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Profile and predictors of service needs for families of children with autism spectrum disorders

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Abstract

Purpose: Increasing demand for autism services is straining service systems. Tailoring services to best meet families' needs could improve their quality of life and decrease burden on the system. We explored overall, best, and worst met service needs, and predictors of those needs, for families of children with autism spectrum disorders.

Methods: Parents of 143 children with autism spectrum disorders (2–18 years) completed a survey including demographic and descriptive information, the Family Needs Survey–Revised, and an open-ended question about service needs. Descriptive statistics characterize the sample and determine the degree to which items were identified and met as needs. Predictors of total and unmet needs were modeled with regression or generalized linear model. Qualitative responses were thematically analyzed.

Results: The most frequently identified overall and unmet service needs were information on services, family support, and respite care. The funding and quality of professional support available were viewed positively. Decreased child's age and income and being an older mother predicted more total needs. Having an older child or mother, lower income, and disruptive behaviors predicted more total unmet needs, yet only disruptive behaviors predicted proportional unmet need. Child's language or intellectual abilities did not predict needs.

Conclusion: Findings can help professionals, funders, and policy-makers tailor services to best meet families' needs.

Keywords

autism spectrum disorders, family-centered care, family functioning and support, service systems, unmet needs

Introduction

Background

Autism spectrum disorder (ASD) is a complex, lifelong, neuro-developmental disorder characterized by communication and social deficits, and restricted interests (American Psychiatric Association (APA), 2013). There is significant heterogeneity in clinical phenotype and many potential comorbidities such as attention problems, impulsivity, notable responses to sensory input, oppositional behaviors, depression, feeding and sleeping differences, fears or anxieties, cognitive delays, and epilepsy and other health problems (APA, 2013; Bryson et al., 2008; Lord and Spence, 2006).

The pervasiveness of ASD demands treatment and support that address a wide array of development and adaptive behavior (Rogers and Vismara, 2008), support the entire family (Hodgetts et al., 2013b), and occur daily and across the lifespan (Mulligan et al., 2010). However, families of children with ASD have more problems accessing health care and family support services than families of children with other special health care needs (Kogan et al., 2008; Thomas et al., 2012). The rising prevalence of ASD is straining health, education, and community service systems, making service access increasingly problematic (Brown et al., 2011). This strain on current service systems has led to recommendations for a national strategy to

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address ASD services across childhood in the United States (Autism Speaks, 2012), Canada (Autism Society of Canada, 2011; Standing Senate Committee on Social Affairs, Science and Technology, 2007), and the United Kingdom (Parliament of the United Kingdom, 2009). Assessing families' priorities for services and tailoring services to best meet families' needs are ways to potentially increase families' quality of life, inform strategies to address ASD services across childhood, and decrease strain on care systems.

Research related to family service needs specific to people with ASD is relatively limited. Although some jurisdictions base service eligibility solely on the diagnosis of ASD, service eligibility in other jurisdictions is based on a combination of severity of ASD symptoms, functional independence, and the presence of other comorbidities (Centers for Disease Control and Prevention (CDC), 2014; Madore, 2006). Given the high prevalence of comorbidity in ASD, and variability in funding mechanisms, literature on service needs related to more broadly defined developmental disabilities may have relevance to service needs for families of children with ASD. Ellis et al. (2002) assessed the needs of 91 families of children with developmental disabilities (90% with a diagnosis of ASD) up to the age of 22 years (average age 8.57 years). They found that parents' greatest identified need was for information, followed by community services, and support. Financial assistance was the lowest identified need. They also evaluated situational variables that predicted needs and found that parents of younger children with ASD report the greatest needs overall, but parents' age, income, education, number of siblings, and involvement with support services did not predict self-reported needs. These findings are relatively consistent with the needs profile of families of children with other special health care needs. For example, in developing the *Family Needs Survey*, Bailey and Simeonsson (1988) found that the most expressed needs of parents of children involved in early intervention services were for "information on how to teach their child," "services available now and in the future," and "reading material about parents who have a child similar to theirs." The most frequently expressed needs of parents of children with chronic health conditions (birth to 17 years) were for information about current and future services and ways to promote child health and development (Farmer et al., 2004). Parents of children with cerebral palsy (birth to 21 years) reported information about current and future services and help finding community activities and personal time as their greatest needs (Palisano et al., 2009). Contrary to the findings of Ellis et al. (2002), age was not a significant factor in number and type of needs expressed for either of these groups (Farmer et al., 2004; Palisano et al., 2009). Parents of 10- to 24-year-old children with intellectual disability most needed support for respite care, child mental health care, information, and emotional support, especially if their child had comorbid emotional and/or behavioral problems (Douma et al., 2006).

