Parents Seeking Adult Developmental Services for their Children: A Provincial Study [Phase 1]

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MAPS (Multidimensional Assessment of Providers and Systems) is a research program to inform the assessment of services and supports for adults with intellectual/developmental disabilities in Ontario, Canada. MAPS (www.mapsresearch.ca) is supported by a research grant from the Government of Ontario's Ministry of Community and Social Services.

Enhanced social inclusion, choice and independence are outcomes central to recently passed legislation in Ontario – The Social Inclusion Act. The goal of MAPS is to achieve a consensus of what is meant by social inclusion, choice and independence and how to best capture information about these outcomes.

MAPS is a provincial interdisciplinary team of researchers working with individuals with intellectual/developmental disabilities, their families, service providers, government representatives and researchers in other provinces and countries. The research team is led by Dr. Hélène Ouellette-Kuntz (Departments of Community Health & Epidemiology and Psychiatry, Queen's University) and is composed of Dr. Virginie Cobigo (School of Nursing Sciences, University of East Anglia), Dr. Robert Hickey (School of Policy Studies, Queen's University), Dr. Rosemary Lysaght (School of Rehabilitation Therapy, Queen's University), Dr. Yona Lunsky (Department of Psychiatry, University of Toronto, and Research Head of the Dual Diagnosis Service at the Centre for Addiction and Mental Health), and Dr. Lynn Martin (Department of Health Sciences, Lakehead University)

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Executive Summary

Family caregivers play an important role in supporting individuals with intellectual or developmental disabilities (IDD) into adulthood. While many family caregivers have expressed frustration with gaps in services, little is known about the process by which families come to request services and what happens while they wait for services to be provided.

Recent changes in Ontario warrant a study of those seeking Developmental Services in the province: who they are, what they seek, when and why they request services, and how individuals and families cope while they wait for services. The MAPS team has developed a three-phase research project – the *Parent Study* -to better understand the experiences of parents as caregivers and as seekers of formal services.

In this report, we address the findings of the first phase of our study. Phase I is a cross-sectional survey of parents at the time they seek services. The research questions for Phase I are:

1. Who are the parents who have requested adult Developmental Services in Ontario for their sons or daughters in the first 9-months since the opening of the Developmental Services Ontario organizations and how are they coping?
2. What is the demographic and clinical profile of the individuals with IDD for whom parents have requested services?
3. What service(s) have parents requested for their son/daughter?
4. What individual, parent (subjective) and family (demographic) variables are associated with the decision to seek different services?
5. How do parents perceive their son/daughter's opportunities for social inclusion and choice?
6. Are parental expectations of social inclusion, independence, and choice for their son/daughter associated with the type of service(s) they want for their child?

This report addresses questions 1 to 4. The other questions will be addressed in a broader report from MAPS on indicators of social inclusion.

In this report, we describe the 211 parents participating in our study, their sons and daughters, the parents' perceptions of support, coping, burden and crisis around the time of the service request to the DSOs, and their request for services. We then examine the extent to which individual, parent (subjective) and family (demographic) variables are associated with the decision to seek different services.

Recruitment Procedure

All nine Developmental Service Ontario regions agreed to assist with the recruitment process by distributing our recruitment forms. The percentage of forms received varied considerably by

region, indicating that particular regions were more successful at promoting the study. Implications of various recruitment methods are discussed.

Parents

Our sample consists mostly of mothers between 46 and 60 years of age. Nearly half the parents reported having at least one significant medical, physical or mental health condition and just over a quarter of parents indicated that they were providing care for at least one more person with special needs, other than their son or daughter for whom they were requesting services.

Persons with IDD for Whom Services are Requested

The individuals with IDD for whom parents participating in our study were requesting Developmental Services were more likely to be male (64.4%) and to be young (91.7% were younger than 35 years of age). Diagnoses varied; approximately one-third were reported to have an autism spectrum disorder and 15.7% had a diagnosis of Down syndrome. Physical and psychological comorbid conditions were common.

Parents' Mental Health and Perceptions of Support, Burden, Coping and Crisis Around the Time of Service Request

Many parents reported significant mental health concerns with over half likely to be living with an emotional disorder. Similarly, more than half of the parents were reporting high burden and a third were reporting a high level of distress. Overall support scores varied tremendously, however parents tended to perceive informal supports including extended family members and friends as unhelpful. Despite the low support scores and high perceptions of burden and distress reported by many parents, as a group, these parents appear confident in their caregiving role and quite resilient.

Services and Supports Requested

Parents requested a variety of services and frequently identified more than one support requested. Community participation support was the most frequently requested service category (68.6%), followed by agency residential support (44.4%) and caregiver respite (32.4%).

