to herself. That's what it felt like.

Lenore continues to recount her partner's experience in terms of burden narratives using terms such as "the stress of disability parenting", "the reason", "could not cope living with a child with such serious disabilities", "no time". She frames this as someone else's experience, apparently, but ends with "That's what it felt like". As listeners, we have to presume this "felt" comes from what her ex-partner has communicated to her about why she was leaving. We still do not know what Lenore, herself, "felt", although we can postulate what feelings being asked to recount this "breakdown" over and over to different professionals might then bring up for Lenore.

Lenore then brings a more systemic analysis together with her ex's explanation of the reasons for separation. In this new formulation, she recounts that while there are so many

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service providers asking questions, there are, in other ways, not enough services. This becomes the new "problem", beyond "stress" or "serious disabilities".

> And we could not get -- she has chronic health issues and we could not get enough respite services or support or anything like that to be able to help fast enough, I think, to be able to meet her need. And so she was really frustrated with that because she said that she didn't want our relationship to break down but it did, just for plain old, what we ended up doing for the last about two years of our relationship was just tag teaming.

Here Lenore explains more about how the "disability parenting" is not the only presence of disability or illness in their lives. When one of the mothers also has "chronic health issues", the absence of services ostensibly for the child becomes a more acute problem. This highlights the possible assumption in service provision that only one person can have a service need within a family. But here Lenore flags that she is offering her own interpretation, "I think", about meeting "her need", and not necessarily repeating what her partner had offered as explanation. She then returns to the language of the partner "because she said that she didn't want our relationship to break down" and offers a new way of explaining the reason: "but it did, for just plain old, what we ended up doing" when they were "tag teaming", or switching off with their daughter. For the first time, we hear "but it did, just for plain old" as a mundane explanation, and she turns to the everyday experience of living with their child.

Lenore then continues with a matter-of-fact recounting of everyday life with their child, but introduced and framed by "Because our child has very serious problems". The everyday demands of parenting Sophie become framed in "very serious problems" and "reason for marriage breakdown", but also by her previous statement that "we could not get enough respite services or support or anything like that". Here she explains why respite or other supports could have made such a difference in their everyday lives, and perhaps in their marriage.

> Because our child has really serious problems and in order to even be able to go to the grocery store or be able to go the bathroom in private, the other person had to be on. So we never saw each other. And when we did we were exhausted.

This passage more clearly circles toward explaining the "reasons for why the marriage dissolved" and "service provider piece", and focuses on presumed universal and everyday experiences such as going to the grocery store or the bathroom with a lens of constantly having to "be on". She describes the impact of everyday exhaustion. She still does not explicitly explain why she so dislikes talking about this topic.

Lenore then offers another piece of the explanation by telling another causal story, explaining why they moved to Toronto. In this explanation, she also provides an example of "really serious problems" and "not enough support".

> So we had some promise of… why we moved to Toronto is my in-laws live north of Toronto. And they had promised they would help. They took Sophie a couple of times and they were like, whoa, we can't do this.

This smaller story describes significant attempt, a family move, in order to get support as a family, this time outside of formal service systems. But, once again, it also describes another failure in support, where the "care providers", here Sophie's grandparents, found they could not continue to offer the promised help. Lenore has listed many people, from her former partner to different professionals to family members, none of whom have been able to meet the "needs" of their daughter, or of Lenore herself.

Only once I, the listener, have enough of the background about Lenore's marriage, her daughter's everyday supervision and support needs, her partner's feelings, their exhaustion, and especially of repeated failed support from systems and from extended family, only then does she come back to why she does not like to talk about the marital breakdown.

> And so we couldn't get the right kind of help fast enough, I should say, to make the difference. And then, so, I'm in the process, since last summer, of dealing with service providers who always ask, 'Are there changes in your family structure?' And I have to say, 'My spouse and I have separated.'

Lenore now brings together the pieces of narrative that she has previously laid out, linking them through "And so" structures. She introduces this fuller explanation by repeating her previous

statement, "And so we couldn't get the right kind of help fast enough" and then adds another

"And so, I'm in the process" when re-introducing service providers. Here the providers are

"always asking" about "changes in your family structure". In going from the tone and narrative

particularity of "why she had to leave" and "whoa, we can't do this", to "changes in your family

structure", Lenore shifts from an informal/everyday to a professional/clinical register. This shift

to a professional discourse suggests that the many providers all have forms and training that

make "changes in your family structure" a category that needs to be asked about and noted. The

effect that Lenore notes, however, is not abstract. "And I have to say" suggests this is a reluctant

and not voluntary disclosure of a separation, a requirement for those much-needed but elusive

and insufficient services. I am reminded as the interviewer that I have just started our

conversation by asking questions, yet again, about her family and how it has changed.

Lenore then returns to "challenge", a term she had introduced as part of her explanation

of why this is difficult to talk about before explaining her ex-partner's rationale for leaving the

relationship. Here, however, the "really big challenging piece" is in meeting the formal and

abstracted notions of "changes in family structure" and the questions it imposes. She starts to

question the questions. Why is this topic, this change, something professionals are so eager to

discuss? And what interpretations do they bring to her answer?

> You know, that's also a really big challenging piece. Because to go right to I think we're
> handling it as well we can, doing the very best that we can given the whole situation, that
> it was like uh, it's not as if anybody's offering me any extra services or supports or
> anything like that.

Lenore describes feeling the need to defend how her family is handling this transition, to

reassure others about what has been a painful and emotional "change in family structure" for

Lenore, and also to point out that, while the lack of services may have contributed to the end of

the relationship, providers certainly don't seem to be recognizing the gap or its impact.

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What is more, services providers who are asking these uncomfortable questions are not offering anything more to her based on her responses. Service providers, Lenore implies, might be more justified in their questions about "changes in family structure" if they were actually going to offer "extra services or supports." Notably, Lenore is still presenting the "doing our best" narrative in the interview rather than illustrating about what might not be going well for her.

> Now I'm doing this on my own, for the most part. With Izz taking Sophie every other weekend, which is surprisingly good respite for me. Which is interesting. Something we didn't have before.

Lenore highlights that she actually has more everyday work, on her own "for the most part", and that the only change in her support is on the alternating weekends when her ex has Sophie stay with her. She pauses in her narrative to note this change as "surprisingly good respite for me. Which is interesting. Something we didn't have before". Only through the dissolution of the couple relationship could they find additional "respite" as individual parents.

But the encounters with service providers have ongoing emotional ramifications in Lenore's everyday experience. Here she starts to summarize but struggles to find the exact word to describe how these interactions continue to make her feel.

> But there ends up being um, almost like a, I'm kind of embarrassed, not that I'm embarrassed but an interaction that happens like, 'Oh, poor Sophie, her family has split up, we'll watch for, if she has bad behaviours or challenging behaviours or things like that, it could be because of the divorce you know.'

Lenore here describes a quickly developing process of attribution in which her daughter's well-being and behaviours are seen as always already *in response to* the parents. The possibility of embarrassment, of being caught doing something socially censured, is floated but rejected as not quite encompassing Lenore's feelings. Perhaps she knows that she is being asked to be embarrassed but that this has its own assumptions of parental wrong-doing as seen in "Oh, poor Sophie". This interpretation of "change in family structure" leads to a particular kind of

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scrutiny, as the professionals "watch for" particular behaviours with a causal explanation on reserve. Thus while Sophie's behaviours may not have been deemed significant enough to respond to with additional services, and may have formed her ex-partner's rationale for leaving the marriage, they may now be seen as "more significant" because the cause can be attributed to her parents and her "changed" family structure.

The relevance, the "what", of the parents' queerness becomes most explicit in Lenore's concluding statement. Indeed, given the way that "child outcomes" are framed as the common concern in debates and research on LGBTQ parents, both "bad behaviours" and "separation" can be framed as part of anti-queer parenting discourses, regardless of the individual providers' intent in the room.

> And some of this stuff is all normal and natural and any child who goes through divorce would get that. But there seems to be some level of just yuckiness of it, when discussing queer divorce with people who are not queer. I just don't want to have that conversation. I just don't want to have it. Yeah.

Lenore starts with an allowance that "some of this stuff is all normal and natural" and would be said in response to "any child who goes through divorce". She conveys that some of the "difficulty" she faces here in her encounters with providers could be part of separation and divorce more generally, and not necessarily only about disability and queerness. Perhaps this is the interpretation or objection she anticipates from me, or from other readers/ listeners, including the providers themselves.

Then Lenore returns to the affective realm and subjective significance of her own experience. With "But there seems to be some level of just yuckiness of it", she echoes the statement about discussing her marital dissolution as "one of my least favourite things" from earlier. By prefacing her following statement with "but", she asserts that the "normal and natural" explanation is not sufficient to account for her subjective experiences in answering providers' questions and anticipating/ responding to their reactions. There is no explicit account

that she highlights where providers start by attributing Sophie's problems to the parents' queerness, or hold the parents directly responsible for causing their daughter pain through their queerness and divorce. And yet her interpretation -- her feelings of "yuckiness", her observation of what "seems to be" -- is central to her explanation.

Lenore highlights the importance of facing "not queer" questioners as key to the "yuckiness". She asserts that in talking to "not queer" people about her "queer divorce", there is a different emotional and interpretive tone than in talking about "not-queer" divorce or in talking with "queer people". In talking with me, a researcher she knows to be a queer parent of a disabled child, she ventures to rely on an emotional and overtly subjective explanation of how out-group questioning from professionals can "seem". She assumes or hazards that I will understand this as a reliable and meaningful explanation. Indeed, she takes the chance that I will understand that queerness does not automatically equate to divorce, and that queer divorce does not share the same sociocultural meanings as non-queer divorce. She finishes with a repeated assertion of not wanting to talk about "that conversation" with non-queer service providers – and possibly with me as well: "I just don't want to have that conversation. I just don't want to have it. Yeah." And yet she has had that conversation with me in letting me know how and why that conversation causes "yuckiness".

In her story of ongoing professional scrutiny and of unmet needs both contributing to and continuing following her divorce, Lenore's presentation of "yuckiness" offers a perspective on how dominant anti-queer and anti-disability discourses operate, an explanation that goes beyond accounts of outright verbal slander or denial of service. Instead, the tone and environment in which questions are asked and answers received emerges as the focus. Notions of desirable reproduction circulate in the assumed, the unasked, and the perpetually questioned aspects of Lenore's everyday experience, as well as in how she feels when called upon to

answer. In asserting that she "does not want" to talk about this, she makes us understand that she may have to talk, and that she knows she cannot fully restrict the interpretation that others bring to her words, to what they think she is talking about. By flagging the power relations and concomitant interpretive frameworks into which her accounts are questioned and received, she asks that we, her audience, question what we ask and how we hear the response. What do we believe is relevant to a particular parent, child, or family, and why? What emotional impact will these beliefs of relevance and causation have on particular parents in a system of scarce and insufficient resources? What explanations are we not even looking for?

Conclusion: Narrative Resistance

In this analysis, I build upon the work of Fisher and Goodley (2007) to the extent that I use parents' narratives to show the inadequacies of individualistic, linear, disability-as-tragedy scripts, or future-oriented "challenge" narratives that prioritize expert-led efforts toward "normalcy". However I have also been influenced by critiques from Ruth Bridgens (2009) that we need to take into account the ways that parents have real limits on their narrative and material resources. Parents should not be typecast as uniquely "creative" and "empowered". My encounters with parents and their narratives in this project reinforce that there is no singular storyline of parenting and disability. Nor is there a stable duality of "dominant narrative" and "counternarrative". It is dangerously reductive to see parents as only and always presenting empowered narrative creativity when there are so many social and institutional forces that impose material constraints on how parents can talk, think, and behave, even as they tell stories about their families to a researcher. In these interviews more than one set or series of emotions, and more than one narrative structure, might be considered "dominant". The stringent requirements of constructing "desirable reproduction" within complex histories and relations may make a coherent narrative unattainable for all parents.

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I find the work of Judith Butler (1993, 1999, 2004, 2005) particularly helpful in steering between seeing parents' narratives as "only" counternarrative or "only" reproductions of dominant stories. Butler highlights that there is no possibility of a pure resistance to any discursive stance, and talks of the "resources inevitably impure" that we all rely upon in the construction of subjectivity and identity (Butler, 1993, p. 241). Since we all act and create meanings within a discursive sociohistorical context, we cannot escape the meanings that are available in our place, time, and particular embodiment, but we also reproduce and repurpose these very meanings in our own daily lives. Thus parents in this study cannot avoid broader discursive meanings and associations of terms like "diagnosis", "mother", "denial", "future". The narrative format and content have both been shaped by what has come before, and parents themselves contend with the connections and causalities that they know are expected and the terms that are, to some extent, pre-determined.

But the telling also has a particular moment, encounter, audience, purpose, and cannot be relied upon to faithfully reproduce the expected terms in **exactly and only** the expected ways. The realm of performative slippage, recombination, and repurposing are where this analysis hopes to focus our attention. These "resources inevitably impure" are all that parents have to draw upon, and yet they do so in varied, creative, and innovative ways. They encourage us, as social work practitioners, policy makers, and parents, to question how our own "impure" materials -- our assumptions and categories and models -- can be similarly retooled to different, and perhaps more responsive, ends.

Chapter 7

How Parents Are Filtered Out

What do we learn from these parents' descriptions of their interactions with special needs service systems and the dominant discourses that surround them? In drawing conclusions from this project, I bring together the strands of analysis that have been articulated in each of the preceding four chapters to create an integrated understanding of the systems and discourses under investigation. Then, I consider these findings' implications for social work as a discipline and practice, and for theory and research more generally.

This final gathering together of conclusions is more than a reiteration of findings; it is also a critique that suggests and supports transformative action (Frampton et al., 2006). This study was undertaken with an intention that it would be useful, particularly in compiling knowledge that could be drawn upon by LGBTQ parents of children with 'special needs' and other users of these systems, but also in promoting new thinking and new actions among service providers, researchers, and policy makers. In the tradition of other researchers in feminist, antiracist, and critical disability studies, I contend that a clearer understanding of *how* social relations and discursive meanings operate in everyday life is central and necessary to determining how they may proceed otherwise, and which alternative approaches may hold the greatest promise.

By proceeding from how things are made both meaningful and material in people's everyday lives, the findings from this study suggest that, when taken as a whole, most current systemic arrangements and discursive beliefs are working against supportive and equitable everyday experiences for all parents of children with 'special needs', and for LGBTQ parents in particular. In grounding these processes and outcomes in everyday experience, the findings also identify who and what may be involved in transforming these arrangements and discourses.

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As have been highlighted throughout the preceding chapters, a number of systemic and discursive blockages and injuries can be seen from the standpoint of those who are particularly disenfranchised within the 'ruling relations' of special needs services – the service users, here LGBTQ parents of children with 'special needs' – while the need for any change may be hidden by and/or from those with more influence, such as the funders, legislators, researchers, administrators, and, to some extent, even front-line service providers. The possible solutions may be similarly obscured. This chapter, therefore, is an attempt to bring to light the way that things are currently "working" from the perspective of LGBTQ parents of children with 'special needs', in such a way that alternatives can be imagined. These findings have direct implications for social work theory, research, and practice, as well as work in related areas of disability studies, kinship studies, and feminist/queer scholarship.

Institutional Filtering Makes Difference Matter

The clearest and most strongly-endorsed finding from this study is that parents find the existing special needs service systems to be daunting, inadequate, and riddled with gaps. The parents I spoke with described having to learn new words, concepts, acronyms, organizations, approaches, interpersonal styles, and strategies as a part of navigating special needs service systems, or even knowing what services may be available to navigate. Parents described devoting a substantial amount of time, energy, emotion, and thought to systemwork: the everyday activities that they did in order to learn about, decide upon, secure, and maintain resources for their children. The systemic absences and inadequacies parents reported pointed to an overall lack of coordination and concurrent scarcity of information and services that required parents to take on the "advocate" role, as described in Chapter 3. In so doing, these parents highlighted that responsibility for navigating systems effectively had been shifted from

collective responsibility (e.g., public sector services such as social workers and case managers) to individual parents.

What was also clear was that special needs service systems are organized around having far more parents and children requesting information and services from them than they are funded or staffed to meet. The ubiquity of waitlists is perhaps the most obvious testament to the mismatch between supply and demand – at least in the publically-funded system. The act of putting someone on a waitlist suggests that parents and children are all given equitable treatment, and that services come to those who wait. Meanwhile, this same waitlist does nothing to alleviate the fundamental imbalance of service users to available services except, perhaps, to move the users' claims/applications into a bureaucratically-contained and largely hidden domain of institutional practice. The length of some waitlists has grown to unimaginable size, as in the case of a parent whose child was over 2000 spaces down on a list for supportive housing. Crucially, once a child or family is on a waiting list, the evident inadequacy of the systemic response is difficult to challenge or even see from outside the institution – the waitlist is a document rather than a visible queue outside a building. Thus the problem of "too many service users, not enough services" is effaced through the appearance of a bureaucratic response that, in effect, fails to meet most people's needs, most of the time.

Indeed, the apparent equity of systemic policies such as waitlists, standardized responses regardless of need (e.g., all children receive the same "blocks" of speech therapy appointments on the same schedule), or formalized responses targeting the few with the most evident/ institutionally-actionable claims as in public education systems ("other children have greater needs") disguises the universality of scarcity, waiting, refusal, and the pressure on parents to "do more" themselves and/or "go elsewhere", particularly within the private service sector. In

Chapter 3 I described this pressure as an "offloading of responsibility" from the collective, public sphere to the individual, private labour and responsibility of the parent as "advocate".

Large-scale "offloading" of this type occurs across multiple systems, described by others as "re-privatization". In re-privatization, costs and labour that had been or was at risk of being seen as a public/ collective responsibility are de-funded and re-positioned under a rationale that the "family" should (and institutionally must) take them on (see Cossman, 2002; Gilmour, 2002). As Brenda Cossman argues, re-privatization is a strategy that fits within both neo-liberal and neo-conservative ideological frameworks, although its exact specifications will vary depending on which ideology undergirds its application and justification.

Within disability studies, it is particularly important that we not view such shifts from the public to the private domain through a lens of nostalgia. Publicly-endorsed and collective "solutions" for disabled children and adults have a particularly horrific history of institutionalization, maltreatment, and neglect. The very option of a disabled child remaining a part of a family was, for much of the last century, highly contested (Snyder & Mitchell, 2006). Further, parents have not been the sole or even primary people affected by such "de-funding", as is evident in the continued overlap between disability and poverty, incarceration, institutionalization, and curtailed citizenship (Barken, 2013; Carey, Ben-Moshe & Chapman, 2014; Carey & Gu, 2014).