More importantly, the instruments used in these studies did not delineate between met and unmet needs, so we do not know to what extent families' needs were already being met. This measurement gap limits specific recommendations and implications for policy and practice change to improve family outcomes.

Reported unmet needs for families of children with ASD could have important policy and practice implications, yet has also received limited research attention. Only one study was found (Brown et al., 2011, 2012; data from same study) that evaluated unmet needs of 101 families of school-aged children with ASD who lived in four Canadian provinces, including Ontario, Manitoba, Prince Edward Island, and Newfoundland. The most common unmet needs were related to social activities for the child with ASD, information on services, and continuous service provision (Brown et al., 2012). They found a negative relationship between the child's functional independence and perceived unmet needs (lower functional independence = greater unmet needs) and a positive relationship between parents' perception of the impact of their child's disability and perceived unmet needs (higher impact = greater unmet needs; Brown et al., 2011). Douma et al. (2006) did not find consistent predictors of unmet service needs for families of children with developmental disabilities, but did find that higher reported needs increased the odds of obtaining many types of formal support, including respite care. They asserted parents with a strong need for support most actively sought, and thereby received, formal services, regardless of their child's age.

Rationale for this study

Identifying consistencies and gaps between families' identified needs and the services offered can help target policies and practices to make the best use of inevitably limited personal, professional, and financial resources. With increasing numbers of people receiving an ASD diagnoses, the societal costs in the United States are estimated at a staggering US $126 billion/year, representing more than a tripling in costs since 2006 (Knapp and Mandell, 2013), and the cost to the much smaller Canadian provincial health and social service systems to support individuals with ASD is estimated at CAD $3 billion/year. However, strategies to improve the quality of life for individuals with ASD and their families, including supports and services that respond to the needs of families of individuals with ASD, could significantly decrease these costs (Autism Society of Canada, 2011). Thus, tailoring supports and services to best meet families' needs may be one way to decrease the burden of care on the system over time.

This is the first study to evaluate overall, met, and unmet service needs in ASD across childhood, supporting

the international call for a lifespan model of services and families' desire for services that are more seamless over time (Hodgetts et al., 2013b, 2014). A lifespan perspective on caregiving recognizes that raising a child with ASD is a nonnormative process whereby roles and stressors fluctuate over time, and parents often remain involved in parenting activities and responsibilities beyond the typical age, and often into adulthood (Haveman et al., 1997). Although some research has looked at service needs for families with other developmental disabilities across childhood (e.g. Douma et al., 2006), studying the distinct service needs of families of children with ASD is warranted because their perceptions of disability and experiences with services often differ from parents of children with other disabilities and special health care needs (Kogan et al., 2008). Brown et al. (2011, 2012) did evaluate unmet service needs specific to children with ASD, but limiting their sample to school-aged children did not allow generalization of findings to inform current strategies for continuity of care across childhood. Ellis et al. (2002) investigated service needs across childhood, including a large proportion of individuals with ASD in their sample, but service delivery models have changed over time, so findings from some of these studies may have limited relevance today. For example, almost half of their sample had a child who lived in a residential school setting, including all of the children older than 12 years. There has been steady decline in residential placements over the past few decades, with most individuals with ASD now living at home throughout childhood (Larson et al., 2012). Furthermore, the diagnostic criteria for ASD have expanded over time (Anagnostou et al., 2014). Therefore, findings from earlier work might not generalize the needs of families currently seeking services.

Findings from this study may have relevance to other jurisdictions within Canada and internationally. Based on previous research, it appears that family needs in ASD are often consistent across jurisdictional boundaries, including many international locales. However, unmet needs likely vary across jurisdictional boundaries since public (government) funding for ASD services varies significantly between jurisdictions within and between countries. Alberta is perceived to be relatively well resourced with respect to ASD services throughout childhood, and across hospital-, educational-, and community-based settings compared to other jurisdictions (Madore, 2006; Standing Senate Committee on Social Affairs, Science and Technology, 2007). Also, this jurisdiction has a funding mechanism that, theoretically, supports continuity of services across childhood related to health-, home-, and community-based services. Therefore, findings from this study may represent a "best-case" scenario that can contribute to the debate on service needs and eligibility criteria for services, and be used to inform practice and policy in other jurisdictions.