Individual, Parent and Family Characteristics and the Decision to Seek Different Services

Stratifying service requests according to individual, parent and family characteristics revealed expected and unexpected patterns. The type of disability the individual with IDD has may have some relevance with regard to need for unique services. For example, parents of adults with ASD were more likely to request respite. In general, parents requesting a greater number of services were also reporting greater burden. Service requests differed according to parent and family characteristics with older parents, of older adult children, more likely to request residential supports.

Introduction

Family caregivers play an important role in supporting individuals with intellectual or developmental disabilities (IDD) into adulthood. This ongoing involvement by family members is often desired, not only by families but also by funders of services. Many authors have drawn attention to the challenges family caregivers experience when supporting an individual with IDD as they become adults, including experiences of depression, stress and caregiver burden (Bianco, Garrison-Wade, Tobin & Lehmann, 2009; Neece, Kraemer & Blacher, 2009; Power, 2009; Rawson, 2010).

Furthermore, caregivers have expressed frustration with gaps in service (Gilbert, Lankshear & Peterson, 2008; Hare, Pratt, Burton, Bromley & Emerson, 2004; Weeks, Nilsson, Bryanton & Kozma, 2009; Davys & Haigh, 2008) and concerns over long-term residential placements (Gilbert, Lankshear & Peterson, 2008; Freedman, Krauss & Seltzer, 1997; Weeks, Nilsson, Bryanton & Kozma, 2009; Davys & Haigh, 2008; Pruchno & Patrick, 1999). Yet, little is known about the process by which families come to request services and what happens while they wait for services to be provided. With an increasingly large population of adults with IDD living with or being supported by family caregivers (Braddock, Emerson, Felce, & Stancliffe, 2001), it is important to understand the experiences of parents as caregivers and as seekers of formal services.

The province of Ontario offers a wide array of supports to adults with intellectual and developmental disabilities. However, Developmental Services are not an entitlement; eligibility determination, prioritization processes, and system capacity contribute to delays from recognition of need to provision of support. Many recent changes in Ontario warrant a study of those seeking Developmental Services in the province: who they are, what they seek, when and why they request services, and how individuals and families cope while they wait for services.

As of July 1, 2011, all individuals seeking Adult Developmental Services are required to apply in the same way. The application processes has been streamlined through the creation of specific access points – Developmental Services Ontario (DSO) organizations in each of the nine (9) regions of the province. There is a commitment to increase equity through better matching of priority with availability of service and enhancing system capacity. In addition, there is growing recognition that planning must keep in mind the unique issues of those transitioning from school settings, the needs of individuals who require a combination of mental health and Developmental Services (dual diagnosis), and the needs of those who have been supported by aging parents, who are suddenly at a point where they can no longer take responsibility for their child.

For the first time, the same information is being collected province-wide on all individuals requesting Developmental Services in a uniform manner. It is clear that the on-going nature and extensiveness of the data being collected through the DSOs offers a new rich source of information including access to a broad population for study. The data collected by DSOs does not, however, adequately capture the experiences of family members while waiting for

supports, such as coping strategies, and innovative local practices. The MAPS team has developed a three phase research project – the *Parent Study* -to gain an understanding of parents' experiences. This *Study* also provides a mechanism for considering how best to collect information from parents relevant to understanding the social inclusion, independence and choice experiences of their adult children with intellectual and developmental disabilities.

Project Goals

The goals of the *Parent Study* are to:

1. develop a profile of families seeking adult Developmental Services;
2. identify individual, parent (subjective) and family (demographic) variables that influence the decision to seek different services;
3. determine how to use parent reports to formulate indicators of social inclusion, choice and independence;
4. identify indicators of parent experiences (distress and mental health problems) that could/should be integrated in system monitoring; and
5. report on innovative practices to support families while they wait for services.

Project Phases

To achieve these goals, the project consists of three phases. Phase I is a cross-sectional survey of parents at the time they seek services. The subsequent sections of this report describe Phase I of the project. The second phase is a follow-up of parents at 3-month intervals for up to one year. Phase III consists of qualitative interviews with a select number families to better understand innovative practices regarding support and care. Separate reports for Phase II and III will be submitted upon completion of these phases in March 2013, and June 2013, respectively.

Phase I Research Questions

1. Who are the parents who have requested adult Developmental Services in Ontario for their sons and daughters in the first 9-months since the opening of the DSOs and how are they coping?

2. What is the demographic and clinical profile of the individuals with IDD for whom parents have requested services?

3. What service(s) have parents requested for their son/daughter?

4. What individual, parent (subjective) and family (demographic) variables are associated with the decision to seek different services?