But there is more than a withdrawal of collective, public responsibility and a generalized "offloading" to parents. In Chapter 5 I described how the need for such "advocacy" occurs through the disjuncture between what parents found portrayed "on paper" such as in official policies, and what they reported actually happened when they tried to obtain the advertised or even legislated services for their families. While systemic rationales for why parents did not receive prompt and appropriate services for their children could be portrayed as universal/

inevitable (e.g., 'it is impossible to get individual educational assistants so don't bother trying' or 'there is a waitlist everywhere unless you can pay for service') or individual/ exceptional (e.g., 'your child does not meet our criteria for service because of they do not have x or y'), the result was the same. Given the persistence of brochures and policies and laws that tout "accessibility" and systemic responsiveness, parents are often encouraged to see their experiences as isolated incidents rather than the expected and usual course.

Taken beyond these individual experiences and stated policies or rationales of service providers and institutional documents, the everyday experiences of parents across multiple points in time and setting suggest that service systems do more than delay, poorly coordinate, or fail to advertise services for parents: **institutional arrangements actively filter potential service users out of publicly-funded systems**. This filtering process, these findings suggest, allow agencies and governmental departments to balance their books even while the total public disbursement for children with disabilities and their parents is set at a reduced level that in no way reflects the actual needs and putative eligibility of the citizenry. Thus, in order to understand the processes described by parents, we need to shift our understanding of what it means for systems to "work". The parents I spoke with were not describing a system that they found to "work" according to their own criteria or even the criteria of stated policies. Nevertheless, systems may "work" very well if assessed in terms that may in no way reflect what parents or even front-line providers believe they are supposed to do, that is to say, they may "work" if they instead meet other institutionally central goals.

This study leads me to conclude that **current institutional arrangements are "working" most effectively if we take their unofficial but very real purpose to be in the reduction of claims made on their budgets and the effective dispersal of potential claim-makers** (i.e., parents and children) elsewhere, while maintaining the appearance of a benevolent

and equitable organizational apparatus (e.g., education system) and state. I describe this process as one of "**filtering out**". Filtering out does not mean a wholescale refusal or an injunction against claims-making. Instead, I use this term to identify cumulative effect of the many textual, discursive, and interpersonal moments in which parental claims/attempts to obtain resources for their children within special needs service systems were sorted and screened, not only by whether they met "eligibility criteria", but also by a range of factors that all decreased the likelihood that these services would be made available within public systems. These are the practices and institutional arrangements that made "advocacy" necessary – indeed, "advocacy" can be seen as the parent's attempt to be "filtered in".

It is important to note that the parents I spoke with were striving to "be successful" in their advocacy and claims-making roles. They were certainly not passive agents in a filtering process. However the burden of potential or actualized "failure" would have fallen primarily on their shoulders, to be remedied by more training, more advocacy, a new "making-do" with parental labour and informal arrangements and/or private services (if the parent had the resources). Similarly, the service providers they encountered were not, as a rule, portrayed as "filtering out" potential service users in an intentional manner. Rather, parents described providers who knowingly went against regulations to offer longer-term or more comprehensive service that was officially "allowed" (and parents expressed concern about the potential impact of such actions), providers who themselves had limited knowledge of how one might successfully obtain resources within the systems in which they were employed, providers who encouraged parents to try informal or less costly supports first, or providers who expressed regret at the limited service options they could offer compared to the range of need that they encountered. The work done by front-line providers was coordinated through institutional texts and practices: budgets, file audits, and even direct confrontations with administrators would all

shape providers' material and relational options when working with parents. While official policies were, as described by the parents, usually supportive of their children's entitlements, the material and procedural constraints on the providers they actually interacted with often thrust these individuals into reluctant "gatekeeper" roles.

What does this filtering out look like? Institutional practices, particularly those involving texts, re-inscribe the unavailability of services for parents and children at multiple, recurrent, and both predictable and unpredictable points in time. Parents told me about how they learned – through their interactions with service systems and accounts from other parents, providers, and online sources – that even being seen as within the pool of eligible applicants, let alone obtaining and retaining needed services and resources, takes active work and, frequently, additional support, knowledge, status, and luck. Effort alone may not be enough, particularly for the most marginalized parents with the fewest resources. Thus while the parents I interviewed had all worked at least partly within "public" systems which were to be universally available, differences between parents became crucial, as I discussed in Chapters 3-5. Since parents would use whatever levers (e.g., income, family structure, profession, gender, race, likeability, poster-parent status, etc.) parents had to advance their claims on behalf of their children, **institutional filtering is how difference was made to "matter": in the varying amount of systemwork parents needed to do, and in the varying resources their children and families received**.

Interpersonal, narrative, and textual encounters with services are what bring parents into institutional social relations and make discourses "matter" in their lives, both in the sense of becoming material in their effects and of having interpretive import (Titchkosky 2007; Butler, 1993, 2004). These encounters are the "how" explored in this study, the everyday moments that take on meaning in their repetition and variation across times, places, and people. In such encounters, parents must anticipate, manage, and modify their own appearances and relations

with providers in order to meet criteria for service. What's more, given the overabundance of possible service users, parents must offer providers an incentive to treat them, not only "like any other parent", but better than and before other parents.

What are some of the effects? The role of "parent advocate" has been commodified to the extent that trainings, workbooks, and professionals consultations are available for parents to learn the interpersonal, linguistic, and organizational strategies that give them and their children the best chance of having their needs met. As a part of this advocacy practice, parents learn to frame their demands and their children's needs in terms and forms that are recognizeable and actionable to providers, allowing the providers themselves to justify meeting the needs of this particular child/ family as "accountable" and "necessary" in an atmosphere of severe budgetary constraint (see Chapters 3 and 4). This systemic emphasis on gatekeeping, or filtering out, thus shapes what providers, parents, and children all do in their everyday encounters, and what discursive, material, and relational impact these encounters can have.

Further, as described in chapter 6, the discursive framework that presents disability and queerness as exceptional and "undesirable" forms of reproduction then saturates parents' institutional encounters with texts and people, and influences the resources available for parents' own narrative interpretations of them. These discourses thus also come to "matter" as they shape not only how parents describe themselves, their children, and their encounters, but whether parents will even engage with the institutions in the first place. They assure that some parents are "filtered out" before they even initiate a claim that would assert their own and their child's entitlement to institutional recognition and resource allocation.

Participants and Privileges

Given that the parents I spoke with self-selected as engaged with and knowledgeable of special needs service systems, the struggles they reported in obtaining resources with and for

their children were particularly noteworthy. The parents who expressed interest in participating in this study likely reflect a subgroup of parents who are particularly aware of systemic operations (seeing the value of research on special needs systems), as well as those who had the time and resources to devote to talking with an interviewer who did not promise to advance their individual material situation in any direct manner. These were parents who had something to say about how systems and social beliefs "work". Most of the parents I spoke with were very aware of their composite systemic privilege in negotiating special needs service systems due to their social location (race, gender, family structure, perceived "respectability" regarding LGBTQ identity), income/ other financial resources, social capital including professional trainings and connections, and, for a number of them, what they construed as "luck" (as in relationships with particular professionals who had helped them circumvent systemic barriers). Many came to this research with advanced skills in related fields and a systemic understanding in which they contextualized their experiences. Furthermore, all of the parents I spoke with had successfully engaged with systems to the extent that they had all had at least one encounter with a special needs professional, and all had children whose needs had been diagnosed/ professionally assessed. Thus they had already passed through considerable systemic "filtering".

The parents I spoke with were also engaging with services in the Greater Toronto Area (GTA), the largest metropolitan hub in Canada and the fifth largest urban centre in North America. This is an urban area with more special needs services providers than almost anywhere else in the country. It has the country's largest public education systems and public healthcare services are available to most people (excepting those without residential or citizenship documents). What's more, the legal protections for and the community visibility of LGBTQ people is particularly high in the GTA as compared to almost any other urban area in North America, and perhaps worldwide. There are numerous LGBTQ-specific parenting programs and

social networks in the GTA (although, as described in Chapter 4, not all LGBTQ parents are connected to these organizations and networks). There are high-profile, 'out' LGBTQ parents, including the provincial premier. Same-sex marriage and divorce rights are well-established in law, as are legal options for the recognition of more than one parent of the same legal sex, or even three legal parents (Court of Appeal for Ontario, 2007). These parents likely represent some of the best-resourced LGBTQ parents of children with 'special needs' in Ontario, and among the best-resourced in Canada and North America.

Thus, the experiences of this particular group of LGBTQ parents offered an opportunity to learn about **how a particularly well-resourced and structurally-aware group of LGBTQ parents had encountered, struggled with, overcome, been thwarted by, or bypassed systemic points at which they and their children might otherwise have been systemically "filtered out" of institutional recognition and response**. Parents who had been effectively "filtered out" from the beginning would have likely had less to say about the everyday operation of systems to which they had been denied access. Nevertheless, the parents I spoke with conveyed an awareness throughout our conversations that current institutional arrangements in an era of cutbacks and offloading might "work" in such a way that any change in the parents' luck, effort, and strategy might again threaten to filter their families out at any point in the future, even if it had not successfully done so before the time of the interview.

Filtering Example: Assessment and Becoming Institutionally Actionable

How does this "filtering" happen in the everyday institutional encounters (interpersonal and textual) that parents have with institutions and providers? The larger assertion that special needs systems "filter out" potential service users from receiving public services warrants further illustration. The assessment and diagnostic process offers a central example that was relevant to all parents I spoke with.

Assessment is presented as a starting requirement for most special needs services including professional services such as speech therapy, occupational therapy, or social work within non-profit agencies; reductions in public transit fare; educational accommodations (a particular focus of parents); disability tax credits; or respite care. In order to be deemed "eligible" for any such service, parents learn, a professionally-produced text that meets the program's specifications is required to be presented to a particular representative of the institution (e.g., vice principal, intake worker, Canada Revenue Agency representative).

However the actual production of the assessment or diagnosis, this institutional "first step", takes systemic savvy, time, and often substantial amounts of money (see Chapter 4). The parents I spoke with also recounted that documentation requirements are a moving target. While many believed that the assessment or diagnostic text, once obtained, would smooth the way to their child receiving resources and accommodations recommended by the text (e.g., frequency of speech therapy sessions) and/or advertised by the system (e.g., school board policy), once they had obtained this document parents reported that this was usually not the case. New texts were required (e.g., additional assessments) or further meetings revealed that service providers and administrators were unable/ unwilling to provide the recommended or promised resources regardless of what the assessment stated. In at least one example, a school administrator even suggested that the assessment be modified to remove a recommendation for costly "one-on-one" support for a child. This gatekeeper function of service providers was not always as evident as in this example, but the resulting failure to receive an anticipated resource was a common experience shared by almost all parents I interviewed.

The major exception to this experience of assessment as a barrier was in the family where the child had received a cancer diagnosis. In this case, the assessment/ diagnosis led directly to the provision of information and services with little call for parents to "push" or

"advocate" in order to have their child's needs responded to. As discussed in Chapters 3 and 5, the exact reasons that these parents had such a different experience are not entirely clear, but the overall impact of which diagnosis a child receives, and with which type of social status (e.g., Cancer vs. more stigmatized/socially marginalized conditions such as Oppositional Defiance Disorder or Fetal Alcohol Spectrum Disorder) was profoundly felt by the parents I spoke with.

But this is jumping ahead to the assessment as a fait accompli. Many parents reported that service providers actively discouraged them from getting an assessment, encouraging a "wait and see" approach (that simultaneously filtered out possible demand on public providers). Many people found that they were unable to obtain the assessment, or that doing so took a prohibitively long time, unless they were willing to "go private" and seek assessment services using private resources including employee benefits. Of course, only parents with the financial means and/or connections to "go private" had this option of leaving the public-agency waitlists. We could also say that waitlists "filtered out" all the parents who had or were willing to find the money to go elsewhere. These parents were not, however, filtered out of the public system permanently, but rather were able to jump back in ahead of those still waiting for a public assessment. Similarly, parents who had the knowledge, skills, and connections to put pressure on public assessment agencies could jump ahead in waitlists. Others stayed on waitlists but had the means to find and secure services that could benefit their child while they were also waiting. We can see more and more points in this one process at which "filtering out" happens to some parents based on who they are and what they have. Those who might be permanently "filtered out" from making any costly demands on public systems are those who did not have the resources to challenge a "wait and see" approach, or to "go private". Such parents would likely be "cost-free" for as long as they were waiting and unable to make systemic demands in the form of an assessment. It is likely that many such parents would reconsider whether it was even

worth engaging with these systems in the first place if their children were minimally served by the immediately available programs.

Once an assessment even occurs and the text is in a parent's hand, differences in parents' social resources continued to matter. Some parents found that the potential ramifications of bringing such a document into their child's dealings with institutions such as schools were so concerning that they decided against disclosing it and asking for accommodations that might, officially, be available. Racialized parents and White parents of racialized children, in particular, talked about the real concern that having a diagnostic label might lead to more problems than it would solve, particularly within education systems where, they feared, their children would been written off as unworthy of a teacher's time and effort (see Chapters 3 and 4).

As LGBTQ parents, participants found many ways in which their LGBTQ identities may – or may not – influence the outcome of their encounters with service systems and providers in the assessment process and then in its later application (see Chapters 4 and 5). Some found that "outness" and/or visibility of their LGBTQ identity and non-heteronormative family structures carried risks of being marginalized within communities of parents and other service users, having their relationships misconstrued and devalued, or having their children's behavior and identity viewed through a lens of inherent difference and pathology, even at the level of the assessment itself. For example, parents described ways that their family formation or structure could be either highlighted or completely hidden in written assessments which would then circulate throughout future interpersonal encounters that might determine if their child would (or would not) receive other services. Given the dominant heteronormativity parents reported encountering across special needs service systems, the ways that their family structure and family formation history (e.g., adoption, alternative insemination) could influence future encounters was a source of uncertainty and ongoing concern. Where assessments were

concerned, some parents had considered not pursuing and assessment due to the fear that having additional "labels" might be too much social exclusion for a child of LGBTQ parents who might already be targeted by others. However the outcomes and the significance of parents' LGBTQ identities was varied and parents could also creatively draw upon their "difference" as a resource. For example, some parents found they were able to use their political activist/ advocacy skills, access to alternative understandings of family and 'normalcy', and their exoticization as LGBTQ parents in heteronormative systems as a part of their strategy in obtaining services – not being "filtered out" – as they then "activated" the assessment texts (Smith, 2005).

As recounted throughout the previous chapters, filtering out continues even once an assessment is obtained and given to/ discussed with service providers. As outlined in chapter 5, parents are told that "other children have greater needs", or that certain recommended accommodations – such as individual assistants – are rare or unlikely to be available. Parents report often feeling uncertain about how their own attributes, and those of their children – such as age, gender, race, family structure, diagnosis, income, education – may be influencing the responses they receive. Some parents are able to draw upon these same attributes as sources of relational or material privilege in particular contexts, such as "writing a big cheque" and putting interpersonal pressure supported by social as well as economic privilege to influence professionals in meeting tight timelines. Others describe feeling unseen and misread to the extent that they are left out of conversations at which they are present, as when one parent wondered "Does he see me as the nanny?" when a White principal spoke only to their White partner.

Furthermore, parents negotiate multiple and often changing relationships with different services, each requiring a particular set of forms, each with its own mandate of who is (or more

often is not) eligible for service, each with its own waitlist, its own series of acronyms, and its own interpersonal encounters with providers and other service users. In each of these encounters, they struggle with how to present and narrate their child and their family, and to make sense of the beliefs and responses from others. Often these struggles involve reconciling their own sense of who they and their children are with dominant beliefs about "desirable" and "undesirable" children, parents, and families (see Chapter 6). This narration and meaning-making takes emotional and often relational work, including the time and effort of sorting through how they can value their children, their families, and themselves beyond the options presented within dominant discourses, while also communicating with service providers in terms that are intelligible and will lead to the desired outcome.

Thus a process that might appear on an organizational chart as a simple sequence of actions – raise concern, get professional assessment, bring assessment to agency representative, receive recommended resources – is in actuality experienced as a jumble of interactions, texts, decisions, discussions, terms, meetings, phone calls, and emotions. In the descriptions of participants, the organizational sequence from identifying a need, obtaining a professional assessment, and obtaining resources, is in fact highly contested, variable, and contingent. This process and its outcome will depend on factors that have to do with how the parent and the child are categorized in texts and encounters (race, gender, diagnosis, etc.) and what resources they can muster to not be "filtered out". The cumulative effect is, however, clear: the easiest path for parents is one along which they do not engage with public special needs service systems at all. In other words, the strongest incentive given is to leave – to be filtered out.

Discursive Filtering and 'Desirable Reproduction'

…Misrecognition is an institutionalized social relation, not a psychological state. In essence a status injury, it is analytically distinct from, and conceptually irreducible to, the injustice of maldistribution, although it *may* be accompanied by the latter. (Nancy Fraser, 1998, 141, emphasis in the original)

So it is not just that a discourse exists in which there is no frame and no story and no name for such a life, or that violence might be said to realize or apply this discourse. Violence against those who are already not quite lives, who are living in a state of suspension between life and death, leaves a mark that is no mark. (Judith Butler, 2004, p. 23).

As described by Nancy Fraser, "misrecognition" through which certain people's needs and very existence are denied or devalued cannot be considered separate from the social and the institutional. Nor should we subsume our attention towards how social and material goods are allocated under a focus on how people are sorted, since the sorting of people and the sorting of resources do not always flow exactly in unison. While Judith Butler and Nancy Fraser have had very public disagreements on the need for and possibility of disentangling "maldistribution" from "misrecognition", or the material from the discursive, both insist on the importance of social acts that produce and reproduce what can and will be "recognized".[24] As in the above quotation, Butler is particularly adamant about the potentially dire consequences of what Fraser terms "misrecognition" and Butler describes in terms of violence. Butler's description of the deadly connection between the discursive and the material exhorts us to keep both central to our analysis.[25]

Too often in both social work and related domains of scholarship such as queer theory, "intersectionality" and "identity" become almost fetishized and impervious to effective analysis in their conceptualization as static and internal essences of individuals and groups (Gibson, 2013). Inspired primarily by the work of Judith Butler but also with an eye to what Fraser identifies as "maldistribution", this study started from conceptualizing intersectionality as a process that takes place between people in particular discursive and material contexts, with

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[24] Details of the debates between Butler and Fraser fall beyond the scope of this dissertation. See Fraser, 1998 and Butler, 1997.
[25] Statistics Canada documents continued violence again LGBTQ people in Canada on the basis of sexual orientation and gender identity (see, e.g. Beauchamp, 2004). For more on violence in the lives of disabled people, see Goodley & Runswick-Cole, 2011; Meekosha, 2011.

observable, everyday consequences. As I have described in this study, while LGBTQ parents I spoke with encountered a great many instances of "misrecognition" within their navigation of service systems, the material resources that they had available to them could soften or sharpen the impact of such experiences of negation. A parent who had gender, racial, and class privilege to draw on might certainly be denigrated on the basis of sexuality, but they might also have more material resources with which to circumvent a "misrecognizing" individual or even organization. At times, however, no amount of money would create options that misrecognition precluded – such as when a public child welfare agency refused to consider a parent's second adoption application after an anonymous tip that "a gay man" was "inappropriate" with "a child". Thus the "status injury" of "misrecognition" could produce real effects through such institutional social relations – however the distribution of resources must nevertheless be taken into account as well. In Butler's terms, when a person is considered "not living" in dominant discourses that are re-inscribed through institutionally-empowered providers, the consequences cannot be effectively challenged.