Aims and hypotheses

This study investigated the needs of families of children with ASD from the perspective of parents. Our aims were to (1) identify overall, best, and worst met needs for families of children with ASD in current systems of care and (2) identify predictors of total and unmet needs for families of children with ASD.

Based on our knowledge of ASD, the service system in the jurisdiction in which data were collected, and previous research on family needs and childhood disability, we hypothesized that (1) greater language and intellectual impairments, and the presence of disruptive behaviors, would predict greater needs overall and (2) child's age would predict overall and unmet needs. Specifically, families of younger children would have more total needs, but families of older children would have more unmet needs.

Methods

Study design and location

The Heath Research Ethics Board at the University of Alberta approved this study. The data were from a larger, mixed-method study that investigated the processes by which families of children with ASD navigate systems of care in Alberta, Canada.

Recruitment

An anonymous questionnaire was completed in 2011 or 2012 by 143 parents with a child with ASD. Potential participants were initially recruited through a mail-out (blinded to researchers) to a stratified (by age and urban/rural location), random sample of families registered with the ASD clinic at the Glenrose Rehabilitation Hospital in Edmonton, Alberta, Canada. (n = 86, 32% response rate). This clinic serves as the primary diagnostic site for central and northern Alberta and had over 1800 children in its registry at the time of recruitment. This clinic is not related to receipt of supports and services beyond diagnosis (i.e. home-based and/or school-based services). Therefore, recruitment through this clinic provided potential access to families who did and did not seek and/or receive services after diagnosis. A letter was attached to the front of these surveys clarifying that recruitment was determined based on stratified, random sampling from the ASD clinic database, anonymous to anyone on the research team. These surveys were numbered to allow the ASD clinic to send reminders to potential participants who had not yet responded (Dillman Method), but the researchers did not have access to the database linking numbers with potential participants. We used the numbers to determine response rate through the recruitment methods.

Additional participants were recruited with assistance from three Autism Societies across Alberta and through

direct requests to the researchers ($n = 57$; blind to researcher). We provided copies of the questionnaire, complete with stamped-return envelops, to each Society. Each organization left copies of the survey, with stamped-return envelopes, on their main counters for parents to take. Two of these societies also posted a notice about the study on their web page and sent a message to their parent email listserv. Parents could then request to have a copy of the survey, with a stamped-return envelope mailed to them from the Autism Society (we reimbursed any postage charges to the societies). Contact or involvement with an Autism Society was also unrelated to the receipt of home- or school-based supports and services in the jurisdiction in which this study took place. Five potential participants also sent an email directly to the primary investigator requesting a copy of the questionnaire. Although not confirmed, we suspect that these potential participants learned of the study through word-of-mouth. Based on this sampling protocol, we obtained responses from across the province, including urban and rural respondents, and across the targeted age range.

Participants

Parents provided demographic and descriptive information, including their child's age and gender, intellectual ability (parent report: 1 = moderate/severe delay, 2 = mild delay, 3 = average/above average), language skills (parent report: 1 = less than five spoken words, 2 = more than five spoken words, but not sentences, 3 = some sentences, but not conversational, 4 = conversational), and the presence of disruptive behaviors (parent report to the question "Does your child have disruptive behaviours that affect his/her ability to participate in everyday activities?" 0 = no, 1 = yes). Parents also reported on their family type (single parent or co-parenting), parental age, gross household income, parental educational attainment, parental employment status, total number of children living in the home, and whether they had more than one child with ASD. The sample was diverse in terms of child, parent, and household characteristics. Table 1 summarizes characteristics of the participants and their families.

Quantitative data collection

Family service needs. Data on service needs were obtained using the *Family Needs Survey–Revised* (FNS-R; Bailey and Simeonsson, 1990). This survey was developed for use in early intervention, but has been since used in studies across childhood and with children with different special health care needs (e.g. Almasri et al., 2011, 2014; Palisano et al., 2009). We also chose to use this survey across childhood because ASD is a pervasive and persistent disorder, with service needs persistent across childhood. Parents rated 36 items, grouped into seven types of support (information, family and social, financial, explaining to others, childcare, professional support, and community services). The original scale asked, "Would you like to discuss this topic with a staff person from our program?" with three response options: (1) "No," (2) "Not Sure," and (3) "Yes." We amended the question to ask, "Would you like professional assistance with this topic?" with four response options: (1) "Not needed"; (2) "Not sure"; (3) "Needed, already provided"; or (4) "Needed, not provided." Table 2 includes all items as they appeared on the survey. These amendments to the responses allowed us to delineate between met and unmet service needs.