5. How do parents perceive their son/daughter's opportunities for social inclusion and choice?

6. Are parental expectations of social inclusion, independence, and choice for their son/daughter associated with the type of service(s) they want for their child?

In this report, we address questions 1 to 4. The other questions will be addressed in a broader report from MAPS on indicators of social inclusion.

Methods

Recruitment and Data Collection

All nine DSO regions of Ontario agreed to assist with the recruitment process by distributing our recruitment forms to parents of adolescents and adults (age 16 and above) with intellectual/ developmental disabilities living at home and seeking services through a Developmental Services Ontario organizations between July 4, 2011 and March 31, 2012. We restricted our study population to those living at home as these families are in a unique situation with respect to their request for services; and to parents since they are the most common family caregivers of adults with IDD.

A total of 1720 Request for Information forms and envelopes were prepared and sent to the DSOs for them to distribute to parents who met the above criteria. The DSOs identified 1191 parents for whom they distributed our forms along with a stamped return envelope so that the parent could return it directly to the MAPS research team. DSO staff were instructed to give this form to parents as early as possibly in the application process and to encourage the parents to complete the form at the initial meeting, but also to note to parents that they had the option of taking it home with them. If requested by DSO staff, we also provided them with an email version of the Request for Information form, where parents were instructed to reply to the MAPS research team if they wanted more information about the study.

Though it was originally intended that the DSO staff deliver the recruitment forms in-person, the process was modified for three of the DSO regions who preferred to do mass-mailings (Toronto, Central East and Hamilton-Niagara). For these regions, it was more feasible for them to mail a modified version of the Consent form directly to eligible parents. A total of 251 Request for Information forms (including modified Consent forms) were returned to the MAPS research team by parents. The percentage of forms received varied considerably by region from 1% to 56%.

When the Request for Information form was received, the MAPS office administrator mailed the parent a package that included a Study Information sheet and Consent form and a questionnaire, along with separate self-addressed stamped envelopes to return the signed Consent form separately from the completed questionnaire. A member of the research team called the parent to follow up two weeks after the package had been mailed out. If the consent form had been received or if the parent provided verbal consent during the call, a suitable time to conduct a telephone interview was scheduled. Once the completed mail-out survey was received by the MAPS research team and the phone interview completed, the participant was mailed a cheque for $20, as a thank you for their time.

The majority of parents who requested more information agreed to be part of the study, which was consistently high across all regions (77% to 100%). However, because the number of requests for information varied across regions, the sample is not representative of the population distribution across the province (see Figure 1). Of a total of 221 parents who consented to participate, 211 provided complete or partial data (209 useable mail-out surveys and 207 completed telephone interviews).

Parents Seeking Services – Phase I
Ouellette-Kuntz et al., 2012

Figure 1: *Breakdown of participants by region* (n=211)
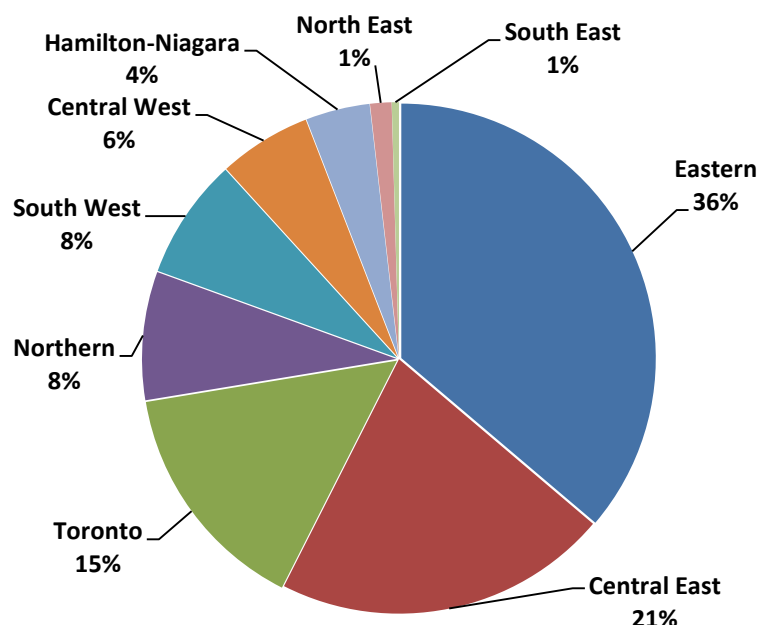
Participating parents were also mailed a Release of Information form and return envelope to allow the MAPS team to obtain a copy of their Application for Developmental Services and Supports (ADSS) held at the DSOs. Of the 181 release forms that were returned by parents, to date, 107 ADSS packages have been sent to the research team from DSOs.[1]

Measures

Several different measures were used in the mail survey and telephone interview to capture information about parent psychological variables in addition to family demographics and information on services requested.