So far in this chapter my description of how special needs service systems can be seen to filter out potential users/costs has largely concerned institutional practices and relations. However there is a danger that such a description, simplified as it is for greater coherence, may tend toward inevitability, as if the flow of parents through the filtering processes is impersonally pre-set rather than produced and reproduced in particular places and times by and between actual people, through the production and use of material objects such as texts. It is crucial to avoid such abstraction and the possible helplessness that can follow. These moments of filtering, while more than individual in origin or effect, nevertheless occur through the actions of people, and these actions are shaped through the discursive interpretations that are available to, and subsequently re-shaped by, the people involved.

Further, as stated at the outset, this project does not see LGBTQ parents of children with 'special needs' as a cordoned off and essential grouping of people that crosses places and times. Instead, the starting conceptual model of intersectionality that undergirds this project is one in which "identity" or "social location" is temporal, interpersonal, and contextual (see Chapter 1). As a result, I have approached these interviews and analyses as a means to observe how a notion of certain people as meaningfully "different", whether due to sexual or gender identity, class, race, or family structure, **actually happens** in everyday interactions and the texts they produce and activate.

The parents in this study were navigating a particular landscape of both institutional relations and dominant discourses. Overall, this study's findings indicate that researchers should not segregate considerations of "identity" and "meaning" from the central analyses of institutional processes and constraints. This admonition is needed for two reasons. First, while the "filtering" description of the ways that special needs systems operate is necessarily simplified into a coherent whole, it has been assembled from individual accounts that contain common occurrences, striking disjunctures, stubborn uncertainties, and thought-provoking exceptions. Parents' accounts present interpretations rooted in particular moments and reflections, as re-told and re-interpreted in the research, and therefore any emergent understanding of institutional tendencies also draws from and reflects upon the available discourses. As described by other feminist ethnographers, the particularly "local" context is what allows for the ethical and useful grounding of larger critiques (Craven & Davis, 2013). In the absence of multiple, experiential interpretations, institutions become seen as smooth and impenetrable wholes that do not require or yield the possibility of effective transformation.

Second, and more specifically linked to the topic of this ethnographic investigation, **the institutional processes here described rely on a dominant discourse that denigrates**

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"different" parental and child identities as a central component of its rationale and functioning. "Special needs" service systems, by definition, connect with dominant understandings of who is deemed "exceptional" rather than "planned for". In designating disabled children and their parents as "exceptional", we have already ensured that the resources they receive have not been planned for in the "mainstream". Further, as I heard about experiences that parents had within special needs service systems, it became evident that current institutional arrangements rely upon notions of desirable reproduction to sustain their current practices, including those of filtering out potential users/costs while maintaining a surface appearance of benevolence.

The ways in which institutional processes of special needs service systems rely upon and reproduce discourses of desirable reproduction in their everyday functioning can be seen in several aspects of parents' experiences. First, the scarcity of resources for children with particularly "undesirable" diagnoses such as mental health problems and intellectual or developmental disabilities is in marked contrast with the resources available for other children, such as those diagnosed with cancer. Second, the ongoing and orderly operation of such under-resourced systems is aided by the fact that **many potential service users will filter themselves out, or at least acquiesce more readily when they encounter inadequate or unavailable services, due to their own awareness that their child's diagnosis is seen as "undeserving"**. Similarly, the more "undesirable" the parent feels they themselves may be seen to be, the less fuss they may make when services are meagre, unavailable, or otherwise inadequate. Thus while the parents I spoke to were an unusually assertive group, those whose children had particularly stigmatized identities talked at length about their own struggles and "denial" about whether and how to initiate a search for services, let alone what to insist upon when they met with resistance from providers. In such examples, the contrast between how they valued their children and their

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families and how they feared others would (de)value them became a space into which claims making could be curtailed, delayed, or suspended. Similarly, when parents encountered providers whom they felt were actively hostile to them because of the parent's own "difference" (race, sexuality, etc.), parents reported having limited options to challenge or avoid such encounters and devaluations because of the scarcity of available services – at least in the public system. Parents who had the means to "go private" had more say in their interactions with all service providers, including within public systems, because they knew they had other options for themselves and their children.

So how can we best understand the role of discourses of desirable reproduction in the filtering out processes described by parents? The ways that differences between parents are made to "matter", and the integral role of larger discourses on (un)desirable reproduction in both institutional practices and their effects, demonstrate the theoretical utility of a temporal and contextual approach to intersectionality. This starting framework has proven its applicability throughout this project in analyses in which I might otherwise have been tempted to engage in denoting and thus creating, in the words of philosopher Ian Hacking, "kinds of people" (2006). When research follows typological models of knowledge which categorize people in groups according to a presumed trait or interest, a focus on how difference happens – and why it may be institutionally and discursively required – becomes unsustainable.

The experiences parents described certainly engaged with the commonly ascribed vectors of social difference in contemporary Canadian society, including race, gender, sexual orientation, disability, and class. However the relative import of these forms of "difference" resulted from cumulative occurrences in a larger social context. This framework redirected me away from labeling abstractions such as "homophobia" and toward accounts such as a lesbian parent explaining why she does not want to talk about her recent separation from her partner

with service providers, or away from simply noting "cisnormativity" and "gender role assumptions" and towards exploring the account of a bi-gender parent describing how a caregiver attributes their child's atypical behavior to the fact that this child "doesn't have a father".

Moments in which participants were "visible" or "stealth" with their LGBTQ identities, or the encounters or texts where children's diagnoses were or were not discussed, focused the investigation on the ways that difference may, or may not, be present in a particular account or interaction and away from explaining the traits and concerns of LGBTQ parents of children with 'special needs' as a stable and uniform group. As participants in a common social context, even as we may have had different experiences within it, the participants and I could reflect, both separately and together, on the dominant beliefs about who "desirable parents" and "desirable children" are taken to be, and the ways that each particular family could and could not embody these ideals (see Chapters 4 and 6). While such interpretive and narrative considerations do not fit within many approaches to institutional ethnography, their inclusion forces us to consider that the people navigating these systems are themselves interpretive beings. Their interpretations reflect and produce material and institutional effects: emotions, decisions, actions, and outcomes. Indeed, some institutional arrangements rely on this fact.

Overwhelmingly, parents talked about how their children's presence in their lives, and their interactions with other people's beliefs about their children and their families, had altered their own identities and beliefs. Many parents talked explicitly about the connections they experienced between their activist experiences and anti-normative beliefs surrounding LGBTQ lives and their understandings of disability and ableism. Motherhood scholars, in particular, have long considered the ways that everyday 'mothering' practices (everyday caring work not limited to practices by women) influence and alter how people think, as well as what they do

and how they feel (e.g., Rich, 1995; Ruddick, 1995; Kinser, 2008). For the parents I spoke with, all described a shift in their understanding of disability, community, and activism as a part of their parenting experience.[26] These findings suggest that it is a particular disservice to participants if we rely on research models that focus exclusively on interpersonal actions and do not consider participants' own interpretive responses in some complexity.

One of the central findings of this study, then, is that **important connections between the realm of the discursive and the realm of the institutional will be missed if researchers rely upon methods and conceptual models that abstract social processes either from their production in specific, everyday moments or from the ways that people make sense of them**. A conceptual understanding of intersectionality as relational, temporal, and contextual can effectively undergird revised and combined methods. Revisiting methodological and conceptual divides that have artificially separated the discursive from the institutional, the intra-personal from the inter-personal from the ideological, becomes not only exciting but necessary. Such revitalized research approaches hold particular promise for the field of social work.

Implications: Social Work, Parents, and Difference

> Institutional ethnography does not ask about 'bad attitudes' towards lesbian, gay, bisexual and transgendered people, but rather asks how versions of these categories of knowledge circulate within a given context. That is, rather than seeing the problem as merely 'homophobic individuals', institutional ethnography investigates the complex, frequently disputed, practices in which all of us -- to some extent -- participate and which are part of the organizational order of social work. (Steven Hicks, 2009, 1)

As Stephen Hicks describes in his own research on foster care systems from the standpoint of lesbian and gay foster carers, a research study that uses institutional ethnography asks different questions and suggests different solutions than may be commonly found in other social work research. In asking about parents' experiences, the current project has **not** been

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[26] See also Landsman, 2009 and Kittay, 1999 on parents of disabled children describing a shift in their own understanding and identity.

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predicated on an assumption that LGBTQ parents are uniquely oppressed, nor that the primary

cause of parents' troubles is that individual special needs service providers are homophobic

and/or transphobic. Parents did offer examples of homophobic/ transphobic encounters,

statements, or texts, but the institutional framing and material effects of these "attitudes" were

the focus of the investigation. In other words, how does parental difference "make a difference"

in special needs service systems? What institutional and discursive frameworks explain the

relevance and impact of the "attitude" of people who work within these systems on the users or

potential users of these systems? What systemic and discursive underpinnings ground the

possibility and consequence of any individual "homophobic" or "transphobic" encounter? How

do the very assumptions and practices of social work and related fields (in healthcare, education,

and social services) create "categories of knowledge" that make particular parents and particular

children differentially susceptible to workers' "attitudes", and how can they continue to receive

differential resources even when these "attitudes" may be, on an individual level, entirely

supportive?

While social workers frequently spend a lot of their time "working with" parents, they

frequently neglect the importance and context of this work (see Chapter 1). Social workers must

not take their understanding of parents as neutral and self-evident. Instead, as Stephen Hicks

exhorts, workers must consider their own inevitable participation in institutional frameworks

and ways of understanding people and problems. It is only through this more nuanced critique of

the meaning of disability, kinship, and sexuality in a particular context and historical moment

that the complex relationship between material and interpretive inadequacies can be accessed.

In shifting the focus from a narrow consideration of how "certain" service users – in this

case LGBTQ parents of children with 'special needs' engaging with special needs service

systems – experience or do not experience their everyday encounters with service systems, the

implications of this research also expanded. The starting methodological standpoint is, as was stated at the outset, deliberately particular and inevitably partial, but the findings shed light on how these services systems operate in ways that impact all users, and the workers themselves. **Thus the finding that services are operating to prioritize a reduction in public expenditure helps to explain the experiences of people with multiple potential points of entry**: non-LGBTQ parents, children in "mainstream" settings, children in "special needs" settings, direct service workers with temporary or fluctuating contracts, and so forth.

Furthermore, the implications of systemic offloading and cutbacks go far beyond special needs services, which is already a loose institutional grouping at best. Almost all organizational spaces in which social workers can practice have been and continue to be influenced by the widespread rise of these strategies as a core component of neoliberal ideology and practice. The current analysis can be situated in the larger national and transnational rise of neoliberal and market-based policies (see Chapters 1 and 3; Craven & Davis, 2013; Duggan, 2003). Neoliberal ideology has come to dominate state practices as well as political and popular discourses, and the effects of its ascendancy are particularly visible in caring and gendered labour practices (Luxton, 2006). As many feminist scholars have identified, neoliberal ideology urges and justifies the large-scale reduction of state or collectively-provided resources to be offloaded onto market-based and/or familial workers, in ways that have particular effects for caregivers (Mosher, 2000, 2010; Neysmith et al., 2012; Vandenbeld Giles, 2014).

Given that human "needs" for resources and care do not conveniently disappear upon ideological demand, a withdrawal from state funding and coordination of social services poses what Janet Mosher calls "an unsettling problem" (2000, 30). The financial and institutional reduction of social supports consistently relies upon and reinforces the discursive de-valuation of their presumed recipients, and suggests that "private" options should not only be available,

but that they will be "better" for all concerned. Many feminist scholars of Canadian social policy have noted similarly dire combinations of discursive re-framing and institutional restructuring (e.g., Cossman, 2002; Neysmith, 2000; Swift, 1995, 2010).

Meanwhile, as Lisa Duggan and other scholars of LGBTQ movements have noted, advocates of neo-liberal processes have repeatedly co-opted the language and direction of social change movements, and of LGBTQ rights movements in particular (Cossman, 2002; Duggan, 2003; Kinsman & Gibson, 2014; Puar, 2007; A. M. Smith, 2009; Ward, 2008). In the creation of "respectable" LGBTQ people as largely white, wealthy, modern, and liberated consumers who reap the benefits of state "tolerance", states and institutions have both co-opted gay liberation movements and diversity rhetoric and further advanced the notion that sexuality and kinship are all about "choice" (Gibson, 2014a; Weston, 1998). Of course, the everyday reality of LGBTQ people within these same contexts is seldom so rosy. It is not surprising, therefore, that 'gay rights victories' have often simultaneously been advanced and endorsed using neoliberal terms and goals, as in the reduction of state supports as a consequence of increased "private" responsibilities such as adoptions, civil unions, marriages, child support, and alimony (Cossman, 2002; Gibson, 2014a; A. M. Smith, 2009).

The findings of this study therefore connect with larger trends across human services. Neoliberalism is intimately produced through and reliant upon gendered, caring labour, including paid work roles as well as unpaid work. Many employees within special needs service systems have a similarly tentative hold on material resources within systemic shifts away from unionized, public, permanent employment contracts. As relatively privileged direct-service employees in human services, social workers may be less vulnerable than some other employees, however cutbacks influence all workers within these systems. Workers are often directly asked to find "alternatives" to public expenditure in ways that can be discursively

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framed as "beneficial". The purported "benefits" may often be listed in terms of "choice", "empowerment", and "equality", as seen in the ways that parent "advocates" are created and sustained (see Chapter 3). Simultaneously, "filtering out" means that social workers and other employees across human services find their own roles increasingly dominated by the requirement that they act as gatekeepers and accountants, managing expectations and demands of both clients and potential clients, and often turning them away.

So what are social workers and other human service providers to do? At a collective level, people involved in the provision, design, and evaluation of special needs services must continue to investigate and voice the true effects and causes of state divestments. Research is a central component of making these connections between governmental priority and everyday experience evident to all concerned. Further investigations into the impact of immigration policy and legislation surrounding Aboriginal families are particularly needed (see e.g. Jennisen, et al., 2014). Many related questions emerge. How does filtering out happen to parents of children with disabilities with different starting resources, such as parents who themselves are living with diagnostic labels of disability? How do special needs services operate when there are systemic rather than parental 'advocates' for children, as in the case of Crown wards? Further research into the impact of cutbacks from the perspectives of service providers and administrators would also be valuable, particularly given the precarity of many employment arrangements and organizational budgets that were noted by key informants in this study. Research is also needed within adult service systems. As a number of key informants and parents I spoke with observed, the resources available for adults with 'special needs' are even more disjointed, restrictive, and institutionally difficult to access.

The research implications from this study are also methodological. In bringing ethnographic attention to how texts are produced and used, this study leaned heavily on the

work of other institutional ethnographers and disability studies scholars. While many researchers may assume that selecting and discussing a document would be a burden on research participants, this strategy was highly successful. Indeed, all of the participants brought at least one relevant document and all had important things to say about them. This section of the interview allowed the operations of the institutions and discourses surrounding the everyday to become more analytically assailable. The more general (and quite commonly used) evaluative interview questions in which parents were asked for suggestions to give other parents and service providers, in contrast, were met with more clearly rehearsed but vague responses from many participants. The questions about how and why texts were produced, used, and responded to consistently inspired rich narrative accounts that allowed the "how" of institutional and discursive filtering to become empirically recognizeable.

Further, by using texts to focus discussion rather than for a document analysis, different lines of analysis also became available. Parents explained how these texts continued to influence what they did and how they felt, but also described their own critiques of and responses to these documents. Thus instead of attending to "actualities" only as they precede (and exceed) the production of a bureaucratic document which organizes "what really happened" following institutional categories (see D. Smith, 1990), the everyday experiences of parents continue alongside and in spite of the document, influencing how parents present and use it in their future institutional interactions and everyday lives with their families. Building upon and repurposing Liza McCoy's method of interviewing women about their wedding photos (1995), this approach to institutional documentation put parents' experiences at the centre of the line of questioning, and highlighted the "gap" between what was "on paper" and what "really happened" in terms of resource allocation and emotional impact. This approach to texts is promising for other research

into how bureaucratic documentation shapes, but does not fully encompass, people's everyday experiences.

As previously cautioned, however, it is crucial that researchers, service providers, funders, and policy makers studiously avoid an assumption that any increase of "state responses" to the families of children with 'special needs' is a welcome move. **Social work has not engaged deeply or critically enough with its own implication in the oppression of disabled people**, particularly through state apparatuses such as education systems, residential institutions, and income support programs (Carey, et al., 2014). Social work researchers and practitioners alike have tended to perpetuate stories of disability as the primary 'problem' and the crucial cause of parental suffering. [27] Without a deeper questioning of both how certain people come to have "needs", and the ways that certain people are devalued as "not quite lives" (Butler, 2004, p. 23), workers, researchers, and parents alike risk dismissing and dehumanizing people with disabilities, with or without state support.

Disability studies itself needs more scholarship on the ways that diverse parents engage with and are influenced by the institutions and discourses that surround disability. As mentioned in the first chapter, parents are both privileged by ableism in being asked to "speak for" their children, and simultaneously oppressed by these same beliefs which marginalize disability and access as "special". Some disability studies scholars have begun to complicate the ways parenting and disability are considered (e.g., Douglas, 2013, 2014; Farrugia, 2009; Goodley & Thegaskis, 2006; McGuire, 2013; Salmon, 2007). These more nuanced considerations of parents of people with disabilities show particular promise in domains of human services in which parents continue to be the primary point of contact, such as special needs services for children. Further, since global economic practices and violence have shaped the prevalence and

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[27] Outside of North America there is a greater attention to critical disability studies from within social work (e.g., Meekosha, 2011; Oliver, 1990, 2009).

experience of impairment and disability, research on parents and children transnationally is sorely needed (Connell, 2011; Meekosha, 2011).

In practice, what can social workers do to respond to these findings of parents being "filtered out"? At the level of "micro" practice, **workers need to be increasingly aware of how their own institutions and the social context shape who they see and what they hear from potential service users**, including parents. Given the tendency of many social work theories to look for psychological explanations, workers may interpret what is said in an intake interview or follow-up session as representing "who the parent is". This approach ignores the impact of systemic factors on how parents' experiences and on their strategies when facing a professional "gatekeeper". For example, when a parent describes their child in terms of percentiles or problems, does this tendency begin with the parent's psychological profile, or has it been socially and institutionally produced? When a parent seems angry and distressed, does this reflect a problem of emotional regulation and grief/trauma, or a response to repeatedly being presented with inadequate resources and offensive interpretations of their family? With LGBTQ parents, in particular, parents may be wary of any and all interaction with professionals, often based on previous experiences of discrimination and even institutional violence. Parents who have been repeatedly scrutinized may be unwilling to reveal any vulnerability. Alternatively, they may wait much longer to seek professional services and be in more dire need of supports.

