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"You Did Everything": Effort, Motherhood, and Disability in Parents' Narratives of Their Attempts to Obtain Services

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Abstract

Increasing proportions of adults with intellectual and developmental disabilities (IDD) live with family members, but families who request adult developmental services are often placed on lengthy waiting lists. To date, however, no research explores in depth the efforts of parents when attempting to obtain services for adult children with IDD, or how assumptions about what parents can and should do for their children might impact service acquisition processes. The current study asked: (1) What types of efforts do parents undertake as they attempt to obtain services for their adult child with IDD in Ontario?; (2) How do parents justify their engagement in these efforts?; and (3) How do these parental efforts relate to the likelihood that families will obtain services? Eight families seeking services in Ontario participated in in-depth interviews about their experiences with care and support. From interview transcripts, 13 narratives about families' attempts to secure particular services were identified. Thematic analysis indicated that families participated in administrative, information gathering, relationship building, and advocacy efforts as they sought services. Results are discussed in terms of the importance of questioning assumptions that parents, especially mothers, can and should expend considerable time and effort to obtain services.

Internationally, a large and increasing proportion of adults with intellectual and developmental disabilities (IDD) live with family members (Barron & Kelly, 2006; Braddock, Emerson, Felce, & Stancliffe, 2001; Brown, Anand, Fung, Isaacs, & Baum, 2003; Emerson & Hatton, 2008). At the same time, research suggests that families who request adult developmental services are often placed on waiting lists, at times for many years, and that developmental service systems are often confusing for families (Barelds, Van De Goor, Bos, Van Heck, & Schols, 2009; Lakin, 1998).

Theoretically, the availability and content of services for adults with IDD are thought to be influenced by assumptions about how parents can and should relate to their children (Almack, Clegg, & Murphy, 2009; Pilnick, Clegg, Murphy, & Almack, 2011; Power, 2008; Todd & Jones 2003; Todd & Shearn, 1996; Shearn & Todd, 1997). In North America, parenting practices and responses to parenting practices are largely guided by an ideology of intensive mothering, which dictates that mothers should spend substantial time, energy, and money raising their children and are expected to place their children's needs and interests above their own (Hays, 1998; Wall, 2010). In this context, parents, especially mothers, are held individually responsible and accountable for "problems" that occur within the family. Persons with IDD are often considered to be perpetually childlike and tend to face ongoing support needs that others their age may not, meaning expectations for intensive parenting might continue into adulthood (Almack, Clegg, & Murphy, 2009; Pilnick, Clegg, Murphy, & Almack, 2011).

Accordingly, qualitative research on the care and service use experiences of families that include an adult member with IDD has revealed that policy or service sector priorities, schedules, regulations, and expectations often presuppose substantial availability and effort on the part of parents (Almack, Clegg, & Murphy, 2009; Pilnick, Clegg, Murphy, & Almack 2011; Power, 2008; Todd & Jones, 2003; Todd & Shearn, 1996; Shearn & Todd, 1997). For example, in their interviews with parents who live with adult family members with IDD, Todd and Shearn (1996) found that even when adult children were using services, such as day programs or respite care, parents were expected to be consistently available and were frequently contacted and expected to respond to any "problems." Consequently, many mothers cited an impossibility of meeting the demands of motherhood and employment as the reason why they did not pursue full time work outside the home. In another example, Pilnick, Clegg, Murphy, and Almack (2011) argued that UK policy that promotes self-determination for adults with IDD ultimately relies on parents or other caregivers to provide the practical support needed to enable the choices people with IDD wish to make. They argue that parents tend to justify decisions to not follow their children's wishes in recognition of the moral imperative that the needs of their children should be put before their own.