The mail-out questionnaire had five sections. The first three consisted of published tools: the Family Support Scale (Dunst, Jenkins & Trivette, 1984), the Compensating Experiences Subscale of the Inventory of Family Protective Factors (Gardner, Huber, Steiner, Vazquez, Savage, 2008) and the Brief Family Distress Scale (Weiss & Lunsky, 2010). The fourth section was made up of questions pertaining to the individual with an intellectual/developmental disability and their involvement in three areas of interest: community connections, planning, and choices and control. The final section contained the 12-item General Health Questionnaire-12 (GHQ-12; Goldberg & Williams, 1988) to screen for mental health problems in the responding parent. The mail-out survey concluded with 7 socio-demographic questions about the family. In all, the mail-out survey included 58 items and took about 20 minutes to complete.

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[1] Due to delays in completing ADSS data collection and processing, the data from these assessments is not included in this report.

The interview booklet included introductory and closing scripts and questions organized into three parts. Part A, requested demographic and clinical information about both the son or daughter with IDD and the parent. Two published tools were included in Part B to describe parents' experiences of coping (5 subscales of the Brief COPE; Carver, 1997) as well as caregiver burden and mastery (9 and 6 items respectively, from the Revised Caregiver Appraisal Scales; Lawton, Kleban, Moss, Rovine & Glicksman, 2000). Part C consisted of the services and supports requested as well as open-ended questions to capture information about what led the parent to request services at this time. In all, the telephone interview included 100 items and took approximately 30 minutes to complete.

Analysis

The analyses presented in this report are largely descriptive. Where stratified analyses are presented, the Chi-square statistic (or Fisher's Exact test) was used to test the statistical significance of the differences observed. A p-value of less than 0.05 was used to determine statistical significance.

Results

Our intent was to first establish the extent to which our study participants were representative of parents requesting services through the DSOs during the period of recruitment. However, we have been informed that the profile will not be available from the MCSS information system (DSCIS) until spring 2013 (Ingrid Lawrence, personal communication, November 5, 2012). Therefore, in this report, we describe the 211 parents participating in our study, their sons and daughters, the parents' perceptions of support, coping, burden and crisis around the time of the service request to the DSOs, and their request for services. We then examine the extent to which individual, parent (subjective) and family (demographic) variables are associated with the decision to seek different services.

The Parents

As shown in Table 1, our sample consists mostly of mothers (85.3%) between 46 and 60 years of age (parents' age ranged from 38 to 91 years). The parents in our study tended to be married to their child's other parent (65.2%) but a quarter were separated/divorced and the remainder were single or widowed. Over two-thirds of parents had completed some post-secondary education and over 60% were employed (Table 2). Nearly half of them reported having at least one significant medical, physical or mental condition themselves (see Figure 2).

Table 1: *Demographic Profile of Parents* (n=211*)

Demographic Information	*n*	(%)
Parent Gender		
Female	180	85.3
Male	31	14.7
Parent Age (n=205)		
45 years and younger	26	12.7
46-60	146	71.2
61 years and older	33	16.1
Relationship Status to the child's Other Parent (n=204)		
Married	133	65.2
Single (never married)	10	4.9
Separated/Divorced	51	25.0
Widowed	10	4.9

*Note: *5 parents completed the survey twice for 2 different children. Those parents are included only once in this table.*

Table 2: *Parent Education and Occupation* (n=211*)

Occupation and Education	n	(%)
Occupation (n=203)		
Working	126	62.1
Education and law	37	17.9
Health	23	11.3
Business and finance	20	9.9
Sales and service	16	7.9
Management	10	4.9
Other (natural and applied sciences, art, culture, trades, transport, natural resources, etc.)	19	9.4
Not working	77	37.9
Retired	30	14.8
Stay at home	26	12.8
Unemployed	11	5.4
ODSP or other beneficiary	10	4.9
Education (n=205)		
Less than high school diploma	20	9.8
High school Diploma	43	21.0
Some college and University	36	17.6
College and technical diploma	65	31.7
Undergraduate degree	21	10.2
Professional or graduate degree	20	9.8

*Note: *5 parents completed the survey twice for 2 different children. Those parents are included only once in this table.*