It is worth highlighting that current "one size fits all" rubrics of service provision tend toward "parent support groups", as discussed by a number of parents in these findings. While some parents expressed a wish to connect with other parents in some formalized way, providers should be aware that "support groups" are not uniformly experienced as necessary or supportive. Such groups' focus is usually on either providing "emotional support" for coping with the child's behaviours or "needs", or on teaching a particular understanding of their child's

diagnosis, all under the presumption that parents' experiences are shared across the group. Indeed, many LGBTQ parents described these groups as unhelpful at best, and actively marginalizing at worst. For service providers to assert that their services "fit" all parents not only prevents the creation of more appropriate options for LGBTQ parents, but also creates additional work for parents who must then decide how to respond given the gradient of provider-parent power. It is very likely that parent support groups are not a good "fit" for a variety of parents, although they are an excellent way for organizations to provide low-cost service options. Providers would do well to challenge their own assumption that the problem with such groups lies within parental "resistance" and instead invite parents to work with them on different types of groups, mentorship or other peer-support programs, or case management and systemic advocacy supports that the parents might find more useful.[28]

Even outside of "support group" formats, social workers can continue to initiate communal responses to collective concerns. Providing material supports (e.g., referrals, spaces, advertising, consultations, childcare) for parent-run mentoring, drop-ins or organizing meetings would be a different approach than either the psychologically-oriented and professionally-facilitated support groups or the fee-for-service advocacy workshops that currently dominate the landscape. Given the impact of dominant beliefs that such concerns are "private" and often stigmatized/shameful, combined with the practical constraints of attending group meetings with children of varying ages and needs, many of these resources might be best offered in ways that are not limited to particular times and places. Online organizing and parent mentors who are available by multiple means could provide more useful and flexible supports for parents, and were suggested by several participants.

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[28] See Gibson, 2014f on LGBTQ parents and "resistance".

Where does this leave social work practitioners who are committed to a mandate of social justice? While there are limits to what an individual worker can do to affect the impact of neoliberal restructuring and discourses of desirable reproduction, parents in this study certainly pointed to the importance of social workers' roles. In particular, given the ways that "filtering out" perpetuates hierarchies between individuals, social workers can work as advocates and resource people to even out the available services for different families. Instead of urging parents to become better advocates or withdrawing on the assumption that parents already "have things under control", workers can take back some of this offloaded responsibility and perform a role that has been social work's strength: effective advocate and case manager. If social workers take this role on, parents will be relieved of some responsibility to research, ask, pursue, and argue with systems representatives. Indeed, in situations where there are no parental representatives, as in Crown wards, social workers already perform a similar role.

In everyday practice when interacting with parents, social workers can highlight the limits and the entry points of seemingly impenetrable service systems, particularly on behalf of those who have fewer professional, educational, and financial resources. As other researchers identified in a recent study, immigrant parents and others who are not "in the know" (both about resources and about their families' rights) are particularly vulnerable to being brushed aside within service systems (Jennings, et al., 2014; Khanlou, Haque, Sheehan, & Jones, 2014). However this social work role needs to come in the form of sharing of knowledge and connections, rather than compiling a list of instructions which would result in more tasks for parents to do. As outlined in Chapter 5, obtaining and working with the textual requirements of these systems is particularly demanding. Instead of sending parents home with more and more documents, workers could support parents in-person and be available to fill documents out together with or on behalf of parents. More generally, social workers can be mindful of what

they ask parents to do, when they ask them to be someplace, and how these tasks might be usefully reduced. Meeting more often and offering more information and service plans may, or may not, be helpful for a particular individual and family. Some may already be overloaded with appointments and documents.

For LGBTQ parents in particular, but not exclusively, the assumptions and demands of institutional texts can be particularly demanding and, indeed, become part of how families are "filtered out". Social workers can be important advocates for changing heteronormative and cisnormative paperwork, clarifying what information is required and how the available options are presented. Any form with "mother" and "father", for example, presents an obvious barrier to families with other parental identities and arrangements (see Chapter 4). Additional questions about how gender and sexuality appear throughout texts such as diagnostic assessments can best be asked by a worker within special needs systems rather than relying on parents and other service users to raise the issue.

Even in the most individualized formats of social work practice such as assessment and counselling, workers can open up conversations with parents about the structural and discursive pressures that they face in their everyday lives. As I learned from the participants in this study, parents can be very astute about how structural forces influence the ways in which they and their children are talked about, viewed, and treated. They had a great deal to say about the pressures and stresses that resulted from their interactions with systems, and the strategies that they used in response. While social workers have been very good at assessing and responding to parents in terms of the distress they face "as a result of disability", they have not consistently addressed how the systems that they work within can contribute to and create parents' distress. Parents are ahead of workers on this, and these conversations can produce more concrete suggestions for organizations to make changes, grounded in parents' everyday experiences.

Finally, service providers of all kinds need to collectively strategize on how best to combat the pressures of neoliberal cutbacks and to create services that **do not rely on advocacy in order for people to get what they need**. If the pressures of scarcity and "filtering" can be reduced or eliminated, and discourses of who is "desirable" and therefore valuable are opened up, differences between individuals and families would no longer "matter" to the same extent in interpersonal interaction and material distribution. While this is an ideal more than an immediate goal, it provides "a moral compass" to practice, policy, and research (Weinberg, 2008). Instead of using professional privileges to define and set apart certain individuals, needs and abilities, how can we use this systemic influence to promote a broadening of what can be considered a worthwhile life, who can be considered family, and how we can support and rely on each other? In creating systemic responses that anticipate and respond to a range of human experiences and relations, resources will become more accessible for all.

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Appendix A: Approved Ethics Protocol

ETHICS REVIEW PROTOCOL SUBMISSION FORM FOR
SUPERVISED AND SPONSORED RESEARCHERS
(For use by graduate students, post-docs, and visiting professors/researchers)

SECTION A – GENERAL INFORMATION

1. TITLE OF RESEARCH PROJECT

Akin to difference: An ethnographic investigation into the everyday experiences of lesbian, gay, bisexual, transgender or queer (LGBTQ) parents of children with 'special needs'

2. INVESTIGATOR INFORMATION
Investigator:

Title (e.g., Dr., Ms., etc.): Ms.	Name: Margaret Gibson	
Department (or organization if not affiliated with U of T): Factor-Inwentash Faculty of Social Work		
Mailing address: 246 Bloor Street West, Toronto, ON M5S 1V4		
Phone: (416) 890-0357	Institutional e-mail: margaret.gibson@utoronto.ca	

Level of Project:

Student Research:	Doctoral ☒	Masters ☐
Post-Doctoral Research ☐	Visiting professor/researcher ☐	Course Based ☐
CBR/CBPR ☐	Other ☐ (specify:)	

Faculty Supervisor/Sponsor:

Title: Dr.	Name: Izumi Sakamoto
Department (or organization if not affiliated with U of T): Factor-Inwentash Faculty of Social Work	
Mailing address: 246 Bloor Street West, Toronto, ON M5S 1V4	
Phone: (416) 946-8224	Institutional e-mail: izumi.sakamoto@utoronto.ca

Co-Investigators:
Are co-investigators involved?   Yes ☐   No ☒

Title:	Name:
Department (or organization if not affiliated with U of T):	
Mailing address:	
Phone:	Institutional e-mail:

Title:	Name:
Department (or organization if not affiliated with U of T):	
Mailing address:	
Phone:	Institutional e-mail:

Please append additional pages with co-investigators' names if necessary.

3. UNIVERSITY OF TORONTO RESEARCH ETHICS BOARD:

Health Sciences ☒   Social Sciences, Humanities and Education ☐
          HIV/AIDS ☐
To determine which Research Ethics Board (REB) your protocol should be submitted, please consult: http://www.research.utoronto.ca/for-researchers-administrators/ethics/human/boards-committees/..

4. LOCATION(S) WHERE THE RESEARCH WILL BE CONDUCTED:

If the research is to be conducted at a site requiring administrative approval/consent (e.g., in a school), please include all administrative consent letters. It is the responsibility of the researcher to determine what other means of approval are required, and to obtain approval prior to starting the project.

University of Toronto   ☒
Hospital ☐   specify site(s)
School board or community agency ☐   specify site(s)
Community within the GTA ☒   specify site(s): locations convenient to participants (e.g. residence)
International ☐   specify site(s)
Other ☐   specify site(s)

The University of Toronto has an agreement with the Toronto Academic Health Sciences Network (TAHSN) hospitals regarding ethics review of hospital-based research where the University plays a peripheral role. Based on this agreement, certain hospital-based research may not require ethics review at the University of Toronto. If your research is based at a TAHSN hospital please consult the following document to determine whether or not your research requires review at the University of Toronto. http://www.research.utoronto.ca/for-researchers-administrators/ethics/human/at-a-glance/where-to-apply-tahsn-institutions/

5. OTHER RESEARCH ETHICS BOARD APPROVAL(S)

(a) Does the research involve another institution or site?   Yes ☐   No ☒
(b) Has any other REB approved this project?   Yes ☐   No ☒
        If **Yes**, please provide a copy of the approval letter upon submission of this application.
        If **No**, will any other REB be asked for approval?
                Yes ☐   (please specify which REB)   No ☒
                Please note that REB approvals from other sites must be submitted to the ORE at U of T

6. FUNDING OF THIS PROJECT

   (a)

Funding Status	Source and Type	Details
Funded ☐	Agency:	Fund #: 4 (6 digits)
	Agency:	Fund # :4 (6 digits)
Applied for funding ☐	Agency:	Submission date:
	Agency:	Submission date:
Unfunded ☒		

> If unfunded, please explain why no funding is needed: Minimal funding required (to be funded by the student)

(b) If one protocol is to cover more than one grant, please include all fund numbers:

7. CONTRACTS

Is this research to be carried out as a contract? Yes ☐ No ☒

If yes, is there a University of Toronto funding or non-funded agreement associated with the research? Yes ☐ No ☐

If **Yes,** please append a copy of the agreement with of this application.

Is there any aspect of the contract that could put any member of the research team in a potential conflict of interest? Yes ☐ No ☐

If yes, please elaborate under #10.

8. PROJECT START AND END DATES

Estimated start date for the component of this project that involves human participants or data: August 2013

Estimated completion date of involvement of human participants or data for this project: August 2014

9. SCHOLARLY REVIEW:

(Please note: for submissions to the **HIV REB** from community investigators, scientific review is a pre-requisite for ethics review. If your study is unfunded, please contact the OHTN to arrange a scientific review prior to completing your ethics submission.)

(a) Please check one:

I. ☒ The research has undergone scholarly review by thesis committee, departmental review committee, peer review committee or some other equivalent (Specify review type – e.g., departmental research committee, supervisor, CIHR, SSHRC, OHTN, etc.): **Thesis committee**

II. ☐ The research will undergo scholarly review prior to funding
(Specify review committee – e.g., departmental research committee, SSHRC, CIHR peer-review committee, etc.):

III. ☐ The research will not undergo scholarly review (Please note that all research greater than minimal risk requires scholarly review)

(b) If box I or II above was checked, please specify if:

☒ The review was/will be specific to this protocol

☐ The review was/will be part of a larger grant

10. CONFLICTS OF INTEREST

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(a) Will the researcher(s), members of the research team, and/or their partners or immediate family members:

(i) Receive any personal benefits (e.g., financial benefit such as remuneration, intellectual property rights, rights of employment, consultancies, board membership, share ownership, stock options, etc.) as a result of or in connection with this study?   Yes ☐   No ☒

(ii) If **Yes**, please describe the benefits below. (Do not include conference and travel expense coverage, or other benefits which are considered standard for the conduct of research.)

| |
| |

(b) Describe any restrictions regarding access to or disclosure of information (during or at the end of the study) that have been placed on the investigator(s). These restrictions include controls placed by the sponsor, funding body, advisory or steering committee.

| Not applicable. |

(c) Where relevant, please explain any pre-existing relationship between the researcher(s) and the researched (e.g., instructor-student; manager-employee; clinician-patient; minister-congregant). Please pay special attention to relationships in which there may be a power differential – actual or perceived.

| As a long-time member, researcher, and social work practitioner within LGBTQ communities in the GTA, some pre-existing relationships with participants may be unavoidable. I will not, however, conduct interviews with any current or past clients of my counselling/ psychotherapy/ group therapy work, or with any current or past students from courses I have taught, due to the power differential inherent in those relationships. |

(d) Please describe the decision-making processes for collaborative research studies. If Terms of Reference exist, attach them. Collaborative research studies include those where a number of sites (e.g. other universities, non-TAHSN hospitals, etc.) are involved, as well as those that involve community agencies.

| Not applicable. |

SECTION B – SUMMARY OF THE PROPOSED RESEARCH

11. RATIONALE

Describe the purpose and scholarly rationale for the proposed project. State the hypotheses/research questions to be examined. The rationale for doing the study must be clear. Please include references in this section.
Research questions
        The proposed study aims to address the following questions:
i) How is the everyday work done by LGBTQ parents of children with 'special needs' shaped by their interactions with special needs service systems (including but not limited to healthcare, education, and community services and professionals)?
ii) What role do texts (e.g. diagnostic criteria, medical or behavioural plans, adoption certificates, legislation, etc.) play in these interactions and experiences?
iii) How do parent narratives connect with, depart from, and otherwise complicate dominant discourses on desirable reproduction (i.e. who should be a parent, who should be born or raised)?

iv) How do intersectional identities operate contextually and relationally, such that 'difference' attributed to one family member can combine with and complicate 'difference' attributed to another?

Rationale

The proposed research offers a previously unexplored, empirical perspective on everyday practices and narratives that have more abstractly been considered as heteronormativity/ cisnormativity, kinship, caregiving, social service provision, and disability. Following ethnographic methods, the proposed research will be grounded in the everyday activities and narratives of LGBTQ parents of children with 'special needs' and augmented by additional interviews and a consideration of central texts.

For the purpose of this study, the term "special needs" is not one that is presumed to be neutral or objectively definable. "Special needs" is instead seen as a contested category to be explored in terms of its influence on parents' experiences and narratives. The research explores how institutional interpretations of "children with 'special needs'" and "special needs services" influence parents' everyday lives. Similarly, lesbian, gay, bisexual, transgender, and queer parental identities are open to exploration and re-definition as the study investigates the institutional, discursive, and experiential components of their everyday import.

Why start from the standpoint of LGBTQ parents of children with 'special needs'? First, in a diffuse, shifting, and multidisciplinary area of service provision such as disability, any gaps within and between texts (e.g. special education legislation) and practices (e.g. parent-teacher interview) may be particularly evident. LGBTQ parents whose children have been identified as having 'special needs' are likely to engage with a variety of different providers, with increased vulnerability to institutionalized inadequacies and interpersonal discrimination. After multiple and ongoing contacts with different professionals and policies, these parents can offer particularly extensive and wide-ranging examples of how systems respond to queer parents and their children.

Second, researchers have seldom considered the perspectives of *any* parents on their interactions with special needs service systems, let alone those who have been otherwise marginalized. The proposed study thus offers a much needed addition to research on parents of disabled children in particular, and service users more generally. This study will move beyond individual attitudes of service providers and instead explicate how institutional relations and policies operate from the perspective of these parents. As such, findings will offer empirical guidance for parents, service providers, and advocates who hope to make institutional arrangements more effective and equitable (Smith, 2006).

Third, ideas of 'normal' and even 'desirable' children saturate our cultural responses to both parenting/ reproduction **and** disability (Goodley & Thegaskis, 2006; Landsman, 2009). Categories and practices surrounding disability as "the rejected body", in Wendell's phrase (1996), reinforce certain beliefs about 'normalcy' and socio-bodily control. Discussions of reproduction often include assumptions of idealized bodily 'normalcy' and 'health' in implicit contradistinction from disability. For example, individuals filling in forms to obtain donor gametes or to adopt a child face questions about what traits they would desire or accept. In the process, certain traits and certain children are deemed more 'desirable', and known or suspected disability is categorized under the rubric of 'risk' and 'bad outcome'. Similarly, when parents interact with professionals who assess some of a child's needs or traits as 'abnormal' or 'exceptional', certain notions of the unexceptional or normal child/person are produced.

In sum, throughout texts and practices that make up the services surrounding family formation (e.g. assisted reproduction, adoption, marriage) and those surrounding disability (e.g. special education, rehabilitation, diagnosis) we can identify dominant discourses on desirable reproduction. The implications of such discourses and their institutionalization spread far beyond

this particular group of parents. They extend to policies, practices, and national-cultural narratives about who should reproduce and parent, and how, and who should be "reproduced" as members of a society and/or nation.

Background

In spite of the lack of consistent and reliable population estimates, there is strong evidence that a wide range of Canadian LGBTQ people are parenting (Bauer, Anjali, Pyne, Redman, Scanlon & Travers, 2012; Milan, Vezina, & Wells, 2007; Nelson, 1996; Tjepkema, 2008). Queer people become parents in a range of ways (Epstein, 2009; Mitchell & Green, 2007; Parks, 1998; Patterson, 2005; Stacey & Biblarz, 2001). Some have children within the context of heterosexual relationships which may or may not continue. Some have current partners with whom they can procreate without donor gametes or surrogacy. Some use donor gametes, from anonymous or known donors, and/or gestational surrogates, to conceive children (Bos, van Balen, & van den Boom, 2007; Gartrell, Rodas, Deck, Peyser, & Banks, 2006; James-Abra, 2012; Pyne, 2011b; Stacey, 2006). Some adopt children, domestically or internationally (Averett & Nalavany, 2009; Bennett, 2003; Erich, Leung, Kindle & Carter, 2005; Kindle & Erich, 2005; Ryan & Whitlock, 2007; Stacey, 2006). Some have children in co-parenting relationships (Rubin, 2009). Some start relationships with partners who already have children, and then either become parents to these children or retain a distinctive "step-parent" role (Brown & Perlesz, 2007; Hequembourg, 2004). A given person may have tried or used more than one means of bringing children into their lives.

LGBTQ people face considerable challenges as they access services to form their families. Many foster and adoption service providers express an unwillingness to place children with LGBTQ caregivers (Downs & James, 2006; Eady, Ross, Epstein & Anderson, 2009; Hicks, 2008; Jayaratne, Faller, Ortega, & Vandervort, 2008; Ross et al, 2009a; Ryan, 2000). LGBTQ participants continue to report discrimination and/or inappropriate service recommendations when they tried to access fertility services (Ross et al., in preparation). Transgender individuals report especially daunting barriers within institutions of all kinds, including fertility clinics and adoption agencies (Bauer, Hammon, Travers, Kaay, Hohenadel & Boyce, 2009; James-Abra, 2012; Pyne, 2011b; Ross et al., 2009a; Ross et al., 2009b; Ross et al., in preparation; Ryan, 2009).