Qualitative data collection

Needs assessments are often based on existing services, which may not reflect the full spectrum of family needs. Thus, participants were also asked the open-ended question, "What is your greatest service need as a parent of a child with ASD?"

Data analyses

Quantitative data. Statistical analyses were completed using IBM SPSS version 20. All data were entered by a research assistant and screened for accuracy by the lead author prior to analysis. Descriptive statistics were calculated to characterize the sample. The *overall need* for individual FNS-R items (i.e. the degree to which an item was identified as a need, regardless of whether or not that need was met) were determined as follows. First, we coded item responses as 0 = "not needed" (including the response "not needed' or "not sure") or 1 = "needed' (including the responses of "needed, already provided" or "needed, not provided"). Notably, only five responses of "not sure" were provided across participants. We then calculated the percentage of participants indicating need for each item. *Needs met* for individual items represents the percentage of participants who identified that item as a need and responded "needed, provided" (as opposed to "needed, not provided"). Thus, needs met is proportional to participants who identified that item as a need and allows us to determine which needs were and were not being well met.

We coded data from the survey responses as indicated above for *overall need* and summed responses for all 36 items to create a "Total needs score." "Unmet needs" scores were determined based on the total number of items with a response of "needed, not provided." Proportional unmet needs were calculated as the total number of unmet needs/total number of needs. Predictors of "Total needs" and "Total unmet needs" were modeled with negative binomial regression. This model is an extension of the Poisson regression model, the benchmark for count data, which accounts for over-dispersion of data (Coxe et al., 2009). Thus, two models were run, considering "Total needs" and "Total unmet needs" as the dependent variables. Predictors

Table 1. Characteristics of participants and their families (N = 143).

Survey completed by mother		92%
Urban residence		90%
Two-parent family		88%
Mother's age (years)	Mean (SD)	41.0 (7.05)
	Range	26–60
Father's age (years)	Mean (SD)	43.1 (7.08)
	Range	29–60
Total number of children at home	Mode (range)	1 (0–7)
Has >1 child with ASD		15%
Child's age (years)	Mean (SD)	9.8 (5.24)
	Range	2–18
Child's age group (years)	Preschool (under 6)	29%
	6–12	38%
	13–18	33%
Official diagnosis	Autism/ASD	76%
	PDD-NOS/Asperger's syndrome	24%
Child with ASD male		88%
Child's language	Nonverbal/single words	29%
	Sentences, not conversational	26%
	Conversational	46%
Child's intellectual ability	No impairment	37%
	Mild delay	19%
	Moderate/severe delay	44%
Has disruptive behaviors		75%
Mother's education	No post-secondary education	11%
	Some college or university	25%
	Completed college or university	52%
	Completed graduate studies	12%
Father's education	No post-secondary education	15%
	Some college or university	19%
	Completed college or university	50%
	Completed graduate studies	16%
Household income	<$45,000	10%
	$45,000–$75,000	25%
	$75,000–$120,000	32%
	>$120,000	33%
Mother's employment	Not working	44%
	Part-time	28%
	Full-time	28%
Father's employment	Not working	8%
	Part-time	7%
	Full-time	86%

ASD: autism spectrum disorder; PDD-NOS: pervasive developmental disorder, not otherwise specified.

of the "Total unmet needs" proportional to "Total needs" were modeled with a binary logistic generalized linear model. This model uses a logit transformation and assumes a binomial distribution, similar to logistic regression (Harrell, 2001). Several child and family variables previously reported to affect access to care for families of children with ASD (Thomas et al., 2007, 2012) were included as predictor variables in these models. Specifically, as indicated in Table 1, scale-level data included mother's age and child's age, and interval-level data included mother's employment, household income, child's language ability, child's intellectual ability, and disruptive behaviors. The scale parameter for the negative binomial regression was estimated by the square root of the Pearson chi-square/degrees of freedom.

Qualitative data. Open-ended survey responses were analyzed using qualitative content analysis (Sandelowski, 2000). Qualitative content analysis is the preferred analysis strategy in qualitative descriptive studies, whereby data

Table 2. Reported overall and met needs by Needs Surveys items (N = 143).