The limited research that has been conducted on experiences of parents waiting for services or attempting to obtain services suggests that assumptions that parents can and should contribute substantial time and effort contributing to the desired outcomes for their adult children may underscore service acquisition processes as well. Shearn and Todd (1997) categorized the type of work parents undertook as they cared for adults with IDD. They noted that most parents engaged in "service work," which included the work required to secure services. Parents described spending time planning well in advance to secure respite care, being expected to learn about the existence of available services themselves, and communicating with and getting to know service providers who were to be entrusted with caring for their children. Investigating sources of "bottlenecks" in service delivery in the Netherlands, Barelds and colleagues (2009) interviewed experts working in the developmental services field. They concluded that all families seeking services were affected by the complexity of the system, a lack of information about the system and the roles they were expected to play, and a general lack of availability of services, suggesting that families would be required to expend considerable efforts to overcome said "bottlenecks."

To date, however, no research explores in depth parents' efforts, or types of work, put forth in attempts to obtain services for adult children with IDD. An examination of these efforts, and parental reflections on these efforts, has both practical and theoretical relevance in terms of understanding how assumptions about parenting might influence the roles families are either formally or informally expected to enact to obtain services.

The current paper therefore addresses the following research questions: (1) What types of efforts do parents undertake as they attempt to obtain services for their adult child with IDD in Ontario?; (2) How do parents justify their engagement in these efforts?; and (3) How do these parental efforts relate to the likelihood that families will obtain services?

Method

The study was conducted in Ontario, Canada between September 2012 and March 2013. Recent changes to Ontario's developmental service system emphasize equity in terms of service acquisition (Ministry of Community and Social Services (MCSS), 2008). In spring 2011, MCSS enacted the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*. Changes to the adult developmental services sector included the implementation of a centralized and standardized application process with the aim of equitably prioritizing the provision of developmental services. Families applying for developmental services now do so through Developmental Services Ontario (DSOs), single access points to services located in nine regions throughout the province, and take part in standardized application and assessment processes. Despite these changes, the provincial Ombudsman has recently received hundreds of complaints from families that include adult members with IDD about long wait periods and a lack of available services for adults with IDD (Ombudsman Ontario, 2013), indicating that waitlists are currently experienced as problematically lengthy.

Study methodology was informed by narrative methods, which involve recognition that personal stories contain both reference to and evaluation of past events (Booth & Booth, 1998; Chase, 2005; Goodley, Lawthom, Clough, & Moore, 2004; Riessman, 2008). Examining these stories, researchers do not seek to produce statistically generalizable results, but rather aim to make theoretical arguments about the context and social forces that shaped each story. This approach was appropriate as the goal was to examine diverse stories about families' experiences seeking services to reflect on the influence of pervasive assumptions about parenting on procedures and outcomes for families attempting to obtain services.

The study was reviewed and received ethics clearance from the Queen's University Health Sciences Research Ethics Board.

Participants and Recruitment

It was decided a priori that in-depth interviews would be conducted with members from eight to ten families. This sample size was selected to be small enough to allow for in-depth interviews and analyses (Goodley, Lawthom, Clough, & Moore, 2004; Riessman, 2008) and large enough for interviews to reflect diverse experiences and perspectives.

Parents participating in a larger study (see Ouellette-Kuntz et al., 2014) were briefly told about the in-depth interviews and asked if they might be interested in participating. From those who answered "yes," a pool of participants who lived in reasonable geographic proximity to the researcher was chosen to reflect diverse experiences and perspectives (i.e., parental and adult child ages, geographical locations (e.g., rural, larger city, smaller city, and caring practices and arrangements). Eligible participants were contacted by telephone by the first author. Recruitment continued until eight families agreed to participate.

The eight participating families included considerable diversity in terms of parental age, age of the family member with IDD for whom services were requested, location of residence, household income (Table 1), and the diagnosis of the family member with IDD (Table 2).

At least one parent participated from each family. Two parents participated from two families

Table 1. Family Demographics and Family Member Characteristics for Participating Families (n = *8)*

Demographic and Family Member Characteristics	*n*
Contact Parent's Age (***n*** = 8)	
45 years and younger	1
46–54	3
55–64	2
65 years and older	2
Age of Person with IDD (***n*** = 9)*	
Less than 21 years	3
21–25	2
26–29	3
30 years and older	1
Location of Residence (*n* = 8)	
Rural, as per second digit of postal code	2
Small Urban (population < 100000)	1
Large Urban (population ≥ 100000)	5
Annual Household Income	
$55,000 or less	2
$55,001–$95,000	2
$95,001 or more	4