Beyond family formation, LGBTQ parents face widespread discrimination including public hostility which portrays them as "selfish" and "harmful" (Clarke, 2001). Indeed, opposition to LGBTQ rights legislation is often expressed in terms how LGBTQ parents will/do negatively affect both their own children and the future society or nation (Gibson, 2010, in press). For example, arguments about LGBTQ parenting have been intertwined with debates on legal recognition for same-sex partnerships in countries including Canada, France, the US, and Australia (Butler, 2004; Herdt, 2009; Hosking & Ripper, 2012). Such public discourses can have profound effects on LGBTQ people, as do the related institutional demands and restrictions. For example, LGBTQ parents who seek legal protections for their families by legally 'adopting' their partners' biological children report emotional and financial hardship (Connolly, 2002; McClellan, 2001). Parents also report stress where access to such 'second-parent' adoption is unavailable and legal protections are inadequate for non-biological LGBTQ parents (Gartrell et al., 2006; Hequembourg, 2004; Stacey, 2006; Ryan, 2009). Many LGBTQ parents develop strong advocacy skills out of necessity (Bos, Gartrell, Peyser, & van Balen, 2008; Broad, Alden, Berkowitz, & Ryan, 2008; Lassiter, Dew, Newton, Hays, & Yarbrough, 2006). Some mourn "ambiguous" losses when children incompletely recognized as theirs are removed from their custody (Allen, 2007).

In investigating the experiences of LGBTQ parents, researchers have documented many ways that people have created families and communities from vulnerable positions within a

shifting socio-legal context. However there are important limitations to the current research literature on LGBTQ parents. Samples have frequently been drawn from American or European jurisdictions which often provide fewer resources and legal rights than are currently available in Canada (Patterson, 2005; Vyncke & Julien, 2007). Most research has been focused on "lesbian" parents, fewer on "gay" parents, and very little attention has been paid to those with other non-heteronormative identities such as "bisexual", "transgender" or "queer" (Eady, Ross, Epstein, & Anderson, 2009). The majority of research has used overwhelmingly white, middle-class samples (Tasker & Patterson, 2007). Similarly, since much of the existing research has focused on "same-sex couples" as compared to "heterosexual couples" and/or "single parents", it precludes any consideration of bisexual or trans identities among parents (Pyne, 2011a).

In addition, the majority of this scholarship on LGBTQ parents has focused on their children and, more specifically, on documenting the children's developmental outcomes (Crowl, Ahn, & Baker, 2008; Gartrell, Rodas, Deck, Peyser, & Banks, 2006; Patterson, 2005; Stacey & Biblarz, 2001). The primary questions that researchers have posed are: Do children of gay and lesbian parents fare as well as children of heterosexual parents? Are there significant differences between their developmental outcomes, especially those related to sexuality and gender identity? These questions have been highly contentious, and the findings have been cited in court cases ranging from individual custody decisions to constitutional challenges (Patterson, 2005; Stacey & Biblarz, 2001). The overwhelming majority of researchers have concluded that there is no evidence that children of lesbian and gay parents are significantly different from those of heterosexual parents. Since difference from child "norms" has been taken to indicate parental inadequacy, this finding has helped advance custody cases and other expansions of legal rights for (some) queer parents (Stacey & Biblarz, 2001; Tasker & Patterson, 2007).

The prevalent focus on child outcomes has also meant that we know comparatively little about LGBTQ parents' experiences. Some researchers have begun to examine LGBTQ experiences of becoming parents and of developing parenting identities (Bergen, Suter & Daas, 2006; Goldberg & Allen, 2007; James-Abra, 2012; Kindle & Erich, 2005; Nelson, 2007; Ross, Steele, & Shapiro, 2005; Ross et al, in preparation; Stacey, 2006). A number of researchers have explored how queer people name and experience their roles as parents, with particular attention paid to how parents negotiate issues of relationship equality, division of labour, children's parental preferences, involvement of adults of different genders, and disclosure (Chan, Brooks, Raboy, & Patterson, 1998; Ciano-Boyce & Shelley-Sireci, 2002; Fulcher, Chan, Raboy, & Patterson, 2002; Gabb, 2005; Gartrell et al., 2006; Goldberg, Downing, & Sauck, 2008; Haimes & Weiner, 2000; Vanfraussen, Ponjaert-Kristoffersen, & Brewaeys, 2003; Vyncke & Julien, 2007). Others have tried to inform best practices for clinicians working with GLBQ parents and families (Ariel & McPherson, 2000; Negy & McKinney, 2006; Rondahl, Bruhner, & Lindhe, 2009). Almost all have explicitly recommended policy changes to improve the legal and social recognition and support of LGBTQ parents.

Both those advocating for and those arguing against LGBTQ parental rights have largely accepted the idea that the relative effectiveness/ value of the parents can be seen in the statistical normalcy of their children. By extension of this logic, the existence of disabled or non-normative children would cast significant doubt on the value, effectiveness and 'normalcy' of their parents, particularly if those parents are already regarded with suspicion. While some scholars have critiqued the dominant pathologization of children's non-normative sexuality and gender expression in contemporary social science research (e.g. Stacey & Biblarz, 2001; Thompson, 2002), few have questioned the more general presentation of children's 'normalcy' or 'health' as an argument for the worth and rights of the LGBTQ parents themselves.

It is perhaps not surprising, then, that very little research attention has been paid to LGBTQ parents who have children with 'special needs'. Of the paltry research that does exist on this topic, most has focused on adoption experiences. Leung, Erich and Kanenberg (2005) examined family functioning in gay and lesbian-parented families of adopted children with 'special needs' and found that these families generally scored similarly to heterosexual adoptive families of similarly categorized children. Ontario research by Philip Burge and Margaret Jamieson (2009), while not focused on LGBTQ parents, documented experiences of queer applicants who had been urged to consider adopting children with 'special needs' in order to increase the likelihood that they would receive any child. These authors also described experiences of other LGBTQ applicants who entered the adoption process specifically seeking out a child in the 'special needs' category. In general, accounts of LGBTQ parents of children with 'special needs' have largely been confined to literary/ experiential narratives rather than empirical studies (e.g. Briccetti, 2009; Moraga, 1997).

The dearth of research attention paid to LGBTQ parents of disabled children may be due to the fact that much of the discourse that is officially supportive of LGBTQ or queer parents has deployed a strategy of **normalization**. This strategy of presenting LGBTQ individuals, especially parents and their families, as 'just like everyone else', has been effectively critiqued (e.g. Epstein, 2005; Clarke, 2000; Hicks, 2005; Malone & Cleary, 2002). While an assertion of queer families' 'normalcy' has a practical rationale in certain contexts, prevalent politico-legal strategies based on queer parents' sameness accept and reinforce the idealized centrality of a heteronormative, 'traditional' family. As noted by Lisa Duggan (2003), Jane Ward (2008), and Jasbir Puar (2007), such strategies of normalization extend beyond parenting; large-scale North American 'gay and lesbian' or even 'LGBTQ' organizations have migrated toward a more market-driven, nationalist model of advocacy. Such moves do not support a fundamental examination of the ways that heteronormativity operates in conjunction with racism, classism, imperialism, sexism, ableism, cisnormativity, and other forms of material inequity.

The proposed study, in contrast, seeks to explore the experiences of LGBTQ parents of children who have been identified as, in some way, special, exceptional, or otherwise not falling under the expected and the 'normal'. Dominant strategies of normalization can be re-considered in terms of their everyday impact on these parents, with a focus on both how institutional arrangements support or challenge certain understandings of normalcy, for both parents and children, and how the parents themselves have engaged with or questioned discourses on normal parents, normal children, and desirable reproduction more generally.

12. METHODS

(a) Please describe all formal and informal procedures to be used. Describe the data to be collected, where and how they will be obtained and how they will be analyzed.

The proposed study will follow an ethnographic method that draws substantially, although not exclusively, on Dorothy Smith's Institutional Ethnography (IE) (2005) and its elaboration through other ethnographic and textual analyses (e.g. Daniel, 2008; De Montigny, 1995; Hicks, 2009; Ng, 1996; Titchkosky, 2008). The initial data collection framework, starting in the everyday world of LGBTQ parents of children with identified differences, is premised on Smith's concept of "the everyday world as problematic" (1987, title). Data collection and analysis will be augmented by methods from narrative and discourse analysis. This data collection and analysis draws particularly upon critical discourse analysis strategies articulated

by James Gee (2005), but follows other narrative researchers in attending to when and how people tell stories, and with what effects (Frank, 2010; Riessman, 2008).

IE approaches situate any investigation in a particular "standpoint", through which institutionalized relations and power arrangements will be viewed. As Smith and others have explained, "standpoint" in this type of research is a methodological practice rather than an essentialized identity (Harding, 2004; Smith, 2004, 2005). By starting from the everyday experiences of LGBTQ parents of children with 'special needs', the proposed study is not looking for a unified experience of LGBTQ parents of children with 'special needs' or asserting that people in this grouping hold a privileged position as knowers. Rather, this study will investigate how diverse people experience and make meaning of being so-designated in their institutionalized relations with others.

1. Interviews

Parent interviews will provide the primary focus of this stage of data collection, since, as explained above, this is the methodological standpoint from which the current project proceeds. Additional interviews with key informants or service providers will therefore be conceptually and methodologically supplementary to parent interviews, such that ongoing analysis of the parent interviews will dictate the specifics of further data collection (see also Data analysis).

All interviews will take place at a mutually agreed-upon location convenient for the participants. Locations could include the participants' residences, workplaces, or reserved rooms at the University of Toronto. Some interviews may take place on the telephone, although this would only be if an in-person interview was undesirable to the participant or otherwise unavailable. Interviews will be audiorecorded with the participants' written consent or, if any participant is uncomfortable with recording, the researcher will take detailed notes. Per ethnographic methods, field notes will be taken to contextualize the interview. Participants will be given the opportunity to select a pseudonym for themselves and their family members for future use in transcripts and any published documents. If they do not select pseudonyms, the researcher will do so. Participants will be offered moderate financial compensation for their time and for related expenses (pending approval by the research ethics board).

Parent interviews

Sample and format of parent interviews

The proposed study will commence with in-depth interviews of 7-10 individuals or couples/co-parents who meet the following criteria:

i) Identify themselves as lesbian, gay, bisexual, transgender, queer, two spirit, genderqueer, transsexual, or other non-heteronormative or non-cisnormative gender and sexual identity terms.

ii) Identify themselves as parents. This term will be open to include adoptive, foster, biological, non-biological parents as well as stepparents, and will not be dependent on particular family formations, legal recognition, or custody arrangements.

iii) State that they have been engaged in some way with professionals and/or systems in regard to one or more perceived 'special needs' pertaining to at least one of their children. Such 'special needs' could include a potential or identified disability (developmental, intellectual, learning, psychiatric, physical); behavioural, educational, and/or emotional concerns; or chronic health conditions. Parents would be eligible whether or not this engagement with professionals/systems has led to a formal or ongoing diagnosis or related categorization. Additionally, parents and/or involved professionals might disagree with the identification of their child as having "special needs". Professionals might include specialists employed within narrowly-defined 'special needs' service organizations (e.g. children's rehabilitation program workers), or might include adoption workers, teachers, family doctors, or others.

iii) Live within the greater Toronto area. This restriction is due to the resources of the researcher to meet with participants and also because parents in a given geographic region may have similar service systems available to them.

Prior to the interview, parents will be screened to ensure they meet the inclusion criteria and to gain demographic information that will facilitate purposive sampling (see Appendix **E**). Screenings will take place on the telephone. Screenings will not be audiorecorded.

The selection process will be designed to maximize diversity of parents according to stated sexual and gender identities, socioeconomic status, racial and ethnic identities, and paths to parenthood (adoption, use of assisted reproductive technologies, stepparent arrangements). Consideration will also be given to the ages of children, particular labels or diagnoses given to children, and types of 'special needs' services parents have experience with (e.g. hospital in-patient unit, educational assessment, community rehabilitation program).

These semi-structured, in-depth interviews will take 1-2 hours, with the possibility of follow-up telephone or in-person conversations to verify the researcher's findings.

Content of parent interviews: Systemwork, narratives, and texts

Interviews will be based on an interview guide (see Appendix B). The focus of the interview will be on the participants' everyday experiences as shaped by interactions with systems and discourses. There will be three primary subsets of questions:

a) Accounts of "systemwork"

One series of questions will investigate parents' "systemwork", that is, the activities which parents undertake in their everyday lives as part of satisfying systemic or institutional requirements in order to access needed resources. My use of this term follows from Sheila Neysmith and colleagues' conceptualization of "provisioning" (Neysmith et al., 2012), but restricts this project's attention to a more narrow range of activities. Neysmith et al. use "provisioning" to describe "the work needed to realize the necessities and conveniences of life" (2012, 4), thus describing a wide range of activities done with the intent of obtaining needed resources for individuals and for those toward whom they have responsibilities. Here, "systemwork" designates the subset of provisioning that is directly connected to the requirements of professionalized and institutionalized service systems, with a focus on special needs service systems.

"Systemwork" also complements and refines institutional ethnographers' expansive understanding of "work":

> By institutional ethnographers, 'work' is used in a generous sense to extend to anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about. It means much more than what is done on the job. (Smith, 2005, p. 151-152).

Thus, "work" can be paid or unpaid, recognized or unrecognized, emotional or intellectual/ physical, and can include waiting or answering questions as well as filling in forms or asking question (see Smith, Mykhalovsky & Weatherbee, 2006). A strength of institutional ethnography has been in its recognition and investigation of work that has been previously rendered invisible, particularly work that has been done by women (see e.g. Griffith and Smith, 2005). The unpaid work that parents, and particularly mothers, do is frequently rendered invisible; consider phrases such as "work-life balance" in which "work" refers exclusively to paid employment outside of "life" and the home (Gibson, 2012a). Similarly, while "service users" and "disabled people" have often been defined in terms of "not working", other ethnographers have identified the extensive work that disabled people and other service users engage in as they attempt to secure needed resources (e.g. Campbell, 2008; Traustadottir, 2008).

The systemwork done by parents of children with 'special needs' will almost certainly vary with the family's particular situation. However the very identification of a child's perceived difference as a 'special need' necessitates engaging with organizational systems, and such encounters usually demand particular activities of parents, all of which take time and effort. 'Special needs systems' include (but are not limited to) medical, educational, community-based, and social service organizations and professionals.

The systemwork this study will examine is not reducible to "paperwork". While it would include filling out forms, it would also include attending meetings, picking up prescriptions, interpreting reports, filing insurance claims, documenting telephone conversations, scheduling and attending appointments, making follow-up calls, sending emails, implementing suggested interventions (e.g. giving medications, preparing specific foods, responding to children's behaviours in prescribed ways), making decisions on programs or plans, researching treatment/service options, addressing unexpected situations (e.g. emergency telephone calls), and integrating the emotional, physical, mental components of these various interactions and activities, all *in addition to* any paid employment and other everyday/everynight work of caring for their children and other people in their lives.

LGBTQ parents also have particular work that they also do to satisfy systemic requirements. Here systemwork might involve an additional layer of assessing and meeting institutional requirements to document their relations and status as family members, often prior or in addition to seeking resources or information. Such systemwork might include selectively revealing or concealing family identities when facing forms and conversations which assume heterosexual/cisgender identities and relations; seeking to create officially-recognized family relations through adoption, marriage, immigration, and other documents when procuring resources based on familial ties; or explaining to multiple others how relations within the family replicate/depart from ideological expectations of "the Standard North American Family" (Smith, 1999).

Proceeding from the assumption that these parents are knowledgeable experts about the work that they do in their everyday lives, the interviews will focus on developing an understanding of parents' everyday systemwork (Neysmith et al, 2012; Smith, 2005; DeVault & McCoy, 2006). Interviews with parent-participants will be designed to help develop an understanding of what this work looks like in their everyday lives. Interviews will also capitalize on parents' embodied knowledge by asking for their suggestions on how systems might be altered to better serve parents.

b) Narratives

In the interviews, selected questions (1 and 2) will depart from institutional ethnographic traditions and follow narrative interviewing strategies (Riessman, 2008; Frank, 2010). These questions will seek to elicit participants' stories about their families in relation to "LGBTQ" and "special needs" categories. While clearly interconnected with questions about systemwork, these will be more open-ended questions about the participants, their children, and their perspectives on what it means to be "LGBTQ parents" of children with "special needs" (See Appendix A). Given the existing discourses surrounding desirable and undesirable reproduction, these questions offer an opportunity to hear stories from parents that may respond to, replicate, integrate, complicate, and/or reject dominant narratives. These questions also supplement more focused questions about systemwork and the role of texts and service providers in participants' lives by offering an opportunity for participants to share a more reflective account of their experiences and how they make meaning of them. Instead of treating participant interviews only as data in the construction of a singular, researcher narrative, as is more traditionally done in

many qualitative traditions including IE, this project seeks to include participants as co-creators of meaning and contributors to emergent analysis (Gibson, 2012b; Walby, 2007).

c) Texts

I will ask participants to talk about significant texts in their everyday lives. I will discuss this during my screening interactions with participants, and explain that "texts" include any written or recorded documents, such as identification forms, photos or videos, medical or educational assessments, and so forth. While many texts that shape parents' systemwork and narratives may not be consciously known to the parents (e.g. education legislation or diagnostic criteria), these questions will allow me to learn about how they see texts as interwoven with their own experiences (or not) and also allow me to highlight texts that might be particularly significant to participants. I will then use participants' responses to inform my analysis of data, and to guide further investigations.

Key informant interviews

Sample and format of key informant interviews

I will interview 2-4 key informants knowledgeable about LGBTQ parenting communities and/or parents of children with 'special needs'. To be eligible as key informants these individuals must have expertise in advocacy, research, or community work with LGBTQ parents and/or parents of children with 'special needs'. For example, I intend to contact the directors of LGBTQ parenting programs at the 519 Community Centre and the Sherbourne Health Centre. I will also contact people who are employed as advocates for parents of children with 'special needs' through organizations such as the Child Advocacy Project (through Legal Aid Ontario), Autism Ontario, Holland Bloorview, People First Ontario, and/or recognized research experts on parenting and disability in the GTA.

These interviews will take up to 1 hour, with the possibility of follow-up telephone or in-person conversations to verify emerging findings.

Content of key informant interviews

Key informants will be asked about what they have heard from parents about their experiences parenting children with identified differences and about their interactions with special needs service systems. They will be asked for themes and examples of problems or successes that parents have reported. The precise questions will vary depending on the area of expertise of the informant (e.g. disability, LGBTQ issues). Informants will also be asked about texts (e.g. forms, policies, identification documents) that they think influence parents' experiences. Finally, informants may be asked to comment on emerging themes from the parent interviews or clarify areas of uncertainty.

Service provider interviews

Sample and format of service provider interviews

I plan to interview 4-6 service providers or administrators who have practical experience in working within systems for children with 'special needs'. These interviews, however, are the most dependent upon the findings from parent interviews; if adequate data has been collected from parents, key informants, and texts, service provider interviews may be deemed unnecessary for this project.