Figure 2: *Proportion of Parents Reporting Significant Medical, Physical and/or Medical Conditions* (n=211)
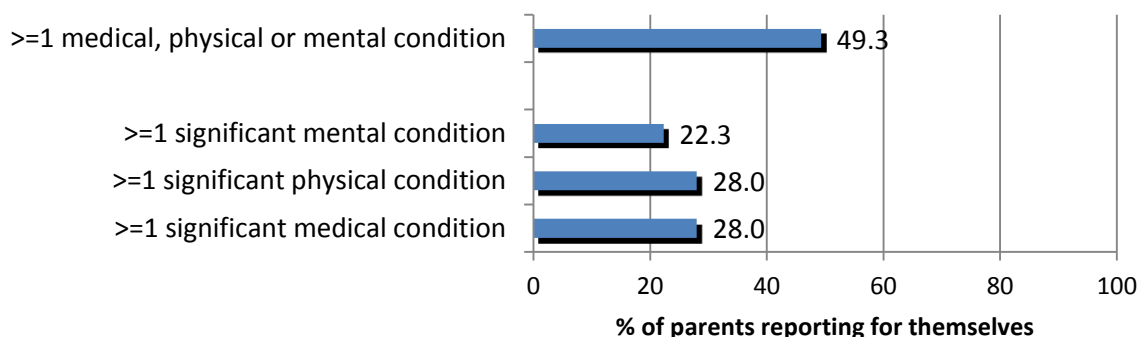
*Note: *'Significant medical conditions' refers to diseases such as heart disease, cancer and multiple sclerosis. Physical impairments such as problems walking or herniated disc are included under 'Significant physical conditions'. 'Significant mental health conditions' refers to mental health problems such as depression and bipolar disorder.*

While the study participants are not proportionally representative of each region of the province, the urban/rural split (~80/20) matches the provincial distribution. Furthermore, the parents reported a wide-range of household incomes (Table 3).

Table 3: *Location of Residence and Household Income* (n=211*)

| Demographic Information	*n*	(%)
Location of Residence		
Urban	170	80.6
Rural	41	19.4
Annual Household Income (n=198)		
Less than 25,000	43	21.7
25,001-35,000	25	12.6
35,001-45,000	15	7.6
45,001-55,000	21	10.6
55,001-65,000	18	9.1
65,001-75,000	9	4.5
75,001-85,000	13	6.6
85,001-95,000	7	3.5
95,001 or more	47	23.7

*Note: *5 parents completed the survey twice for 2 different children. Those parents are included only once in this table.*

Just over a quarter of parents (26.0%) indicated that at least one more person other than their son or daughter for whom they were requesting services has special needs. In five instances, the other household member was a second child for whom the parent was also requesting services. In other cases, it was other children, their spouse or their own elderly parent who relied on support. There was a wide range of disabilities as well as medical, physical and mental health conditions listed. Common disorders in other children included autism spectrum disorders, attention deficit hyperactivity disorder, and obsessive compulsive disorder, as well as general learning disabilities. Many identified mental health conditions, particularly among other adult household members, with depression and anxiety as the most common. Examples of medical conditions ranged from heart conditions, diabetes, seizures, and different forms of cancer. For some household members, physical assistance was needed due to mobility issues from paraplegia, arthritis, or recent surgeries.

Persons with IDD for Whom Services are Requested

The individuals with intellectual/developmental disabilities (IDD) for whom parents participating in our study were requesting Developmental Services were more likely to be male (64.4%) and to be young. Nearly half were between 16 and 20 years of age (47.2%) and very few were 35 years or older (7.9%). Only 12 (5.6%) were born outside Canada. (See Table 4)

Table 4: *Characteristics of Person with IDD for whom Service is Requested* (n=216)

Characteristics	n	%
Age(n=215)		
20 years and younger	102	47.4
21-34 years	96	44.7
35 years and older	17	7.9
Gender		
Male	139	64.4
Female	77	35.6
Country of origin (n=207)		
Canada	195	94.2
Other (Pakistan, Palestine, Columbia, El Salvador, Germany, Jamaica, Kosovo, Nigeria, Saudi Arabia, USA)	12	5.8

As shown in Table 5, approximately one-third (31.5%) of sons and daughters were reported to have an autism spectrum disorder and 15.7% had a diagnosis of Down syndrome. Physical and psychological comorbid conditions were common. Nearly one-quarter (23.6%) were reported to have mobility impairments, with many requiring the assistance of a wheelchair or other mobility support devices. Approximately 34.7% of the sons and daughters were reported to have a dual diagnosis.