* *Note: Services were requested for two family members with IDD from one of the participating families.*

*Table 2. Diagnoses of Persons with IDD for whom Services are Requested (*n *= 9)**

*Diagnosis***	*n*
Disorder/syndrome	
Autism spectrum disorder	1
Down syndrome	3
Cerebral palsy	2
Epilepsy/seizure disorder	2
Developmental disability diagnosis not specified	
Physical and Sensory Impairments	3
Mobility impairment/wheelchair dependent	2
Hearing impairment	3
Dual diagnosis	1

**Note: Services were requested for two family members with IDD from one of the participating families*
*** Note: Diagnoses are not mutually exclusive.*

and a parent and a live-in partner participated from one family. In the five cases where only one parent family member took part, all participants were mothers. In all families except one, mothers were the primary contact persons.

Interviews

Prior to participation in interviews, all participants completed consent procedures. To generate detailed accounts, interviews were conversational, and were largely led by participants and their stories (Riessman, 2008). Lists of questions related to topics of interest were used as a guide to ensure conversations addressed the stated research questions; however, each interview proceeded differently. This open-ended approach is often desirable when the aim is not to produce generalizable results, but to develop an understanding of participants' lives from their perspective and to make claims about process or context (Booth & Booth, 1998; Chase, 2005; Riessman, 2008).

All participants chose to be interviewed at home, with the exception of a mother who participated while at work and a mother who participated in an empty room at her son's day program. Most participants took part in two interviews. Interviews ranged from 40 minutes to several hours in length; most interviews took between one and a half and three hours.

Following interviews, participants had the chance to review transcripts and communicate whether they wanted to add, change, or remove anything. No participants expressed a desire to make substantial changes to content.

Analysis

Analysis methods may be described as blurring the lines between narrative thematic analysis and thematic analysis of narrative (Lichtman, 2014). While methods were generally consistent with Riessman's (2008) discussion of narrative thematic analysis, which involves analyzing stories holistically to make claims about process and theoretical arguments, it can be argued that the methods more closely resemble thematic analysis of narrative, as the analytical focus did not include the narrative elements that comprised each story, which were not relevant to the current research questions (Creswell, 2013; Lichtman, 2014). Generally agreed upon methods for thematic analysis, which involve closely reading text to identify repeated patterns of meaning in terms of "what" was said in interviews (Riessman, 2008), and revisiting, comparing, and extending initial codes until more complex concepts are developed, were followed for each interview to categorize parental efforts and justifications of efforts undertaken in attempts to obtain services (Aronson, 1994; Braun & Clarke, 2006; Lichtman, 2014). The specific procedures used for analysis are outlined below. While the steps are written as linear, in actual practice qualitative analysis is iterative and circular, meaning the procedures are less straightforward than suggested here (Braun & Clarke, 2006; Lichtman, 2014).

Because participants discussed a range of issues and did not typically communicate individual stories about seeking services in singular, continuous segments, the first stage of analysis involved constructing stories about successful or, at the date of final interviews, unsuccessful attempts to obtain MCSS-funded developmental services, a standard practice in narrative analysis (Booth & Booth, 1998; Creswell, 2013; Goodley, Lawthom, Clough, & Moore, 2004; Riessman, 2008). Parents were at times unsure about when they had requested particular services and about whether they had requested MCSS-funded services or services from an agency not funded by MCSS. To access as many stories as possible while ensuring results pertained to the search for services since the implementation of the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, only narratives that involved MCSS-funded services and that, when successful, were first received since June 2011 were eligible for inclusion in the analysis. To construct narratives, the first author created a new word file for each participating family. During multiple close readings of each participating family's interview and survey transcripts from the first and second phases of the larger study, text relating to the attempt to obtain a particular service was copied and pasted into the new file. Subheadings were used to differentiate multiple stories told by the same parents. From the eight participating families, 13 narratives were identified.