The need to interview service providers will be determined by the findings of the parent interviews, following established institutional ethnographic methods developed by Dorothy Smith (2005) and others. Under this model, the researcher designates an initial "standpoint" and speaks to people from this perspective first, subsequently determining from initial data whom to interview next. If the initial data indicate that particular categories of service providers (e.g. occupational therapists, educators, adoption workers, etc.) are especially pivotal in the experiences of "systemwork" among parents, or if the documents that parents identify as central

to their experiences are all written with/by/for particular types of providers, the relevant types of service providers would then be interviewed based on these observations. If, on the other hand, parents talk about more divergent or diffuse service systems and the use of selected documents is either quite straightforward or differs entirely from parent to parent, service provider interviews would not advance the overall investigation in terms of answering the primary research questions. In this case, no service provider interviews would be completed.

If conducted, service providers will be selected to interview based on what types of providers are identified as particularly important in the parent interviews. These interviews will take up to 1 hour, with the possibility of follow-up telephone or in-person conversations to verify findings.

Content of service provider/ administrator interviews

Providers/ administrators will be asked about their experience working with parents, and with LGBTQ parents in particular. While individuals selected as "key informants" might also be service providers, the sampling for and content of provider interviews will be different. Providers will be selected because of their institutionalized position within particular systems relevant to the investigation rather than due to their expertise on this group of parents. Thus, unlike key informants, these providers will not be asked to share expert knowledge of the parents in question, but rather to provide details about their own everyday work, documentation practices/ use of texts, and decision-making within particular service systems. Consistent with IE methods, the questions will be designed to provide additional information and perspectives on processes and texts described in parents' interviews.

Texts

A final, and interrelated, domain of data collection will be in the selection and acquisition of texts for further analysis. As is common in both ethnographic work and discourse analysis, the process of selecting texts will be integrated into other domains of data selection and will also be part of an iterative process with data analysis. For example, interview parent participants might mention a document, such as an individualized education plan (IEP), that I then discuss with key informants and service providers. Service providers might identify connections between this document and budget documents for school boards. In further analysis of the IEP text and these interviews, I might find I need to focus on a particular piece of education legislation to understand how IEPs are structured and how they in turn shape the experiences of parents (Smith, 2005). Finally, using discourse analysis techniques on a term like "exceptionality", I might reconnect texts to the narratives told by parents about their child and see how the terms and stories available in each overlap and depart (Gee, 2005).Thus, while I anticipate that 2-3 texts will be identified as key documents for in-depth analysis, many other texts will be referenced. Possible texts include: gamete donor selection forms and legislation; adoption selection forms and legislation; birth or adoption certificates and legislation; special education forms and legislation.

Data Analysis

As in many branches of qualitative and interpretive research traditions, the proposed study will not have a distinctive data analysis stage that can easily be separated from data collection (Charmaz, 2006; Riessman, 2008). As has been discussed, interview findings will be analyzed on an ongoing basis so that further participants and texts can be selected, and emerging findings can be clarified, modified, or challenged.

Such initial data analysis will be modeled on methods from institutional ethnography, as described in Campbell and Gregor (2002) and Dorothy E. Smith (2005). Thus, each interview will be analyzed in terms of what it addresses in the research questions, what additional questions it raises, what texts or other interviews it suggests, and overall what we learn about

existing institutional relations in special needs systems from the standpoint of LGBTQ parents. Textual analyses are similarly integrated with IE methods, in which texts are seen as a part of human activities, both produced by people's doings (often in consultations with other texts) and influencing other people's behaviours as they are 'activated' in future and ongoing social interactions (Smith, 2005, 2006). Thus interviews will be transcribed and analyzed on an ongoing basis, and the resulting transcripts will be considered alongside texts collected in order to form tentative explanations of how parents' systemwork is shaped by institutional arrangements.

Also consistent with ethnographic and interpretive methods, analysis will be iterative. As further information is obtained from the interviews and from textual investigations, I will return to earlier analyses of texts and transcripts. If deemed necessary, interview participants will be re-contacted to see if they would be willing to discuss emerging analyses. Further, textual analyses will consider how texts operate through hierarchies, such that dominant texts create categories that subordinate texts much satisfy (Kinsman, 1995). This process will be highlighted in the 2-3 key texts that are examined, and the impact of such textual hierarchies and their institutional implementation on the everyday systemwork of parents will be a central piece of the analysis (Namaste, 2006; Smith, 2006; Turner, 2006; Eastwood, 2006).

This stage of initial data analysis will be completed when the first two research questions of the study have been thoroughly answered. As the data collection stage winds down, additional analyses addressing the third and fourth research questions will commence. This will entail discourse analysis of key excerpts from parent transcripts alongside key texts, and will incorporate insights and information gained in the initial data analysis stage. While the IE approach lends itself to an ever-broadening "mapping" of social relations (Campbell & Gregor, 2002; Turner, 2006), discourse analysis techniques offer opportunities to consider selected pieces of data in greater depth.

All transcripts will be considered for inclusion in the discourse analysis, but ethnographic field notes written following the interviews will highlight particular interviews or moments that address questions about normalizing discourses and relational identities. In addition, as I conduct the transcription and initial analysis of the institutional shaping of parents' everyday "systemwork", I will also use research memos to highlight sections of transcript that will warrant further consideration in the discourse analysis stage. Finally, the textual analysis of institutional documents may overlap in time with some of the narrative discourse analysis; these analyses will inform each other through ongoing research memos and analytical reflection. For example, I might identify that phrases used by parents to describe their experience also reflect categories in a particular text and connect to other pieces of legislation.

 Narrative discourse analysis will commence with a consideration of questions posed by Gee (2005) as applied to excerpted parent narratives and texts. For this in-depth analysis, 2-3 parent narratives will be selected. This selection will be made based on which excerpts best address research questions 3 and 4. Discourse analysis techniques from Gee will be used to consider syntax, key terms, images, or plotlines examined while situating them in the particular contexts and relations in which they occurred and where recounted. This will be done using the questions for discourse analysis described in James Gee's work (2005, pp. 110-115). Detailed analysis will not proceed through "coding", but rather in creating "stanzas" of narrative meaning as described by Gee (Gee, 2005, pp 118-136; Riessman, 2008, pp. 93-103). This process of organizing data into stanzas may require listening to audiorecordings again to note where there are breaks in speech or meaning or changes in intonation. The excerpts will be analyzed within the context of the entire interview with that parent, and in light of demographic and situational particulars. Thus, in contrast with grounded theory or some other forms of qualitative social

science research, and distinctive from the initial IE analysis of patterns in the parents' systemwork, this second phase of analysis will look more closely at how individuals make meaning of their experiences. The accounts will be seen as unavoidably in conversation with others, and intertextual analysis will be used to consider the connections between these excerpts and other texts, narratives, and terms seen in the data (Gee, 2005; Smith, 2005). At the same time, and in keeping with the project's ethnographic commitments, the discursive terms will be considered in conjunction with their material production and effects. That is, the stories will not be treated as disembodied or immaterial, but rather as produced through and productive of material, relational, and embodied experiences.

In this way, findings from the initial analysis (research questions 1 and 2) will inform the analysis for questions 3 and 4, as an emerging understanding of the social and material implications of discourses and texts will be critical in considering the stories that participants present. The research interview is not the only instance in which parents will have recounted or conceived of these narratives. For example, if a participant describes a changing understanding of their child's development from "normal" to "abnormal", it is important to consider how this narrative of growing alarm may have been used in multiple interactions with service providers as part of the parent justifying a request for resources. Institutional requirements of a diagnosis or a diagnosable narrative may thus frame how parents talk about intimate experiences. The analysis in this study might particularly investigate where these scripts seem to falter, considering silences and contradictions as well as word choice or metaphor. The detailed discourse analysis of narrative excerpts will proceed until a coherent explanation is achieved of how these accounts respond to or challenge the research questions (3 and 4).

(b) Attach a copy of all questionnaires, interview guides and/or any other instruments.

(c) Include a **list of appendices** here for all additional materials submitted (e.g., Appendix A – Informed Consent; Appendix B – Interview Guide, etc.):

Appendix A -- Informed Consent
Appendix B -- Interview Guides
Appendix C -- Recruitment Text
Appendix D -- Handout for Participants
Appendix E -- Parent Screening Guide

13. PARTICIPANTS AND/OR DATA

(a) Describe the participants to be recruited, or the individuals about whom personally identifiable information will be collected. List the inclusion and exclusion criteria. Where the research involves extraction or collection of personally identifiable information, please describe from whom the information will be obtained, what it will include, and how permission to access the data is being sought. (Strategies for recruitment are to be described in section #15.) Where applicable, justify the sample size.

Participants will be recruited via emails and flyers at appropriate community organizations and listserves (see section 15 for details). The starting sample size of 7-10 individual parents or co-parents/couples is consistent with both institutional ethnographic and narrative methods. The sample size is also consistent with the relatively small community of parents who might be available and the limitations of the researcher's resources. However, as is also common within narrative and ethnographic methods, further participants may be recruited if a greater diversity of experience is found than anticipated and additional interviews are required to properly understand the relevant issues.

As listed above, parents will be eligible to participate if they:
i) Identify themselves as lesbian, gay, bisexual, transgender, queer, two spirit, genderqueer, transsexual, or other non-heteronormative or non-cisnormative gender and sexual identity terms.
ii) Identify themselves as parents. This term will be open to include adoptive, foster, biological, non-biological parents as well as stepparents, and will not be dependent on particular family formations, legal recognition, or custody arrangements.
iii) State that they have been engaged in some way with professionals and/or systems in regard to one or more perceived 'special needs' or disabilities pertaining to at least one of their children.
iv) Live within the greater Toronto area. This restriction is due to the resources of the researcher to meet with participants and also because parents in a given geographic region may have similar service systems available to them.

Exclusion criteria will be any potential participants with whom I have a preceding or concurrent relationship as a therapist/ social worker or teacher.

Also consistent with these approaches, sampling will be purposeful and aim for a diversity of gender and sexual identities, family structure and history (e.g. adoptive, birth parent, stepparent), race and ethnicity, socioeconomic status, and children's 'special needs'. Thus some parents may not be interviewed if their demographic identities match those of the other participants too closely (e.g. all white lesbian couples of children with autism).

(b) Is there any group or individual-level vulnerability related to the research that needs to be mitigated (for example, difficulties understanding informed consent, history of exploitation by researchers, power differential between the researcher and the potential participant)?

There is often justifiable suspicion within LGBTQ communities towards researchers and service providers; this is due to a legacy of research and healthcare or social services that have exploited, marginalized, and harmed people with LGBTQ identities. Such wariness may be compounded among participants who also belong to other communities with histories of exploitation by researchers (e.g. Aboriginal participants). As a means of addressing concerns regarding exploitation, my own background belonging to and working within LGBTQ communities will therefore be mentioned in the recruitment text that is sent to LGBTQ organizations and in the informed consent letter for parent participants. Concerns about confidentiality might also be particularly acute for some individuals who are not able to disclose their LGBTQ identity in other domains of their lives. Also, the LGBTQ community can sometimes seem small and people might be concerned about who will find out about their participation. I will take particular care in discussing confidentiality and who does and does not have access to identifying information (see Confidentiality).

14. EXPERIENCE OF INVESTIGATORS WITH THIS TYPE OF RESEARCH

(a) Please provide a brief description of previous experience with this type of research by (i) the principal investigator/supervisor or sponsor, (ii) the research team and (iii) the people who will have direct contact with the participants. If there has not been previous experience, please describe how the principal investigator/research team will be prepared.

I have relevant research experience that will inform my work in this project. I have worked as a research project coordinator with Professor Michael Saini in the past. In this role, I screened participants, set up a focus group, discussed and obtained informed consent, facilitated focus groups, and analyzed transcript data. I have also conducted individual research interviews before as a part of coursework in the doctoral program. I have many years of experience as a social work practitioner and therapist that have given me certain skills in guiding conversations in a respectful and purposeful manner, but I recognize that the practitioner role has some important differences from that of a researcher. My thesis committee members all have expertise in qualitative research methods and will be guiding my work.

I will be the only person contacting and interacting with participants and potential participants in this project.

(b) For projects that will involve community members (e.g., peer researchers) in the collection and/or analysis of data, please describe their status within the research team (e.g., are they considered employees, volunteers or participants?) and what kind of training they will receive?

I will be the only person involved in the research apart from the guiding role of my supervisor, committee members, and the participants themselves.

15. RECRUITMENT OF PARTICIPANTS

- Where there is recruitment, please describe how, by whom, and from where the participants will be recruited
- Where participant observation is to be used, please explain the form of insertion of the researcher into the research setting (e.g., living in a community, visiting on a bi-weekly basis, attending organized functions)
- If relevant, describe any translation of recruitment materials, how this will occur and whether or not those people responsible for recruitment will speak the language of the participants.
- **Attach a copy of all posters, advertisements, flyers, letters, e-mail text, or telephone scripts to be used for recruitment.**

I will be sending email announcements about the research project to community organizations and listserves that have a focus on LGBTQ community members and/or parents of children with special needs in the Greater Toronto Area. Sample organizations would include the Sherbourne Health Centre, the 519 Community Centre, Holland Bloorview Children's Rehabilitation Hospital, Toronto Partnership for Autism Services, Integra, LGBT Parenting Connection. I also anticipate that recruitment will be furthered by word of mouth as previous participants tell other people that they might know. The email/ flyer text is attached as Appendix C. The wording of the document is slightly different for LGBTQ organizations than for services that focus on children with disabilities/ special needs and their families.

Key informants will be recruited individually based on their professional expertise. I will also ask key informants if they have suggestions as to other people I should speak with. If needed, service providers will be recruited from agencies or programs that belong to a service sector (e.g. special education) or professional role (e.g. psychologist) that previous data suggests warrants further investigation (see Methods).

16. COMPENSATION

Please see U of T's [Compensation and Reimbursement Guidelines](#).

(a) Will participants receive compensation for participation?

Financial	Yes ☒	No ☐
In-kind	Yes ☐	No ☐
Other	Yes ☐	No ☐

(b) If **Yes**, please provide details and justification for the amount or the value of the compensation offered.

 I will offer $30 plus expenses for interviews. This total is compensation for 1-2 hours of interview plus possible travel time. If the participant selects to have the interview completed in 2 parts, the total compensation will remain the same. If more than one person (e.g. a couple or co-parents) is

interviewed at the same time, the total compensation remains $30 plus expenses. Possible expenses to be covered include parking or transit costs and childcare.

(c) If **No**, please explain why compensation is not possible or appropriate.

(d) Where there is a withdrawal clause in the research procedure, if participants choose to withdraw, how will compensation be affected?

If participants withdraw before the interview stage then they will not be compensated. If they choose to withdraw at any time during or after the interview, they will receive the full compensation.

SECTION C –DESCRIPTION OF THE RISKS AND BENEFITS OF THE PROPOSED RESEARCH

17. POSSIBLE RISKS

(a) Please indicate all potential risks to participants as individuals or as members of a community that may arise from this research:

(i) Physical risks (e.g., any bodily contact or administration of any substance):   Yes ☐
No ☒

(ii) Psychological/emotional risks (e.g., feeling uncomfortable, embarrassed, or upset): Yes ☒
No ☐

(iii) Social risks (e.g., loss of status, privacy and/or reputation):   Yes ☒
No ☐

(iv) Legal risks (e.g., apprehension or arrest, subpoena):   Yes ☐
No ☒
(b) Please briefly describe each of the risks noted above and outline the steps that will be taken to manage and/or minimize them.

There is a possibility that some participants may feel upset or vulnerable in discussing their experiences. I will attend to this possibility during this interview and allow people time to recover as needed. I will also use clinical skills in crisis management should this situation arise. In addition, I will offer all participants a handout of local resources that they can contact and offer further referrals if these are needed. Social risks include the disclosure of parents' LGBTQ identity or their child's 'special needs' status (if these are not generally disclosed by participants). Social risks will be mitigated through guarding confidentiality and through restricting the access to interview data to **myself and my supervisor. I have also included information about minimizing social risks on the consent form.**

18. POSSIBLE BENEFITS

- Describe any potential direct benefits to participants from their involvement in the project
- Describe any potential direct benefits to the community (e.g., capacity building)
- Comment on the potential benefits to the scientific/scholarly community or society that would justify involvement of participants in this study

Some participants might find it rewarding to have an opportunity to talk about their experiences and make suggestions for improvements to existing systems. There are definite benefits to the scholarly

and service provider communities from this research, since this is a topic that has not been addressed by researchers. Findings will have direct implications for the theory and practice of providing services to these parents and their families.

SECTION D – INFORMED CONSENT

19. CONSENT PROCESS

(a) Describe the process that will be used to obtain informed consent and explain how it will be recorded.   Please note that it is the quality of the consent, not the form that is important. The goal is to ensure that potential participants understand to what they are consenting.

(b) If the research involves extraction or collection of personally identifiable information from or about a research participant, please describe how consent from the individuals or authorization from the data custodian (e.g., medical records department, district school board) will be obtained.

The informed consent form will be offered by email or mail prior to the interview, and will also be available at the beginning of the interview. Forms will be printed on Faculty of Social Work letterhead. I will discuss the form and any questions or uncertainties that participants may have about it and make sure that they understand they may withdraw consent at any time. The interview will not commence unless the document has been signed. Audiotaping will not commence until and unless the participant has initialed their consent.

20 CONSENT DOCUMENTS

(a) **Attach a copy of the Information Letter/Consent Form.**
For details about the required elements in the information letter and consent form, please refer to our informed consent guide (**http://www.research.utoronto.ca/wp-content/uploads/2010/01/GUIDE-FOR-INFORMED-CONSENT-April-2010.pdf**)

Additional documentation regarding consent should be provided such as:
- **screening materials introductory letters, letters of administrative consent or authorization**

(b) If any of the information collected in the screening process - prior to full informed consent to participate in the study - is to be retained from those who are later excluded or refuse to participate in the study, please state how potential participants will be informed of this course of action and whether they will have the right to refuse to allow this information to be kept.

See Appendix E for parent screening materials. I will inform the participants that I am taking written notes during the screening process and obtain verbal consent to do so (over the phone) or written consent (email). I will clarify that this information will only be kept for the duration of the project and will be **kept confidential if they agree to participate, and destroyed if the do not consent to participate further or withdraw from the study**.

21. COMMUNITY AND/OR ORGANIZATIONAL CONSENT, OR CONSENT BY AN AUTHORIZED PARTY

(a) If the research is taking place within a community or an organization which requires that formal consent be sought prior to the involvement of individual participants, describe how consent will be obtained and attach any relevant documentation. If consent will not be sought, please provide a justification and describe any alternative forms of consultation that may take place.

No additional organizations will be required to give consent.

(b) If any or all of the participants are children and/or others who are not competent to consent, describe the process by which capacity/competency will be assessed, and the proposed alternate source of consent.

    i)   Submit a copy of the permission/information letter to be provided to the person(s) providing the alternative consent

    ii)   Describe the assent process for participants and attach the assent letter.

Not applicable.

22. DEBRIEFING and DISSEMINATION

(a) If deception or intentional non-disclosure will be used in the study, provide justification. Please consult the Guidelines for the Use of Deception and Debriefing in Research

Not applicable.

(b) Please provide a copy of the written debriefing form, if applicable.

Not applicable.

(c) If participants and/or communities will be given the option of withdrawing their data following the debriefing, please describe this process.