Section	Item	Needed[a]	Need met[b]
Information	How children grow and develop	40	60
	How to play or talk with my child	50	82
	How to teach my child	64	64
	How to handle my child's behavior	77	62
	About ASD	65	82
	About services presently available for my child	82	52
	About services my child might receive in the future	79	22
Family and social support	Talking with someone in my family about concerns	60	71
	Having friends to talk to	71	70
	Finding more time to myself	74	42
	Helping my spouse accept that our child has ASD	43	52
	Helping our family discuss problems and reach solutions	53	43
	Helping our family support each other during difficult times	58	37
	Deciding who will do household chores, child care, and other family tasks	43	50
	Deciding on and doing family recreational activities	47	52
Financial	Paying for expenses such as food, housing, clothing, or transportation	38	57
	Getting special equipment	35	57
	Paying for therapy or day care	54	50
	Counseling or help getting a job	28	52
	Paying for respite care	60	76
	Paying for toys my child needs	30	58
Explaining to others	Explaining my child's condition to my parents/spouse's parents	31	64
	Explaining my child's condition to siblings	35	46
	Knowing how to respond when friends, neighbors, strangers ask questions about my child	44	34
	Explaining my child's condition to other children or peers	48	31
	Finding reading materials about other families who have a child like mine	51	42
Child care	Locating respite-care workers able to care for my child	57	32
	Locating a day-care program or preschool for my child	31	68
	Getting appropriate care for my child in a church/religious event	28	33
Professional support	Meeting with a minister, priest, rabbi, or other religious leader	17	67
	Meeting with a counselor	54	64
	More time to talk with my child's teachers or therapists	53	55
	Community services	66	52
	Meeting and talking with other parents who have a child with ASD	66	58
	Locating a doctor who understands me and my child's needs	66	59
	Locating a dentist who will see my child	58	63

ASD: autism spectrum disorder.
[a]Percentage of total respondents who indicated area of need ("needed, already provided" + "needed, not provided").
[b]Proportion (%) of previous column who responded "needed, already provided."

are summarized and described on a "surface" level to inform practice or policy, without attempting to conceptually or theoretically over-interpret data (Sandelowski, 2000). Informed by the five stages of thematic analysis outlined by Braun and Clarke (2006), three team members independently coded qualitative responses to the open-ended question, then compared codes and applied broader themes depicting areas of greatest need. Team members used different identifying codes, but achieved 100% consensus in identifying the broader themes. The original analysis was done in one 2-h meeting. Team members then reflected on our themes throughout the process of article preparation and did not make any changes from our original analysis. This was not surprising since easy consensus among researchers is common with qualitative description (Sandelowski, 2000).

Results

Overall needs

Table 2 summarizes responses for individual FNS-R items. The average number of needs reported on the FNS-R was 19 (out of 36 choices; SD = 8.863; normally distributed,

Table 3. Families' single greatest identified service need (open-ended question; *N* = 143).

Theme	Example(s) of contributing data	Responses (%)
1. Respite	"Breaks," "Periodic free time for myself," "Sleep – I have the skills, I need the energy"	26
2. Long-term planning for adulthood; Availability of adult programs and supports	"Security for his future – vocational and housing," "Transitional supports after high school"	20
3. Transparent information about available supports and how to access them	"To know what services are available so I can choose to access them"; "Not to have to fight for each service"	19
4. Seamless access to supports and services over time	"Predictability in services from year to year"	8
5. Community integration and societal acceptance of persons with ASD	"People who understand," "Community awareness"	6
6. Availability of social skills programs for my child	"My programs only focus on academics and routines. Social groups have long waitlists."	6
7. Parent and sibling emotional supports	"Time for our other child," "A peer group for ME"	5
8. Funding and local expertise in biomedical treatments	"Paradigm shift to understand that autism is medical, and funding for biomedical treatments"	4
9. Services for difficult behaviors/aggression	"Strategies for aggression. He's getting stronger"	3
10. Better qualified professionals/more ASD-specific training for professionals	"Autism specific training for teachers and aides"	3

ASD: autism spectrum disorder.

skewness = 0.51, *kurtosis* = 0.56). Six families (4%) indicated no needs, and one family indicated a need for help on all items (range 0–36 items). The most frequently identified needs were for information related to services available now (82% of participants; *n* = 117) and in the future (79%; *n* = 113). The majority of respondents also indicated the need for help with "handling my child's behavior" (77%; *n* = 110) and "finding more time to myself" (74%; *n* = 106). Needs based on the FNS-R subcategories ranged from 69% to94% as follows: 94% of participants (*n* = 135) needed information, 90% (*n* = 129) needed professional support; 89% (*n* = 127) needed family and social support; 87% (*n* = 125) needed financial support; 75% needed help explaining to others; and 69% needed help with childcare.