Only the first author was involved in the first and all subsequent stages of analysis. While interpretive agreement is a mark of validity in many post-positivist approaches to qualitative research, the search for analytical agreement is based on the assumption that there are "right" concepts to find in the data (Lichtman, 2014). This assumption is inappropriate for critical research, which involves interpreting data to make convincing arguments that contribute new knowledge that can be used to make a difference (Lichtman, 2014).

Throughout interview, transcription, and narrative construction processes, the first author kept notes on emerging themes and relevant excerpts in a notebook (Lichtman, 2014). To identify initial codes, the first author carefully read one narrative at a time, highlighting segments of text relating to parental work and inserting corresponding brief phrases in the margins (Braun & Clark, 2006). Once this process was completed for all 13 narratives, each narrative was revisited to develop codes into more complex themes (Braun & Clarke, 2006; Lichtman, 2014). Codes were compared to one another to collapse similar themes, ensure consistent language use, redefine codes, and consider the connections between codes and themes. Following narrative methodologies (Creswell, 2013; Riessman, 2008), themes were reworked with consistent reference to each story in its' entirety, as well as each participant's life more broadly to make theoretical consideration of the connections between efforts to obtain services and reflections on outcomes of those efforts possible. Themes for each narrative were also reworked with reference to the other stories, to ensure consistency of language for common categories and to inform the development of theoretical arguments for all narratives.

To facilitate the development of more complex concepts, themes were listed in a table. The table included thematic findings for each story under the following topics: What parents did and did not do in their pursuit of services, associated justifications, and notes on other important issues raised in narratives (Lichtman, 2014). The table was used to illustrate connections between themes and to allow for comparison between successful and unsuccessful stories. The primary researcher made notes and conceptual maps to record and continue consideration of concepts derived from examination of the table and reference to entire narratives (Braun & Clarke, 2006).

Analytical procedures continued through the writing stage of the research process, meaning concepts were strengthened and deepened with each draft (Braun & Clarke, 2006). Because the goal of the current research was to make conceptual arguments, results are not presented as distinct themes with associated counts. Braun and Clarke (2006) argue that frequency of a theme is not necessarily indicative of the importance of a theme because one participant's insights may have significant theoretical relevance and some topics are difficult or impossible for participants to discuss.

Pseudonyms are used to protect the identities of both the participants and their children.

Results

Analysis of parents' narratives suggests that pervasive assumptions about both motherhood and disability impact service acquisition processes to the extent that parents put forth multifaceted and often resource intensive efforts in their attempts to obtain services. The parental role, the necessity of particular activities to secure services, and the best interests of their adult children with IDD pervaded parental justifications for engaging or not engaging in particular efforts to obtain services.

In keeping with the analysis process, which involved developing more complex concepts from initial themes, findings are not presented as discrete themes, but are rather described throughout the results section in support of the above stated argument. To this end, results include an overview of identified narratives, descriptions of parental efforts, comparison of successful versus unsuccessful attempts to obtain services, and parents' justifications for pursuing or not pursuing MCSS-funded services.

Analysis resulted in the identification of 13 narratives describing efforts undertaken to obtain particular MCSS-funded services. Services sought were spread across community participation supports, agency residential supports, respite, and professional and specialized services (Table 3).

Two success stories were identified: one family acquired a professional and specialized service and another acquired respite services. Families began using both services before the commencement of interviews. The professional and specialized service took approximately one year to obtain and the respite care took between two and three years to obtain.

*Table 3. MCSS-Funded Services for Which Parents Told Stories About Seeking. (n = 13)****

*Services Seeking****	*n*
Community Participation Supports	5
Agency Residential Supports	4
Activities of Daily Living: In-Home Support	0
Caregiver Respite	2
Person-Directed Planning	0
Professional and Specialized Services	2

****Note: Some families requested more than one service or services for more than one family member with IDD and some families were uncertain about what they had requested. This table best represents what families communicated they requested during interviews.*

Parental Efforts to Secure Services

Administrative efforts. All parents described undertaking administrative tasks as they sought services. This involved completing applications for funding and services, completing profiles and needs assessments as part of the DSO intake processes, and filing and keeping records of activities, diagnoses, and ongoing applications to prove eligibility or determine suitability for services.