On the consent form I specify that participants can have their data removed from the project **up until the data analysis has been completed, within 4-6 months of the interview.** In this case, their data will be expunged from any subsequent reports, presentations, or publications and all relevant files will be deleted. **I have included information on restrictions to withdrawing data on the consent forms.**

(d) Please describe what information/feedback will be provided to participants and/or communities after their participation in the project is complete (e.g., report, poster presentation, pamphlet, etc.) and note how participants will be able to access this information.

On the consent form participants are given the option of indicating if they would be available for consultation on initial findings, and also whether they would like to be informed of any final results from the study. Depending on available resources, these final findings will be presented via an emailed or mailed research summary, hosted on a website, and/or presented in a community forum.

23. PARTICIPANT WITHDRAWAL

(a) Where applicable, please describe how participants will be informed of their right to withdraw from the project and outline the procedures that will be followed to allow them to exercise this right.

On the consent form I specify that participants can have their data removed from the project. They can contact me to do this, whether in-person, by telephone, or by email **up until the data analysis has been completed, within 4-6 months of the interview. I have included information on restrictions to withdrawing data on the consent forms.**

(b) Indicate what will be done with the participant's data and any consequences which withdrawal may have on the participant.

If a participant chooses to withdraw from the study, their data will be expunged from any subsequent reports, presentations, or publications and all relevant files will be deleted.

(c) If participants will not have the right to withdraw from the project at all, or beyond a certain point, please explain. Ensure this information is included in the consent process and consent form.

Participants will not be able to withdraw data once the dissertation analysis is complete, **within 4-6 months of the interview.** This limitation is listed on the consent form.

SECTION E – CONFIDENTIALITY AND PRIVACY

24. CONFIDENTIALITY

Data security measures must be consistent with UT's *Data Security Standards for Personally Identifiable and Other Confidential Data in Research*. All identifiable electronic data that is being kept outside of a secure server environment must be encrypted, consistent with the standards described at: *http://www.utoronto.ca/security/UTORprotect/encryption_guidelines.htm:*

(a) Will the data be treated as confidential?   Yes ☒   No ☐

(b) Describe the procedures to be used to protect the confidentiality of participants or informants, where applicable

Confidentiality procedures are discussed on the confidentiality form. I will be the only person contacting participants and **only my supervisor and I will have access to any identifying information**. Transcripts will be de-identified within four weeks of the interview, and participants will be asked to select pseudonyms or one will be chosen for them. **Data files and other identifiable documents will be kept on an encrypted USB key under password protection.** Identifying information will be destroyed within six months of the end of the study, and earlier if requested by the participants.

(c) Describe any limitations to protecting the confidentiality of participants whether due to the law, the methods used, or other reasons (e.g., a duty to report)

Limitations to confidentiality are listed on the consent form as situations in which child maltreatment is suspected or someone is in imminent danger.

25. DATA SECURITY, RETENTION AND ACCESS

(a) Describe how data (including written records, video/audio recordings, artifacts and questionnaires) will be protected during the conduct of the research and dissemination of results.

Data files will be kept on an encrypted USB key. Signed consent forms will be scanned and stored on this USB key, and the originals will be destroyed.

 (b) Explain how long data will be retained. (If applicable, referring to the standard data retention practice for your discipline) Provide details of their final disposal or storage. Provide a justification if you intend to store your data for an indefinite length of time. If the data may have archival value, discuss how participants will be informed of this possibility during the consent process.

Audiorecordings will be destroyed within six months of the interview, as specified on the consent forms. Other identifying and contact information for participants will be destroyed within six months of community dissemination of the findings (emailed to participants or presented in a community forum), and earlier if requested by the participants.

(c) If participant anonymity or confidentiality is not appropriate to this research project, please explain.

Not applicable.

(d) If data will be shared with other researchers or users, please describe how and where the data will be stored and any restrictions that will be made regarding access.

No identifying information will be shared with other researchers or users.

SECTION F – LEVEL OF RISK AND REVIEW TYPE

See the *Instructions for Ethics Review Protocol Submission Form* for detailed information about the Risk Matrix.

26. RISK MATRIX: REVIEW TYPE BY GROUP VULNERABILITY and RESEARCH RISK

(a)   Indicate the Risk Level for this project by checking the intersecting box

		Research	
Risk			
Group Vulnerability	**Low**	**Medium**	**High**
Low	1 ☐	1 ☐	2 ☐
Medium	1 ☐	2 ☒	3 ☐
High	2 ☐	3 ☐	3 ☐

(b) Explain/justify the level of research risk and group vulnerability reported above:

The most vulnerable group of participants to be involved in this study will be lesbian, gay, bisexual, transgender, or queer parents of children who have been identified as having 'special needs' or disabilities. This group can be seen as having "medium" group vulnerability. Some participants may not have disclosed either their LGBTQ identities or their child's diagnosis or disability, and/or may have previously experienced discrimination based on these identities. Such participants could be seen as moderately vulnerable. At the same time, other parent-participants may have extensive experience of disclosure and advocacy and may not experience such disclosure and discussion as difficult. In terms of the research risk, interviews will not pose any threat to the financial, legal, or physical well-being of participants. However the interview process of discussing experiences that may have been trying, including previous experiences of marginalization or learning of a child's diagnosis, poses some emotional risk of upsetting participants. **In addition, if participants disclose their own participation in the project to others, then there may be some social risk associated with their disclosure of their identity as an LGBTQ parent of a child with 'special needs'; this risk can be minimized by participants themselves, as is described on consent forms. The social and emotional risks combined can be considered a medium research risk.**

(Please note that the final determination of Review Type and level of monitoring will be made by the reviewing University of Toronto REB)

Based on the level of risk, these are the types of review that a protocol may receive:

Risk level = 1: Delegated Review;   Risk level = 2 or 3: Full Board Review

For both delegated and full reviews (SSH&E, HS, or HIV), please submit one electronic copy of your protocol and all appendices (e.g., recruitment, information/consent and debriefing materials, and study instruments) as a **single** Word document or a pdf. *Do not submit your entire research proposal.* Please ensure that the electronic signatures are in place and e-mail to **new.ethics.protocols@utoronto.ca**

The deadline for delegated review (SSH&E or HS) is EVERY Monday, or first business day of the week, by 4 pm. Information about full REB meeting and submission due dates are posted on our website (SSH&E, HS or HIV).

HIV REB reviews all protocols at full board level but applies proportionate review based on the level of risk.

All other submissions (e.g., amendments, adverse events, and continuing review submissions) should be sent to ethics.review@utoronto.ca

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| SECTION G – SIGNATURES |

27. PRIVACY REGULATIONS

My signature as Principal Investigator, in Section G of this protocol form, confirms that I am aware of, understand, and will comply with all relevant laws governing the collection and use of personally identifiable information in research. I understand that for research involving extraction or collection of personally identifiable information, provincial, national and/or international laws may apply and that any apparent mishandling of personally identifiable information must be reported to the Office of Research Ethics.

For U of T **student researchers**, my signature confirms that I am a registered student in good standing with the University of Toronto. My project has been reviewed and approved by my advisory committee or equivalent (where applicable). If my status as a student changes, I will inform the Office of Research Ethics.

Signature of Investigator: _____   Date:

For **Graduate Students**, the signature of the Faculty Supervisor is required. For **Post-Doctoral Fellows** and **Visiting Professors or Researchers**, the signature of the Faculty Sponsor is required. In addition to the supervisor/sponsor, the chair or the dean of the department is required to approve and sign the form

As the **Faculty Supervisor** of this project, my signature confirms that I have reviewed and approve the scientific merit of the research project and this ethics protocol submission. I will provide the necessary supervision to the student researcher throughout the project, to ensure that all procedures performed under the research project will be conducted in accordance with relevant University, provincial, national or international policies and regulations that govern research involving human subjects. This includes ensuring that the level of risk inherent to the project is managed by the level of research experience that the student has, combined with the extent of oversight that will be provided by the Faculty Supervisor and/or On-site Supervisor.

As the **Faculty Sponsor** for this project, my signature confirms that I have reviewed and approve of the research project and will assume responsibility, as the University representative, for this research project. I will ensure that all procedures performed under the project will be conducted in accordance with all relevant University, provincial, national or international policies and regulations that govern research involving human participants.

Signature of Faculty Supervisor/Sponsor:	Date:

As the **Departmental Chair/Dean**, my signature confirms that I am aware of the requirements for scholarly review and that the ethics protocol for this research has received appropriate review prior to submission.

In addition, my administrative unit will follow guidelines and procedures to ensure compliance with all relevant University, provincial, national or international policies and regulations that govern research involving human participants. My signature also reflects the willingness of the department, faculty or division to administer the research funds, if there are any, in accordance with University, regulatory agency and sponsor agency policies.

Print Name of Departmental Chair/Dean (or designate) :

Signature of Departmental Chair/Dean: _____   Date:
(or designate)

Appendix B: Ethics Approval Letter

UNIVERSITY OF TORONTO

OFFICE OF THE VICE PRESIDENT, RESEARCH

PROTOCOL REFERENCE # 29363

November 18, 2013

Dr. Izumi Sakamoto
FACULTY OF SOCIAL WORK
Ms. Margaret Gibson
FACULTY OF SOCIAL WORK

Dear Dr. Sakamoto and Ms. Margaret Gibson,

Re: Your research protocol entitled, "Akin to difference: An ethnographic investigation into the everyday experiences of lesbian, gay, bisexual, transgender or queer (LGBTQ) parents of children with 'special needs'"

ETHICS APPROVAL	**Original Approval Date: November 18, 2013**
	Expiry Date: November 17, 2014
	Continuing Review Level: 2

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol, for a period of **one year**. Ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.
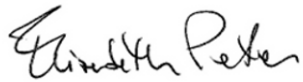
If your research is funded by a third party, please contact the assigned Research Funding Officer in
Research Services to ensure that your funds

are released. Best wishes for the successful

completion of your research.

Yours sincerely,

Elizabeth Peter, Ph.D. REB Chair

REB Manager

Daniel Gyewu

Appendix C: Recruiting Documents

i.   Key Informant LGBTQ parents

I am a doctoral student in social work at the University of Toronto who has worked with and been a part of Toronto's LGBTQ (lesbian, gay, bisexual, trans, or queer) community for many years. I am currently conducting research on LGBTQ parents of children with 'special needs' and their interactions with service providers.

I am interested in interviewing you as a "key informant" or person knowledgeable about LGBTQ parents and communities. Because of your expertise, you would offer a valuable perspective to this research. The project has a goal of suggesting improvements to the current policies and services and increasing researchers' understanding of parents' perspectives. You would receive $30 for their time, plus expenses and we can talk at a time and place that is convenient for you.

Please let me know if you would like to talk further about this research, or if you know of anyone else who might be interested in participating in this study. I can be reached at (416) 890-0357 or margaret.gibson@mail.utoronto.ca.

Thank you for your time,
Meg

Margaret (Meg) Gibson, MSW RSW
Doctoral Candidate
Factor-Inwentash Faculty of Social Work
University of Toronto

ii.   Key informant, parents of children with 'special needs'

I am a doctoral student in social work at the University of Toronto and I am currently conducting research on LGBTQ parents of children with special needs and their interactions with service providers.

I am interested in interviewing you as a "key informant" or person knowledgeable about parents of children with special needs. Because of your expertise, you would offer a valuable perspective to this research. The project has a goal of suggesting improvements to the current policies and services as well as increasing researchers' understanding of parents' perspectives. You would receive $30 for their time, plus expenses.

Please let me know if you would like to talk further about this research, or if you know of anyone else who might be interested in participating in this study. I can be reached at (416) 890-0357 or margaret.gibson@mail.utoronto.ca.

Thank you for your time,
Meg

Margaret (Meg) Gibson, MSW RSW
Doctoral Candidate
Factor-Inwentash Faculty of Social Work

University of Toronto

 iii. Lists and organizations focused on LGBTQ parents

Are you an LGBTQ parent who has a child with special needs or disabilities? Do you know someone who is?

I am a doctoral student in social work at the University of Toronto who has worked with and been a part of Toronto's LGBTQ (lesbian, gay, bisexual, trans, or queer) community for many years. I am currently interviewing LGBTQ parents who have children with suspected or identified special needs.

The project has a goal of suggesting improvements to the current policies and services and improving service providers' understanding of parents' perspectives. Interviews focus on parents' experiences with service providers and other community members. Interviews last 1-2 hours and participants will receive $30 for their time, plus expenses. We would meet at a time and place that is convenient for you.

I am hoping to talk to parents from a range of experiences and identities, including diverse gender and sexual identities, racial and ethnic identities, economic backgrounds, and family structures.

If you or anyone you know might be interested in participating, or if you would like more information about the project, please contact me at (416) 890-0357 or margaret.gibson@mail.utoronto.ca. I would also appreciate you forwarding this information to your networks.

Thank you for your time.

Meg

Margaret (Meg) Gibson, MSW RSW
Doctoral Candidate
Factor-Inwentash Faculty of Social Work
University of Toronto

 iv. Lists and organizations focused on children with 'special needs' and their parents

Are you a parent of a child with special needs or disabilities? Are you also lesbian, gay, bisexual, transgender or queer (LGBTQ)?

I am a doctoral student in social work at the University of Toronto. I am currently interviewing LGBTQ parents who have children with suspected or identified special needs.

Interviews will last 1-2 hours and participants will receive $30 for their time, plus expenses. We would meet at a time and place that is convenient for you. I am hoping to talk to parents from a range of experiences and identities, including diverse gender and sexual identities, racial and ethnic identities, economic backgrounds, and family structures.

Due to limited researcher resources, only parents who live or receive services in the greater Toronto area are eligible to participate.

If you are interested in more information about this project, or you know of anyone who might be interested in participating, please contact me at (416) 890-0357 or margaret.gibson@mail.utoronto.ca. I would also appreciate you forwarding this information to your networks.

Thank you for your time.
Meg

Margaret (Meg) Gibson, MSW RSW
Doctoral Candidate
Factor-Inwentash Faculty of Social Work
University of Toronto

v.   Revised recruiting email for targeted sampling

Are you an LGBTQ parent who has a child with special needs or disabilities? Do you know someone who is?

I am a doctoral student in social work at the University of Toronto who has worked with and been a part of Toronto's LGBTQ (lesbian, gay, bisexual, trans, or queer) community for many years. I am currently interviewing LGBTQ parents who have children with suspected or identified special needs.

I am particularly looking to speak with people from any of the following groups: **LGBTQ parents of colour or Aboriginal heritage**, **trans parents**, and **gay/bi/queer men**. Only parents who live or receive services in the Greater Toronto Area are eligible to participate.

The project has a goal of suggesting improvements to the current policies and services and improving service providers' understanding of parents' perspectives. Interviews focus on parents' experiences with service providers and other community members. Interviews last 1-2 hours and participants will receive $30 for their time, plus expenses. We would meet at a time and place that is convenient for you.

I am hoping to talk to parents from a range of experiences and identities, including diverse gender and sexual identities, racial and ethnic identities, economic backgrounds, and family structures.

If you or anyone you know might be interested in participating, or if you would like more information about the project, please contact me at (416) 890-0357 or margaret.gibson@mail.utoronto.ca. I would also appreciate you forwarding this information to your networks.

Thank you for your time.

Meg

Margaret (Meg) Gibson, MSW RSW
Doctoral Candidate
Factor-Inwentash Faculty of Social Work
University of Toronto

Appendix D: Parent Screening Guide

<u>This is a brief initial conversation to talk about your interest in participating</u> in the study. I will ask for some information from you that will help me to determine if you fit with the study's requirements. I will take notes on your responses. I will be the only person with access to these notes. You can choose not to answer questions at any time, and you can also ask me to destroy any resulting notes. You can ask me any questions you might have along the way.

If you end up participating in an interview for this study, you will receive a detailed consent form and you will have a chance to answer many of these questions in greater detail. This is just a quick series of questions about you, your family, and some of your experience with service providers.

I'll just need your verbal consent or "okay" to continue.

Informed consent and retention of screening info discussed and verbal consent for screening received? Yes   No

Comments?

Questions or concerns?

What is your name?

How did you hear about the study?

Do you identify with any of the LGBTQ letters (lesbian, gay, bisexual, trans, queer)? Which one(s)?

What gender pronouns do you prefer?

Where in the GTA do you live/ work?

Who is in your family?

Can you briefly tell me about the diagnosis, difference, or special needs that you or someone else has identified in your child?

[If not eligible for the study at this point, move down to option B]

How old is your child/ children?

Have you been involved with service providers regarding your child's (possible) special needs or disability? Briefly, which ones?

I am trying to include a diverse range of parents in this study so I have some demographic questions to ask. Again, this information will be kept confidential.

How do you describe your race, ethnicity or heritage?

Religion?

Can you describe your citizenship or immigration status?

What is the highest level of education?

Are you employed? Doing what type of work?

Select one option below.

A. I now have enough information from you to set up an interview, if you would like to do so. Would you like to proceed with this now?

Yes   No

When and where would be convenient for you?

What is the best way to contact you?

Email address:

Telephone number:

Is it okay to leave a voicemail?

What are the best times of day to reach you?

Planned date, time, location:

Would you like to receive your informed consent forms, with information about the study, by email or by mail? Or would you like to receive it face to face on the day of the interview? We will discuss it at the start of the interview regardless.

Email?
Mail?
At interview?

Comments

Questions

For the parents I interview, I am asking that you select significant "texts" or documents that have influenced your lives and your interactions with service providers. These could include birth or adoption or citizenship certificates, forms, letters, diagnoses, policies, laws, or anything else that is written down or printed, even on a screen. At the interview, you would be asked to show me the document so we could discuss it and how it has been a part of your experience. You would not need to give me a copy.

Do you have any comments or questions about this? Possible documents in mind?

Comments?

Questions or concerns?

Possible document(s)?

Please feel free to contact me before the interview if any other questions occur to you. I appreciate your time today.

B. I now have enough information from this conversation. It seems that your experiences will not fit with the needs of this study right now, but I appreciate you taking the time to talk with me.

Comments

Questions

Appendix E: Informed Consent Forms

Project Title:
Akin to difference: An ethnographic investigation into the everyday experiences of lesbian, gay, bisexual, transgender or queer (LGBTQ) parents of children with 'special needs'

Researcher:
Margaret F. (Meg) Gibson, MSW, PhD Candidate. Please contact me with any questions: (416) 890-0357, margaret.gibson@mail.utoronto.ca.

Overview
You are being invited to participate in a research project. I am conducting this research as part of obtaining a PhD from the Factor-Inwentash Faculty of Social Work at the University of Toronto. This project is being supervised by Izumi Sakamoto; other thesis committee members include Sheila Neysmith and Tanya Titchkosky.

What are the goals of the project?
The goals of this research are:

1. To understand more about LGBTQ parents' experiences with service systems, especially those designed for children with 'special needs'.
2. To understand more about what LGBTQ parents of children with 'special needs' see as important about their experiences.
3. To suggest improvements in service systems and policies. These will be presented to service providers and policy makers through academic publications, community talks, and/or information sheets.
4. To provide information to help other parents in navigating existing systems. These will be presented through community presentations and/or information sheets.