Table 5: *Diagnoses of Person with IDD for whom Service is Requested* (n=207*)

Diagnosis**	n	%
Disorder/syndrome		
Autism spectrum disorder	68	32.9
Down syndrome	34	16.4
Other syndromes (For example: Fetal alcohol spectrum disorder, Prader-Willie syndrome, Angelman syndrome, Ring 22)	20	9.7
Cerebral Palsy	28	13.5
Epilepsy/Seizure disorder	44	21.3
Physical and Sensory Impairments		
Mobility impairment/wheelchair dependent	51	24.6
Limited or no vision-Legally blind	20	9.7
Hearing impairment-Severe or profound	14	6.8
*Dual Diagnosis***	75	36.2

*Note: Nine parents did not identify their son/daughter as having any diagnosis.
**Note: All conditions are not mutually exclusive.
***Note: Dual Diagnosis is defined as having at least one of the following diagnoses –
  Drug or alcohol dependency/ addiction; Alzheimer disease or dementia;
  Psychiatric disorder/ mental illness; Behaviour disorder/ Serious behavior problems

Parents' Mental Health and Perceptions of Support, Burden, Coping and Crisis Around the Time of Service Request

Recognizing the critical role that parents play in supporting their sons and daughters with IDD, we inquired as to their mental health, their perceptions of the adequacy of supports they were receiving and how well they were managing when they approached the DSOs.

Mental Health

Parents' mental health was assessed with the General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988). Past studies of parents of children with IDD have used a score of >2 as indication of "caseness" or the presence of possible emotional disorder (e.g., Bromley, Hare, Davison & Emerson, 2004; Emerson, 2003). Using this criterion, over half of parents (59.1%) are likely to be living with an emotional disorder.

Perceptions of Support

Perception of support was assessed using the Family Support Scale (Dunst, Jenkins & Trivette, 1984). The scale includes 20 items describing different sources of social support (e.g. assistance from family members, support groups, professional services and agency supports), with each support source rated in terms of its helpfulness. The total number of supports available to parents ranged from 2 to 20, with parents reporting on average 10.6 supports available to them. Each support is rated as to its helpfulness (on a scale of 1 to 5) with higher scores representing greater perceived helpfulness. Overall support scores varied tremendously from a low of 3 to a high of 60 (out of a possible total score of 100). Across the parents surveyed, only 6 sources of support were deemed as at least somewhat helpful (mean score >1.5); among these, parents tended to perceive their spouses and other children as most helpful (see Figure 3). As shown in Figure 4, parents tended to perceive informal supports including extended family members and friends as unhelpful (mean score <1.5).

Figure 3: *Parents' Perceptions of Unique Sources of Supports Around the Time they Made the Service Request – Supports Rated as Helpful on Average* (n=207)

0=not available/not applicable
1=not at all helpful
2=sometimes helpful
3=generally helpful
4=very helpful
5=extremely helpful
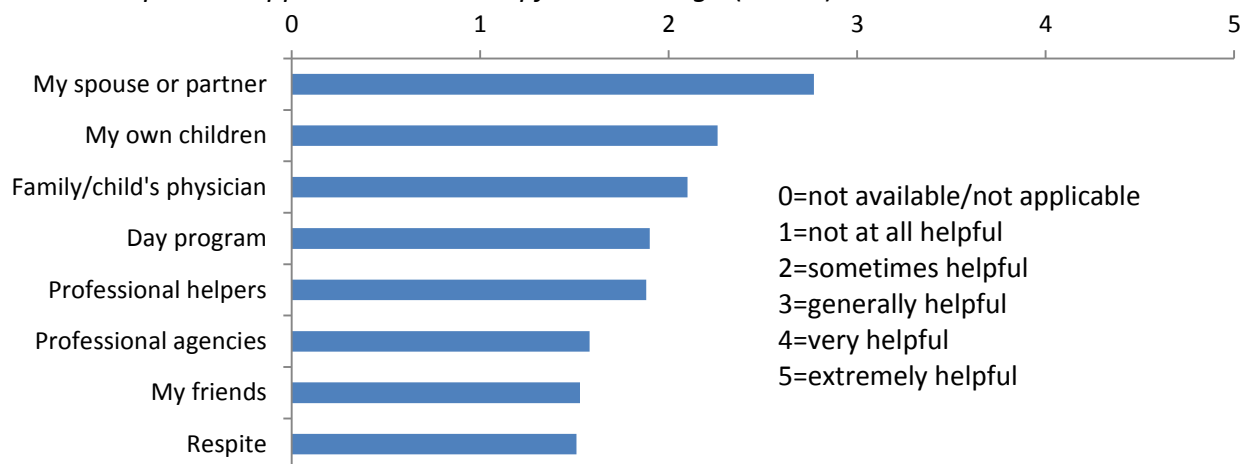
Figure 4: *Parents' Perceptions of Unique Sources of Supports Around the Time they Made the Service Request – Supports Rated as Unhelpful on Average* (n=207)