Half of parents reflected that to obtain services it was necessary to define goals for family members with IDD in terms of ministry priorities and definitions of need, meaning effective administrative work often involved research and information gathering.

> *I go to a family support meeting once a year to find out the buzzword. It changes all the time. If you put down what they are looking for it pushes the application further.* (Sarah)

Similarly, having proof that individuals and families were in need as per ministry definitions was often seen as necessary, something which was described as taking effort, difficult to come to terms with, requiring assistance, or not always possible given the administrative processes in place.

> *We've been told if we can get Vanessa at a crisis level on the service coordination list we can do the transition to a group home right away if another spot comes up rather than waiting until we are in full crisis.* (Felix)

Information gathering efforts. In large part because the developmental services system was experienced as confusing, all parents reportedly engaged in information gathering efforts to determine which services exist, whether services would adequately meet their needs as well as their children's developmental and safety needs, how to apply for particular services, and how to best ensure eligibility for services.

> *We were told you are going to want to get educated and figure out which agency to align yourselves with to meet Mike's needs.* (Jane)

Relationship building efforts. Many parents explained that developing relationships with either an informal network or a developmental services system "insider" was important to gather necessary information, to help secure a particular service, or for "insiders" to advocate for services on their behalf. Relationships were especially helpful when "insiders" could offer flexibility in service provision or advocate for services that would meet children's and families' perceived needs.

Some parents commented that professionals they contacted were unable to provide desired assistance or that establishing a relationship would take more effort than was possible or worthwhile.

> *Getting him services was very isolating. It was very frustrating because you phone and phone and phone and the first couple of people I phoned never called me back. There was never really any one person that would sit down and say these are some of the resources and services you are entitled to.* (Lily)
>
> *If I could just find someone to help me figure out what to do next. But I've got so many issues now it's difficult. One inch at a time.* (Sherry)

One parent was ambiguous regarding whether establishing a relationship with a ministry insider would be helpful or not.

> *I don't have any agency advocating for my son; I can do it myself. Which is probably a hindrance. At one point I did try to get a worker to do it. But it's just more red tape for me and in the end it's the same result.* (Sarah)

Advocacy efforts. Parents described advocating to the ministry, to DSOs, or to particular agency staff for forward movement within the system or for the provision of services they thought would better meet their son or daughter's needs than services that currently existed or were available. Referring to the bi-weekly respite care his family received, Felix stated:

> *Well we were sort of lucky but we were also sort of asking for it. We went with the executive director to meetings with her board. It gradually worked out. It took 2 or 3 years before she got approval.* (Felix)

Effortful waiting. Parental narratives revealed that the very act of waiting without seemingly actively pursuing a particular service required effort. Parents described facilitating development work for their children so they did not lose skills, paying for and coordinating access to programs in the meantime, and coordinating appointments with professionals to ensure or enhance their children's eligibility. Parental narratives suggest that caring activities undertaken in the meantime can contribute, or are at least perceived to contribute, to the likelihood of obtaining services.

> *Our service coordinator told us "You did everything you were supposed to and nothing was working so he got selected."* (Jane)

Because the act of waiting for a particular service requires effort, parents often communicated that waiting has to be perceived as worthwhile and possible given families' situations. Otherwise, parents may pursue non MCSS-funded avenues in attempts to meet their own and their family member's needs.

> Interviewer: *So how did you start thinking of the long term care facility as an option?*
>
> Elaine: *Desperation. We just needed to get him somewhere. We can't cope with him at home.*

Success Stories: What Did it Take to Obtain Services?

The narratives of parents from the two families who received MCSS-funded services they desired suggest these parents both engaged intensively in the above described activities and benefitted from positive relationships with service providers who were able to advocate on their behalf, assist them in application processes, or provide them with flexible service options. These parents trusted that the services they had obtained or continued to seek would be able to meet their needs and their adult children's needs.

Both "successful" families were comprised of two parents living together where the mother did not work outside of the home and was not responsible for the primary care of a second person. These parents reflected on the importance of this type of arrangement both for securing services and for ensuring the possibility of ongoing access to services.