In response to the open-ended question "What is your greatest service need as a parent of a child with ASD?," the single greatest needs of 65% (*n* = 93) of our sample fell into three categories: (1) respite, (2) planning for and availability of adult supports and services, and (3) transparent information about supports and services that might be available now and in the future. The remaining 35% of responses fell into seven categories. These categories are summarized in Table 3.

Best- and worst-met needs

Analyzing data in terms of best- and worst-met needs can provide insight into strengths and gaps of current service structures and systems. In terms of best-met needs, parents expressed that certain matters were recognized needs, but were already being met. The last column in Table 2 summarizes the percentage of respondents, proportional to those who identified each item as a need, for whom each need was met. The best-met needs were for information about "how to play or talk with my child" (82% met; 59/72 respondents who identified this item as a need), information about ASD (82% met; 76/93 respondents), financial support to hire a respite worker (76%; 65/86 respondents), and talking with friends (70%; 71/101 respondents) or someone in my family about concerns (71%; 60/85 respondents). All items in the subcategories financial support and professional support were met for at least 1/2 of the respondents who indicated those items as an area of need.

There were 10 of the 36 items that identified an area of need that more than 1/2 of respondents reported as unmet. These items were related to information about services, family and social support, explaining to others, and childcare. Only 22% (25/113) of families had their needs met regarding information about future services. Almost all items in the section on explaining to others were frequently unmet, including explaining ASD to siblings (46% met; 23/50 respondents), friends, neighbors, or strangers (34% met; 22/64 respondents), and peers (31% met; 21/68 respondents). Almost half of the items in the section of family and social support were frequently unmet, including helping their family discuss problems and reach solutions (43% met; 33/76 respondents); "finding more time for myself" (42% met; 44/105 respondents), and feeling supported in other difficult times (37% met; 31/83 respondents). Although not a frequently identified need, access to childcare for religious events was poorly met (33% met; 13/40 respondents). Locating qualified respite workers was one of the worst-met needs (32% met; 26/82 respondents), even though financial support to hire a respite worker was one of the best-met needs. Information related to

Table 4. Results from regression analysis.

Variable	Total needs		Total unmet needs		Unmet needs proportional to total needs	
	B (SE)	Exp(β)	*B* (SE)	Exp(β)	*B* (SE)	Exp(β)
Child's age	−0.019 (0.006)	0.981**	0.031 (0.011)	0.970**	−0.024 (0.0761)	0.976
Mother's age	0.012 (0.004)	1.013**	0.020 (0.009)	1.020*	0.056 (0.072)	1.057
Mother's employment	−0.054 (0.029)	0.948	−0.177 (0.061)	0.838**	−0.135 (0.261)	0.873
Household income	−0.027 (0.010)	0.974*	−0.036 (0.018)	0.964*	−0.062 (0.107)	0.940
Language ability	0.028 (0.021)	1.028	0.006 (0.044)	1.006	0.345 (0.296)	1.412
Intellectual ability	−0.025 (0.031)	0.975	0.006 (0.057)	1.006	0.239 (0.279)	1.270
Disruptive behaviors	0.100 (0.068)	1.105	0.280 (0.084)	1.323***	1.660 (0.603)	5.257***

ASD: autism spectrum disorder.
*$p < 0.05$; ** $p < 0.01$; ***$p < 0.001$.

current services was also frequently unmet (52% met; 61/117 respondents), even though this was the most frequently reported need.

Predictors of total needs and unmet needs

Table 4 summarizes results from the regression analysis relating child, family, and household variables to total needs, total unmet needs, and unmet needs proportional to total needs. Child's age, mother's age, and household income were significant predictors of total needs. Mother's employment, disruptive behaviors, child's language, and intellectual ability did not predict total needs. Similarly, child's age, mother's age, and household income were significant predictors of unmet needs. Older mothers had greater total needs and unmet needs, and mother's who worked more had fewer unmet needs. Increased household income predicted fewer total and unmet needs. However, the strength of these relationships was not overly strong, representing a 1%–4% change in need per unit change in each variable. For example, there was a 2% decrease in total needs for each year the child is older ($0.981 - 1 = -0.019 \times 100 = 1.9$, or approximately 2%). Maternal employment and disruptive behaviors were relatively strong predictors of unmet needs. Compared to mothers who were not employed, mothers who were employed part-time had a 16% ($0.838 - 1.00 = -0.162$) decrease in the total number of unmet needs, and mothers who were employed full-time had approximately 1/3 ($2 \times (0.838 - 1) = -0.324$) decrease in the total number of unmet needs. Having a child with disruptive behavior did not predict total needs, but predicted a 32% increase in total unmet service needs ($1.323 - 1 = 0.323$). Of consequence, when unmet needs were considered relative to the number of total needs, the only significant predictor of unmet needs was disruptive behavior. Having a child with disruptive behavior increased the odds of unmet service needs by more than 400% ($5.257 - 1 = 4.257$).