0=not available/not applicable
1=not at all helpful
2=sometimes helpful
3=generally helpful
4=very helpful
5=extremely helpful
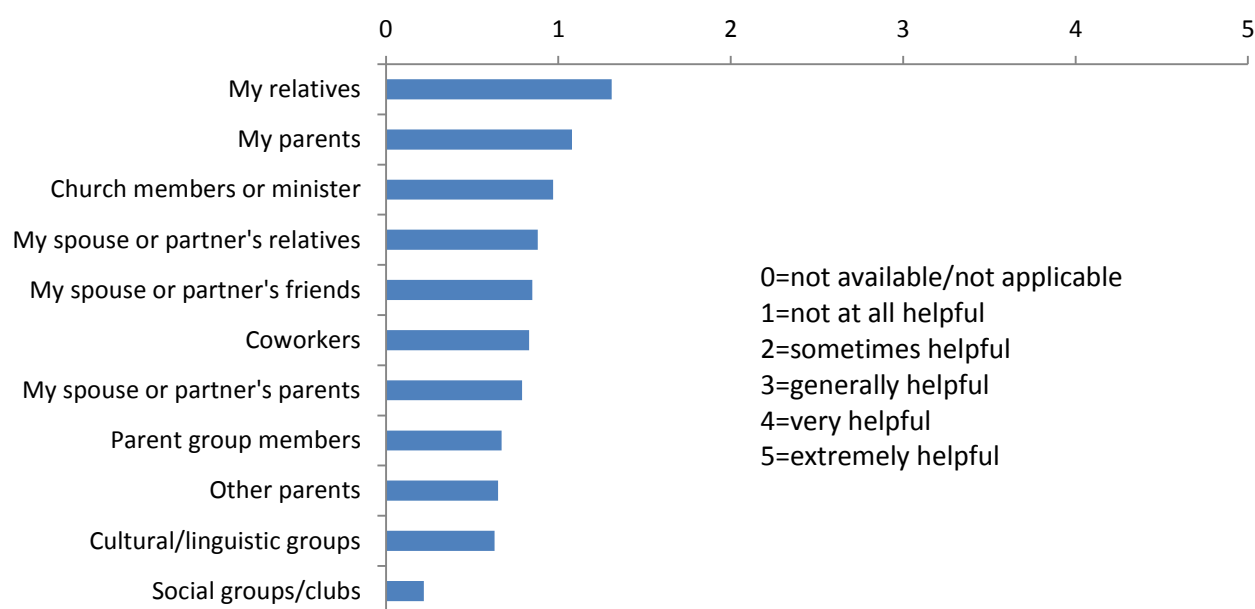
Perceptions of Burden

Parents' subjective sense of caregiver burden was measured using nine items from the Revised Caregiver Appraisal Scale (Lawton, Kleban, Moss, Rovine & Glicksman, 2000). Summed scores can range from 9 to 45 with higher scores indicating higher levels of perceived burden. Scores could be computed for 195 parents who answered all items. Their scores ranged from 12 to 30. Parents were categorized into three groups (as was done by Pruchno & McMullen, 2004): low, moderate and high burden (see Figure 5). More than half of the parents were reporting high burden.

Figure 5: *Parents' Perceptions of Burden Around the Time they Made the Service Request*
(n=195)

Pie chart segments:
- low (score <22): 25.1%
- moderate (score 22 to < 27): 18.5%
- high (score= 27 or higher): 56.4%
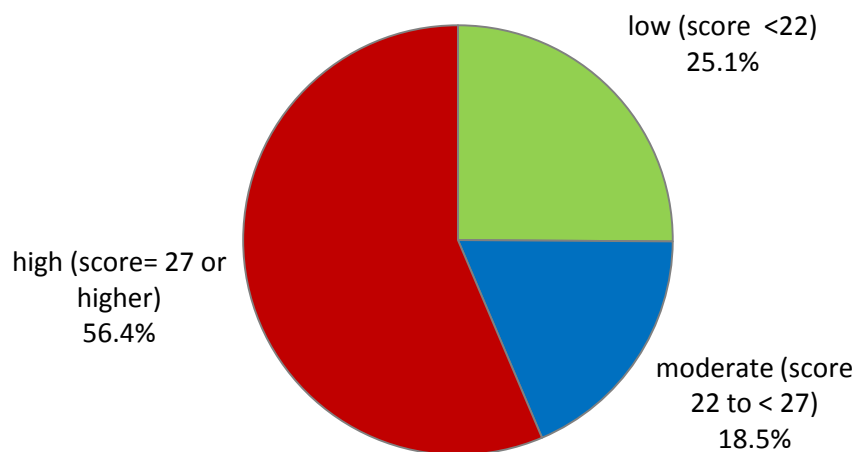
Perceptions of Coping