> Clara: *He takes care of the paperwork, I take care of the rest. If it was only one person doing it, they would lose it. We do 50/50.*
>
> Felix: *I apply for grants and do the taxes.*
>
> Clara: *One person doing this wouldn't work.*
>
> Felix: *A single mom or dad could not take care of a child like Vanessa. You need a lot of support.*

The perception that parents needed to and should be undertaking efforts to secure services were further elucidated in the justifications "unsuccessful" parents provided for not doing so. Some parents cited a lack of time to pursue services because they were caring for others or because they were employed.

> *I was looking into counselling, but since the emergency when mom came to live with us I'm stuck between so many things. I can't deal with everything.* (Sherry)

One parent said she now understood she had misplaced faith that the system would respond to what she saw as obvious needs.

> *I thought because this was kind of a drastic measure to put someone who's 49 years old into a long term care facility surely they're going to do something to help us. But I was wrong.* (Elaine)

The decision to pursue MCSS-funded options. Additionally, for parents to put forth substantial efforts pursuing MCSS-funded options they often described needing to believe that something would become available that was appropriate to their situation. Concerns with the imminence and appropriateness of service provision were largely related to adult children's developmental skills and abilities, especially for parents of children between 20 and 30 years of age.

> *With these kids they work so hard to get to the point they are at. I was desperate not to have a big gap from when he finished high school. I could see him losing ground quickly and as a parent you spend a lot of money when they are little to get them to a certain level, but that goes like that.* (Sarah)

Parents were also concerned about their children's mental health when lack of services meant their children had "nothing to do."

Parents who did not believe appropriate services would become available in a timely manner often directed their resources and efforts towards obtaining services and programs outside the MCSS-funded developmental services sector. For example, Lily moved to another province, MJ bought into a business so her son would be employed, and Sarah helped start a private day program. As they reflected on pursuing MCSS versus non-MCSS options, parents' narratives frequently involved an attempt to balance timeliness with appropriateness of service and their own needs with their children's needs. When no services were available, parents reported feeling guilty about their adult child's situation and reported taking measures to ensure their child had something to do. But, when services were perceived as potentially developmentally inappropriate, parents often explained they would not invest time pursuing the option, and would instead undertake caring practices themselves or pursue alternate options. The latter is the case in MJ's decision to focus energies on her son's skill development instead of actively pursuing residential services, which she applied for through the DSO:

> *He can't be independent until he learns to read and write, otherwise people will rob and steal from him. These are issues when we are dealing with disability… They are just service providers, who really knows what's good for you is your mother and father. We mothers know what's best.* (MJ)

Other parents accessed what they saw as less than optimal non-MCSS options, justifying the decision to do so as better than having nothing. Lily explained how she thought MCSS-funded opportunities in Ontario would have been better than opportunities available in her home province, but not to the extent they were worth waiting for an indefinite period.

> *Had we stayed, eventually I think, he would have gotten engaged in some awesome opportunities. I wasn't willing to take that chance because we had already been there a year and we had nothing.* (Lily)

When parents did not provide care themselves as they waited for MCSS-funded services or on a permanent ongoing basis, or did not exert efforts needed to access developmentally "ideal" available programs (e.g., by providing transportation), they often justified not doing so for their children's best interests or physical impossibility.

> *I could stay home with him and entertain him. He'd be happy, but eventually he's going to drive me crazy and it's not realistic or fair to him either. He's got to have some level of independence. And everyone needs a purpose to get out of bed in the morning.* (Sarah)

Discussion

Analysis of parents' stories about pursuing MCSS-funded services indicated that most parents involved in the study expended considerable and varied efforts seeking MCSS-funded services. However, those who ultimately obtained services had strong relationships with agency or ministry insiders, and were from two parent families where at least one parent (a mother in both cases) could contribute substantial time and resources to the caring role. Participants who did not contribute as much effort seeking MCSS-funded services often justified their inactions in terms of other commitments or decisions to utilize efforts to obtain non-ministry funded services, which would more effectively or more imminently provide for their children's developmental needs.