Discussion

This is the first study to systematically look at met and unmet service needs of families of children with ASD across childhood. It is reasonable to assume that family needs in ASD are consistent across jurisdictional boundaries. Therefore, our findings related to families' needs are likely generalizable to other jurisdictions, at least those within westernized societies. However, unmet needs likely vary across jurisdictional boundaries. The jurisdiction in which these data were collected is recognized as being well resourced related to ASD services (Madore, 2006; Standing Senate Committee on Social Affairs, Science and Technology, 2007) and unique to many funding models-, home-, and community-based services in this jurisdiction fall under one funding mechanism across childhood. Therefore, our findings may reflect a "best-case" scenario related to unmet service needs. These data can contribute to the debate on service needs in ASD and inform the evolution of strategies to support families with children with ASD across childhood.

Overall, families of children with ASD in this jurisdiction had many needs relatively well met. Our participants indicated approximately twice as many overall needs than parents of children with cerebral palsy (Palisano et al., 2009), and greater needs overall than parents of children with a variety of developmental disabilities, including ASD, in the Northeastern United States (Ellis et al., 2002). However, this previous work did not delineate between met versus unmet needs, so it is difficult to determine whether items were not desired, or whether those needs were already being met through services or other resources. Comparing met versus unmet needs provides important information for policy-makers, funders, and clinicians regarding current funding utilization and where to target refinements to systems and practices.

Participants generally reported positive experiences with the *funding* and *professional support* available for

services. However, *information* on services available was a significant unmet need identified by parents, which is consistent with previous research on the self-reported needs of families of children with a variety of chronic conditions (Brown et al., 2012; Ellis et al., 2002; Farmer et al., 2004; Palisano et al., 2009). Therefore, it appears that needs are often well met *only if* families can actually learn about and access available services. Parents may interpret a lack of transparency about services as reflecting a lack of trust in parents' ability to use only what is actually needed (Hodgetts et al., 2013b). Parents also report that the resulting time spent looking for services takes away from other productive activities and can result in parent burnout (Hodgetts et al., 2014). Locating and retaining qualified respite-care providers was identified as the single greatest need and often unmet, despite funding in place to pay for this service. Receipt of respite care has been linked to improved marital quality and decreased stress in parents of children with ASD (Harper et al., 2013). Thus, it is imperative that systems of care create and support mechanisms to train, find, and maintain qualified respite-care providers for families of children with ASD. Parents of children with ASD experience increased stress, depression, anxiety, and marital discord and decreased social support than parents of other children, including those with other chronic conditions (Estes et al., 2009; Gabovich and Curtin, 2009). Streamlining respite care processes could have substantial positive impact on parents' well-being and quality of life. This may be especially important for parents of children with disruptive behaviors (Brown et al., 2012; Douma et al., 2006; Hodgetts et al., 2013a), which was the largest reported risk for unmet needs. Disruptive behaviors, especially violent behavior, predicted improved service receipt for adults with developmental disability (Pruchno and McMullen, 2004), yet decreased service receipt for families of children with ASD (Hodgetts et al., 2013a). Reasons for this discrepancy warrant further investigation, especially since disruptive behaviors contribute to parental fatigue, increased stress, and decreased maternal well-being (Seymour et al., 2013). Social support from family, friends, neighbors, and professionals is a powerful and appropriate mechanism to decrease stress and improve well-being of families of children with ASD (Zablotsky et al., 2013). Even though facilitation of family and social supports could be cost-effective, time-effective, and impactful for families, our participants identified family and social supports as a poorly met area of need.