Who is the researcher?
In addition to currently being a doctoral candidate and course instructor at the University of Toronto, I have worked as a social worker, counsellor or therapist, and researcher with LGBTQ communities, parents, and youth for many years. I am also an LGBTQ parent who has interacted with special needs service systems on behalf of one of my children. My research has been motivated by these personal and professional experiences, as well as by the lack of research on this important topic.

Who are the participants?
For this research, I will be interviewing LGBTQ parents with at least one child who has been identified as definitely or possibly having special needs. I may also interview community advocates, researchers, service providers and administrators.

By "LGBTQ parents" I mean parents who identify as lesbian, gay, bisexual, transgender, transsexual, Two-spirit, genderqueer, queer, or who have any non-heterosexual or non-cissexual identity. In this document I refer to these parents as "LGBTQ" parents, while I realize this term may not fit everyone's identity. During the interview you will be able to talk about and clarify your own sexual or gender identity in the process of the research. Please ask me if you have

questions. By "parent" I include stepparents, foster parents, birth parents, adoptive parents, and anyone else who identifies as a parent.

Under the term "special needs" I mean any physical, intellectual, learning, sensory, developmental, and behavioural differences that you or a professional (e.g. doctor, teacher, social worker, psychologist) have suspected, assessed or diagnosed. Your child does not need to have a formal diagnosis and you do not need to agree with professionals' assessments of your child in order to participate in this research. You do not need to believe that your child has 'special needs', only to have interacted with service systems about this possibility. You can talk more about how special needs assessments and categories fit with your experiences as a parent as a part of the interview.

I will conduct all interviews and analysis myself**,** in consultation with my supervisor (see Confidentiality). Interviews will be done with individuals or couples/ co-parents only. You will have an opportunity to receive a summary of the study's findings if you are interested.

What would happen if I decide to participate?
Your participation in this research would consist of some or all of the following.

i) A 10-20 minute screening conversation (usually on the telephone). This conversation is to determine if you are a good fit for the project, to give you a chance to ask questions, and also to arrange the time and place of the interview. This screening will not be audiorecorded but I will take written notes with your verbal consent. If you are found eligible for and consent to participat**ing** in an interview then information from this screening may be used in the research analysis. If you are not interviewed or if you withdraw from the study, this screening information will be destroyed.

ii) A 1-2 hour interview about your experiences as a parent interacting with service providers and systems. The interview will be audiorecorded with your written consent. The interview can be done all at once or in two parts. It will be conducted at a time and place that is convenient for you.
As part of the interview, I will also ask you to discuss a document that has been important in your experiences as a parent. Possible documents could include birth or adoption or citizenship certificates, forms, letters, diagnoses, policies, laws, or anything else that is written down or printed, even on a screen. At the interview, you would be asked to show me the document so we could discuss it and how it has been a part of your experience. You do not need to give me a copy of this document.

iii) I will also ask if I can contact you again if I have questions later, and if you would like to hear about and comment on my initial findings. You can refuse any further contact or change your mind at any time.

Your participation in this research is entirely voluntary. You can change your mind and withdraw from the study**.** You can choose not to answer any questions for any reason. You can choose to end the interview at any time. After the interview, you can request a copy of your transcript to review and edit any sections out that you no longer wish to include, as long as you do so before the dissertation analysis is complete.

If you decide you do not want to participate at all after your interview is complete, I will erase the audiorecording and transcript and remove your data from the findings. If, however, the

analysis of the research data has been completed (within the 4-6 months following the interview) I will no longer be able to remove your information from the study's findings.

Please contact the Office of Research Ethics at the University of Toronto at 416-946-3273 or ethics.review@utoronto.ca if you have questions or concerns or would like more information on your rights as a research participant.

Confidentiality
Your participation in this project is confidential, and only my supervisor and I will have access to any identifying information about you. I will not tell anyone that you participated in this project unless there is a legal requirement that I do so. Please note that I am legally mandated to report child abuse or an immediate threat of harm to yourself or others to the appropriate authorities.
If we encounter each other in the community, I will not initiate contact or conversation (but will happily respond if you wish to initiate conversation). If you do initiate discussion, I will not tell other people how we know each other. You are, of course, not bound by confidentiality guidelines and can share anything you like about your participation.

You will be asked to choose a pseudonym, or pretend name, that will be used in any community presentations or publications. Any identifying information will be removed from research documents so that nobody will be able to tell that you participated in this study. Audiorecordings of the interviews will be transcribed and transcripts will have any identifying information removed within four weeks of the interview's completion. Audiorecordings will be destroyed within 6 months of the data collection. Contact information for participants will also be destroyed within 6 months of the end of the project (when findings are presented to participants and community members). Until that time, all contact information, audiorecordings, and any other documents that include identifiable information will be stored on an encrypted USB key.

Please ask me if you have questions about confidentiality. If you have a particular concern, we can arrange an earlier date to erase your interview audiorecording and you can check over and edit the transcript of your interview. I can take detailed notes instead of audiorecording if you prefer.

What will I get for participating? Are there any risks?
You will receive $30 for your participation. I can reimburse further costs you might have as a result of your participation (e.g. parking or transit costs, childcare expenses). I have a limited budget so please let me know in advance if you anticipate significant expenses related to your participation.
There may not be any other benefits to you from participating in this study. It is possible that participating in this project will give you a chance to think and talk about your experiences. Your participation will also contribute to building knowledge that has a goal of improving services. You may find these aspects of participation rewarding.

There is a possible risk that talking about your experiences may be upsetting or make you feel uncomfortable. We can take a break if this occurs. I will also provide a list of community resources that can offer further support. If you reveal to others that you participated in this study, there may be social risks associated with disclosing your identity as an LGBTQ-identified parent of a child with special needs. There may also be the risk that if whomever you tell of your participation attends a conference presentation or reads a research article or report based on this

project, they might attribute an anonymous quotation or situation to you. You can minimize the risk of such attributions by your own decisions on whether and how to disclose your participation in this research.

Participating in this research project will not offer any assessment opportunities for you or for family members. I will refer you to relevant services in the community.

Please sign below if you agree to participate in this study.

I, _____ (please print name), consent to participate in this study. I understand that I can withdraw my consent to participate at any time.

Participant signature: _____

Please initial one of the following:
_____ I consent to having my interview(s) audiorecorded
_____ I DO NOT consent to having my interview(s) audiorecorded

The researcher may wish to consult with you about initial findings from the project or to clarify any questions about your interview.

Please initial one of the following:
_____ I consent to being contacted again by the researcher to clarify findings.
_____ I DO NOT consent to being contacted again by the researcher to clarify findings.

The researcher may make a research summary available and/or present the study's findings in a community forum.

Please initial one of the following:
_____ I would like to be informed if the study's findings are being presented or are otherwise available.
_____ I DO NOT want to be informed if the study's findings are being presented or are otherwise available.

Project Title:

Akin to difference: An ethnographic investigation into the everyday experiences of lesbian, gay, bisexual, transgender or queer (LGBTQ) parents of children with 'special needs'

Researcher:
Margaret F. (Meg) Gibson, MSW, PhD Candidate. Please contact me with any questions: (416) 890-0357, margaret.gibson@mail.utoronto.ca.

Overview
You are being invited to participate in a research project. I am conducting this research as part of obtaining a PhD from the Factor-Inwentash Faculty of Social Work at the University of Toronto. This project is being supervised by Izumi Sakamoto; other thesis committee members include Sheila Neysmith and Tanya Titchkosky.

What are the goals of the project?
The goals of this research are:

1. To understand more about LGBTQ parents' experiences with service systems, especially those designed for children with 'special needs'.

2. To understand more about what LGBTQ parents of children with 'special needs' see as important about their experiences.

3. To suggest improvements in service systems and policies. These will be presented to service providers and policy makers through academic publications, community talks, and/or information sheets.

4. To provide information to help other parents in navigating existing systems. These will be presented through community presentations and/or information sheets.

Who is the researcher?
In addition to currently being a doctoral candidate and course instructor at the University of Toronto, I have worked as a social worker, counsellor or therapist, and researcher with LGBTQ communities, parents, and youth for many years. I am also an LGBTQ parent who has interacted with special needs service systems on behalf of one of my children. My research has been motivated by these personal and professional experiences, as well as by the lack of research on this important topic.

Who are the participants?
For this research, I will be interviewing LGBTQ parents with at least one child who has been identified as definitely or possibly having special needs. I will also interview community advocates, researchers, service providers and administrators.

What would participation involve?
As a key informant (person knowledgeable about this topic or community), your participation in this research would consist of some or all of the following.

i) A brief initial conversation (usually on the telephone, but possibly on email). This conversation is to talk with you about the project, to give you a chance to ask questions, and also to arrange the time and place of the interview. This conversation will not be audiorecorded but I may take written notes, which will be treated as confidential research data if you participate in the study, and destroyed if you decide not to participate.

ii) An interview of approximately 1 hour about your knowledge and experiences as a "key informant", a person who is knowledgeable about LGBTQ parents, parents of children with 'special needs', or both.

The interview will be audiorecorded with your written consent. The interview can be done all at once or in two parts. It will be conducted at a time and place that is convenient for you.
iii) I will also ask if I can contact you again if I have questions later, and if you would like to hear about and comment on my initial findings. You can refuse any further contact or change your mind at any time.

Your participation in this research is entirely voluntary. You can change your mind and withdraw from the study. You can choose not to answer any questions for any reason. You can choose to end the interview at any time. After the interview, you can request a copy of your transcript to review and edit any sections out that you no longer wish to include.

If you decide you do not want to participate at all after your interview if complete, I will erase the audiorecording and transcript and remove your data from the findings. If, however, data analysis has already been completed on the project (within 4 to 6 months after the interview), I will no longer be able to remove your data.

Please contact the Office of Research Ethics at the University of Toronto at 416-946-3273 or ethics.review@utoronto.ca if you have questions or concerns or would like more information on your rights as a research participant.

Confidentiality
Your participation in this project is confidential, and only my supervisor and I will have access to any identifying information about you. I will not tell anyone that you participated in this project unless there is a legal requirement that I do so. Please note that I am legally mandated to report child abuse or an immediate threat of harm to the appropriate authorities.

Audiorecordings of the interviews will be transcribed and transcripts will have any identifying information removed within four weeks of the interview's completion. Audiorecordings will be destroyed within 6 months of the data collection. Contact information for participants will also be destroyed within 6 months of the end of the project (when findings are presented to participants and community members). Until that time, all contact information, audiorecordings, and any other documents that include identifiable information will be stored on an encrypted USB key.

What will I get for participating? Are there any risks?
Participating in this project can give you a chance to think and talk about your experiences. Your participation will also contribute to building knowledge that has a goal of improving services. You may find these aspects of participation rewarding. You will receive $30 for your

participation, and I can reimburse further costs you might have (e.g. parking or transit costs, childcare expenses). I have a limited budget so please let me know in advance if you anticipate significant expenses related to your participation.

There is a small risk that you might feel uncomfortable when describing your experiences. If this occurs, I can discuss possible community supports. If you discuss your participation in this project with others then they may attribute anonymous quotations or other findings to you in final reports, presentations, or articles resulting from the project. You can minimize the risk of such attributions through your own decisions around discussing your participation in the project.

Please sign below if you agree to participate in this study.

I, _____ (please print name), consent to participate in this study. I understand that I can withdraw my consent to participate at any time.

Participant signature: _____

Please initial one of the following:

_____ I consent to having my interview(s) audiorecorded
_____ I DO NOT consent to having my interview(s) audiorecorded

The researcher may wish to consult with you about initial findings from the project or to clarify any questions about your interview.
Please initial one of the following:

_____ I consent to being contacted again by the researcher to clarify findings.
_____ I DO NOT consent to being contacted again by the researcher to clarify findings.

The researcher may make a research summary available and/or present the study's findings in a community forum.

Please initial one of the following:

_____ I would like to be informed if the study's findings are being presented or are otherwise available.
_____ I DO NOT want to be informed if the study's findings are being presented or are otherwise available.

Appendix F: Parent Resource Handout

Services for Parents in the Greater Toronto Area

The 519 Church Street Community Centre: Groups, events, and services for LGBTQ people and families of all kinds.
519 Church Street
Toronto, ON
M4Y 2C9
(416) 392-6874
www.the519.org

ARCH Disability Law Centre: Legal clinic devoted to advancing the rights of people with disabilities in Ontario.
(416) 482-8255
1-866-482-2724
TTY 416-482-1254
archlib@lao.on.ca

Child Advocacy Project: Free (pro bono) legal consultations regarding public education rights of children and youth in Ontario for middle- and lower-income families.
(416) 977-4448
1-866-466-5329
info@childadvocacy.ca
www.lawhelpontario.org/educationlaw/

Holland Bloorview Kids Rehabilitation Hospital: School programs, assessment services, and inpatient rehabilitation services for children with disabilities.
150 Kilgour Road
Toronto, Ontario, Canada
M4G 1R8
416-425-6220
Toll Free: 1-800-363-2440
www.hollandbloorview.ca

Hospital for Sick Children: In- and outpatient services for children with health care needs. Also includes a Family Centre with information about a range of medical conditions.
555 University Avenue
Toronto, Ontario
Canada
M5G 1X8
General inquiries: 416-813-1500
www.sickkids.ca

Integra: Mental health services for children with learning disabilities and their families, including parent and family therapy.
25 Imperial

Toronto, ON M5P 1B9
(416) 486-8055
www.integra.on.ca

LGBTQ Parenting Connection: Listserve and website with information and referrals for LGBTQ parents. Housed at the Sherbourne Health Centre.
www.lgbtqparentingconnection.ca

Respiteservices.com: Respite is a break from caring for someone with special needs. (416) 322-6317 ext. 1
info@respite-services.com
www.respiteservices.com

Sherbourne Health Centre: Health care, health promotion, and counselling with programs for LGBTQ people and families.
333 Sherbourne Street
Toronto, Ontario M5A 2S5
E-mail: info@sherbourne.on.ca
www.sherbourne.on.ca

Toronto Partnership for Autism Services (TPAS): Joint services for individuals and families across several Toronto autism agencies.
TPAS Registration Assistant at (416) 925-5141, ext. 2289
The lead agency for TPAS is Surrey Place.
Surrey Place Centre
2 Surrey Place
Toronto, ON M5S 2C2
(416) 925-5141
www.surreyplace.on.ca

Appendix G: Interview Guides

I. Parent Interview

As you know from our earlier conversation, this study is on the experiences of lesbian, gay, bisexual, trans, and queer parents who have children with identified differences or 'special needs'.

1. Which, if any, of these LGBTQ terms fits for you?

Prompts:

What other terms would you use to describe your gender and sexuality?

Who is in your family? How did they come into your life?

2. Can you tell me about your child and how 'special needs' and 'special needs services' have been in your lives?

Prompts:

What 'special needs' categories have influenced your family?

What types of services (including assessments, consultations, treatments, information) have you used?

What can you tell me about what that these terms/diagnoses/categories miss?

Before you had your child, what did you know or think about 'special needs'? Has that changed?

3. One of the things I'm particularly interested in hearing about is the activities that parents do to get the things that their families need.

a) What sort of things do you do to find or hang on to resources and services?

b) What sort of things do you do to work with service providers?

Prompts:

Making or preparing for appointments?

Researching (diagnoses, treatments, assessment, services, etc.)?

Responding to emergencies (at home, school, hospital, or elsewhere)?

Implementing treatment plans or medical protocols?

Coping with feelings, ailments, or stress (your own or anyone else's)?

Writing or reading (e.g. forms, applications, logs, etc.)?

4. Have you encountered any problems getting services (or working with service providers) that were related to your LGBTQ identity?

Prompts:

Have you encountered any problems related to any other identity or grouping you or your family members belong to (race, ethnicity, class, education, family structure, religion…)?

Do you usually disclose your LGBTQ identity (or family structure) to service providers?

5. As we discussed on the telephone, I am interested in documents that you have found important as an LGBTQ parent of a child with 'special needs'.

Can you tell me about the document(s) you have chosen?

Prompts:

How did you get this document?

What has changed since you got this document?

When/ how do you use this document?

Are there ways that this document has been helpful? Hurtful? To you and/or your child?

Are there things missing or things you would like to change?

Are there documents that you wish you had?

How do you feel when you look at this document? [Added after the first interview]

6. Based on what you have learned, what suggestions do you have for how to improve special needs services?

Prompts:

What would you tell other parents? Other LGBTQ parents?

What would you tell service providers? Policy makers? Funders?

II. Key Informant Interview

This study is on the experiences of lesbian, gay, bisexual, trans, and queer parents who have children with identified differences or 'special needs'.

1. What experience or expertise do you have with LGBTQ parents? With parents of children with 'special needs'? Please describe your relevant work, research or advocacy with and on behalf of these parents.

2. What issues do you see as particularly important for the parents you have worked with? Please clarify if these are parents of children with 'special needs', LGBTQ parents, or both.

Prompts:

Are there problems you often hear about from parents? From service providers?

Are there any situations or stories that stand out for you?

Are there any stories of things going well or improving that you can share?

Are there particular groups of parents that you see as struggling more, or less, than others?

How do you see parents' identities and resources coming into the struggles and successes they encounter? E.g. class, race, sexual identity, gender identity, family structure

3. What policies or legislation do you see as particularly important in shaping the experiences of the parents you work with?

Prompts:

Can you describe how this policy/ legislation affects parents' experiences?

When and where have you seen this document used (or used it yourself)?

4. What suggestions do you have for how to service systems could better serve the needs of parents of children with 'special needs', LGBTQ parents, or parents in general?

What could help or hinder turning these ideas into action?

 III. Service Provider Interview

1. Please describe your job title and briefly explain your work.

Describe some of the things you do in a typical day.

Are there ways that your job description doesn't always match up with how you spend your time?

2. What experience, if any, do you have with LGBTQ parents? With parents of children with 'special needs'? Please describe your work experience with and on behalf of these parents.

What issues do you think you might encounter in working with these parents?

Do you feel prepared to work with LGBTQ parents of children with 'special needs'?What strengths or weaknesses do you think you would bring to this work?

How do you see working with these parents as similar to or different from working with other parents?

3. When you do your work, what documents do you see as particularly important in your day-to-day role? These could include forms, policies, job descriptions, birth or adoption certificates, diagnoses, case notes.

What legislation or policies do you have to make sure your work follows?

When and where do you use this document?

Please describe what you do with the forms you fill out with or about parents. What do they help you to do? Where do they go next?

Are there any documents that parents absolutely must have in order to work with you?

Are there any documents that cause particular problems for you in your work?

4. What suggestions do you have for how to service systems could better serve the needs of parents of children with 'special needs', LGBTQ parents, or parents in general?

Are there things you wish you could do differently?

Are there things you think you (or service providers in your role) do particularly well?

Are there situations that you have felt unprepared for?

Are there ways that you have felt constrained in what you could offer parents?