While findings presented in this paper shed light on parents' understandings of the efforts they do and should undertake as they seek services, the sample size and sampling methods mean results about parental experience or specific actions needed to obtain services in particular cases are not generalizable. Further, interviews were conducted beginning one year and four months after the implementation of the DSO system. Some parents' stories were about services they began pursuing or researching before the implementation of the new legislation, meaning it is not possible to determine whether parental reflections or experiences would have been the same entirely in the context of the new system. Despite these limitations, the results do speak to the environment in which caring activities take place, which is of course only partially influenced by MCSS policy.

Equity in Service Provision

It has been argued that services can be provided (Shearn & Todd, 1997; Todd & Shearn, 1996) and policy can be created (Pilncik, Clegg, Murphy, & Almack, 2009) for adults with IDD with the assumption or consequence that parents will be consistently available and able to engage in intensive and varied caring practices. This appears to be the case in terms of the processes whereby families actually obtain services in Ontario. Reflecting the pervasiveness of this understanding, even parents who did not expend substantial efforts seeking MCSS-funded services justified their reasons for not doing so. The centralized and standardized application processes put in place as part of the MCSS's transformation of Ontario's developmental services are informed by a principle of equity. In line with this principle, intake, prioritization, and service allocation processes should include explicit consideration that not all families have the time, resources, and relationships that may increase or be thought to increase the likelihood of receiving services.

The phenomenon whereby parents feel they should or need to expend considerable efforts seeking services appears to be perpetuated by dominant understandings of development for people with disabilities and parental care. An ideology of intensive mothering dictates that mothers should invest substantial resources to promote their children's development and well-being (Wall, 2010). In line with pushes for interventions and independence for people with disabilities, parents of children with IDD often take on quasi-professional and rehabilitative roles to optimize their child's development (e.g., Landsman, 2009; McKeever & Miller, 2004; McLaughlin & Goodley, 2008). Research with adults with IDD suggests these expectations might continue through adulthood (Pilnick, Clegg, Murphy, & Almack, 2011). In the current study, a perceived lack of developmentally optimal or appropriate services led some parents to advocate for particular services, establish relationships with service providers, and at times take on caring tasks themselves or pursue non MCSS-funded services. These findings point to the importance of examining how pervasive understandings about disability and parenting might clash with available MCSS-funded services, discouraging parents from actively pursuing MCSS-funded services or contributing to additional caring tasks parents feel compelled to undertake as they seek services.

Relationships

Despite the MCSS's move to centralized application and service allocation for developmental services, many parents described their success or lack of success obtaining services in light of relationships and ground level responsiveness to their needs and their children's needs. Parents who had positive, trusting relationships with service providers were more likely to have appropriate services come available to them; parents attributed this success in large part to the advocacy and flexibility of particular insiders or service providers.

While the importance of relationship may appear to counter the MCSS's commitment to equity and standardization, it has been argued that some disability policy may be written for an ideal citizen who does not face the multiple demands and changing relations of actual people's lives (Malacrida, 2010), a concern which was reflected in some parents' narratives and the finding that services were perhaps more accessible for families that included a mother who did not work outside of the home or had additional caring responsibilities. Increasing the capacity of ground level service providers to flexibly respond to families' perceived needs might therefore enhance equity in service provision to the extent that it could help ensure that services are as available to families whose structures and needs differ from those assumed in policy.

Conclusion

Our study suggests that system improvements are needed to ensure equitable access to services and supports to adults with IDD in the province. Such improvements must include consideration of expectations placed on parents both as caregivers and system navigators. This consideration must acknowledge the diversity of families in need of services.

Key Messages From This Article

Persons with disabilities: Parents of adults with disabilities do work that seems to affect who gets services. To make decisions about who gets services fairer, we suggest that it is important to remember that not all families have the same resources.

Professionals: Parents of adults with disabilities need knowledge, skills, time, resources, and support to obtain services. Professionals need to be mindful that some parents will require more support than others.

Policymakers: Parents of adults with disabilities expend considerable efforts in their attempts to obtain services. Acknowledgement of a diversity of familial situations and consideration of expectations placed on parents both as caregivers and system navigators is important to increasing equity in service provision.

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