Contrary to our hypothesis and previous research (Brown et al., 2011), language and intellectual level and the presence of disruptive behaviors did not predict perceptions of need. This finding demonstrates the impact that ASD can have on the family regardless of varying abilities in discrete domains, and the importance of service access that is not based on impairment or functional ability in specific domains. Consistent with previous research (Ellis et al., 2002), having a younger child predicted greater *total* needs, and having an older child predicted greater *unmet* needs (Thomas et al., 2012). Service issues are generally recognized to become more severe as children get older across jurisdictions (Brown et al., 2012; Standing Senate Committee on Social Affairs, Science and Technology, 2007). This study adds further data to support the increase in unmet needs as children get older, even when services fall under the same funding mechanism. Although families of older individuals often become more resilient and/or more accepting of their child's diagnosis over time (King et al., 2009), ASD is a lifespan disorder and tailored services should be available accordingly. In addition, contrary to previous work (Ellis et al., 2002), older mothers indicated greater needs, and mothers who worked more had fewer unmet needs. Older mothers may have more experience with child development, increasing their recognition of "atypical" development and their desire for services, and lower unmet needs likely enabled mothers to work more. Finally, increased household income predicted both fewer total and unmet needs. Household income did not predict service needs for families of children with cerebral palsy (Almasri et al., 2014) or unspecified developmental disabilities (Ellis et al., 2002). Household income did predict unmet service needs for families of children with ASD in the context of the American service system (Thomas et al., 2012), but not in the context of the Canadian service system (Brown et al., 2011). Therefore, our findings may represent a bias, or advantage, in service allocation to wealthier families in this jurisdiction, which, in the context of publically funded services, is concerning and warrants future investigation.

Limitations

Our study provided important information on met and unmet needs of families of children with ASD, but it was not without its limitations. Some of our findings, for example, that parents of younger children have greater overall needs, may be artifacts of the assessment tool since it was originally designed for early intervention. Therefore, our findings are unlikely to represent the full spectrum of family needs. We hope that the inclusion of open-ended questions helped fill these potential gaps. We also did not include families with a child over 18 years old in this analysis. ASD is a lifespan disorder and parents often remain the primary caregiver beyond childhood. The inclusion of parents of older children with ASD could have important implications for policy and practice. To shorten the survey to increase response rate, we relied on parental report for clinical descriptors, such as language and intellectual level, rather than incorporating additional standardized measures into the questionnaire. We were comfortable with the level of reporting for our purposes since parents' subjective perception of function in various domains is reflected in their perceived need for help (Baker and Heller, 1996). However, this method of assessing intellectual ability may not be

valid and may limit generalizability of our findings. Assessing the presence of disruptive behaviors through a yes/no question might also have inaccurately represented the nuances of this construct, affecting findings.

We do not know how our findings generalize to the broader population of families of children with ASD in this jurisdiction or elsewhere. We did have diversity in child, parent, and household characteristics in our sample. However, the representativeness of our results may be limited due to over-representation of two-parent families and relatively well-educated parents. Although a more normally distributed sample would have been ideal, we anticipate that these factors bias our findings toward a "best-case" scenario if anything. In addition, 88% of the children diagnosed with ASD were male, which is slightly higher than the well replicated and accepted ratio of 4:1 (male:female) (Zwaigenbaum et al., 2012). However, we did not expect gender to affect family needs. The majority of our respondents were also mothers. Therefore, findings may not be generalizable to fathers of children diagnosed with ASD. A focus specifically on the needs of fathers is an important area for future research. Because service access and delivery varies across Alberta and across the lifespan, our sample diversity in these variables improves generalizability. Regression does not indicate the causal direction of the relationship between variables. For example, do disruptive behaviors predict increased unmet service needs, or do more unmet service needs predict an increase in disruptive behavior? We need to infer the probable direction of relationships based on existing knowledge and qualitative feedback. Finally, our data provides a cross-sectional picture of overall and unmet service needs for families of children with ASD across childhood. A longitudinal perspective on service needs would contribute to our understanding of the complexities of family service needs.

Conclusion

The increasing prevalence of ASD and the resulting strain on the service system has led to legislation or recommendations for national strategies to address ASD services in the United States (Autism Speaks, 2012), Canada (Autism Society of Canada, 2011; Standing Senate Committee on Social Affairs, Science and Technology, 2007), and the United Kingdom (Parliament of the United Kingdom, 2009), including a greater focus on service availability across childhood and beyond. Determining consistencies and gaps between families' identified needs and the services offered can contribute to the debate on service needs, and help target policies and practices to make the best use of inevitably limited personal, professional, and financial resources. Determining services that best meet the needs of families, as identified *by* families, is an important step in this process that could translate into improved quality of life for individuals with ASD and their families, and eventually more sustainable ASD services.

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