Several measures were used to assess how well parents were coping with their caregiving
responsibilities around the time they made the request for service through the DSOs. Six items
from the Revised Caregiver Appraisal Scale (Lawton, Kleban, Moss, Rovine & Glicksman, 2000)
assessed the parents' feelings of mastery. The Compensating Experiences Subscale of the
Inventory of Family Protective Factors (Gardner, Huber, Steiner, Vazquez, Savage, 2008) was
used to measure resilience; that is feelings of positive control over adversity. Finally, five
subscales of the Brief-Cope (active coping, planning, acceptance, emotional support,
instrumental support; Carver, 1997) identified dominant coping strategies used by parents.

As shown in Table 6, despite the low support scores and high perceptions of burden reported
by many parents, the caregiver mastery, compensating experiences and coping scores suggest
that, as a group, these parents are confident in their caregiving role and quite resilient.
Furthermore, as a group, they appear to cope by combining acceptance (an emotion focussed
strategy) with problem focussed coping strategies (active coping and planning). Strategies (both
emotion focussed – emotional support, and problem-focussed – instrumental support)
requiring the support of others are not as commonly used.

Table 6: *Indicators of Coping Among Parents Around the Time they Made the Request for Service* (n=211)

Scale (possible range of scores)	Range	Mean	SD
Caregiver Mastery (6-30) (n=200)	12-30	21.60	3.79
Compensating Experiences (4-20) (n=208)	4-20	13.95	3.45
Brief Cope			
Acceptance subscale (0-6) (n=201)	0-6	4.72	1.72
Active copings subscale (0-6) (n=201)	0-6	4.70	1.56
Planning subscale (0-6) (n=201)	0-6	4.66	1.73
Instrumental support subscale (0-6) (n=201)	0-6	3.33	1.85
Emotional support subscale (0-6) (n=201)	0-6	2.95	1.99

Perceptions of Crisis

The Brief Family Distress Scale (BFDS; Weiss & Lunsky, 2010) was used to measure crisis. It indicates a family's level of distress along a continuum. Parents were categorized into three levels of perceived crisis (as per Weiss & Lunsky, 2010): low, moderate and high (see Figure 6). Responses were evenly distributed into the three distress levels. It is relevant that a third were reporting a high level of distress because, even for those parents, services are not typically immediately available.

Figure 6: *Parents' Perceptions of Crisis Around the Time they Made the Service Request* (n=208)
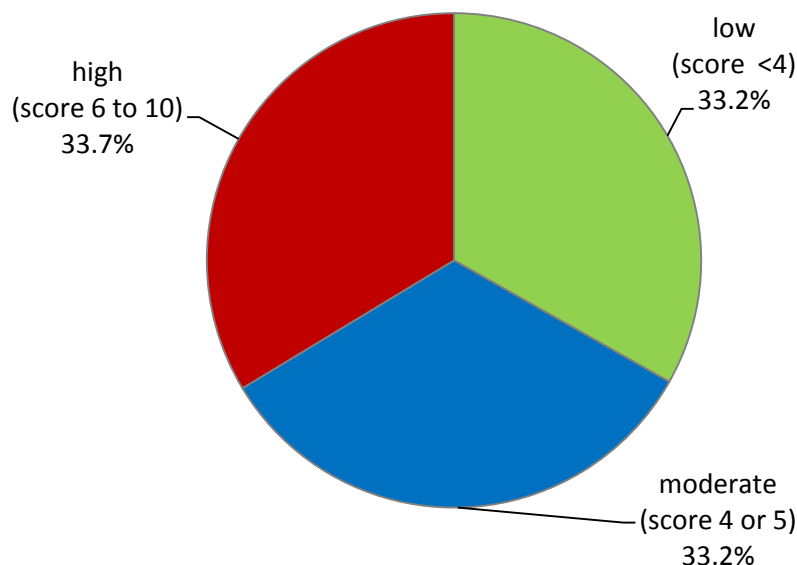
The Services and Supports Requested

Parents requested a variety of services and frequently identified more than one support requested. As shown in Figure 7, community participation support was the most frequently requested service category (68.6%), followed by agency residential support (44.4%) and caregiver respite (32.4%).

Figure 7: *Breakdown of Service Requests** (n= 207 persons with IDD)

Number of Service Requests
*Note: Service categories are not mutually exclusive.

Individual, Parent and Family Characteristics and the Decision to Seek Different Services

Stratifying service requests according to individual, parent and family characteristics revealed expected and unexpected patterns. Stratified analyses were restricted to the four most commonly requested services as the other two had fewer than 15 parents requesting them.
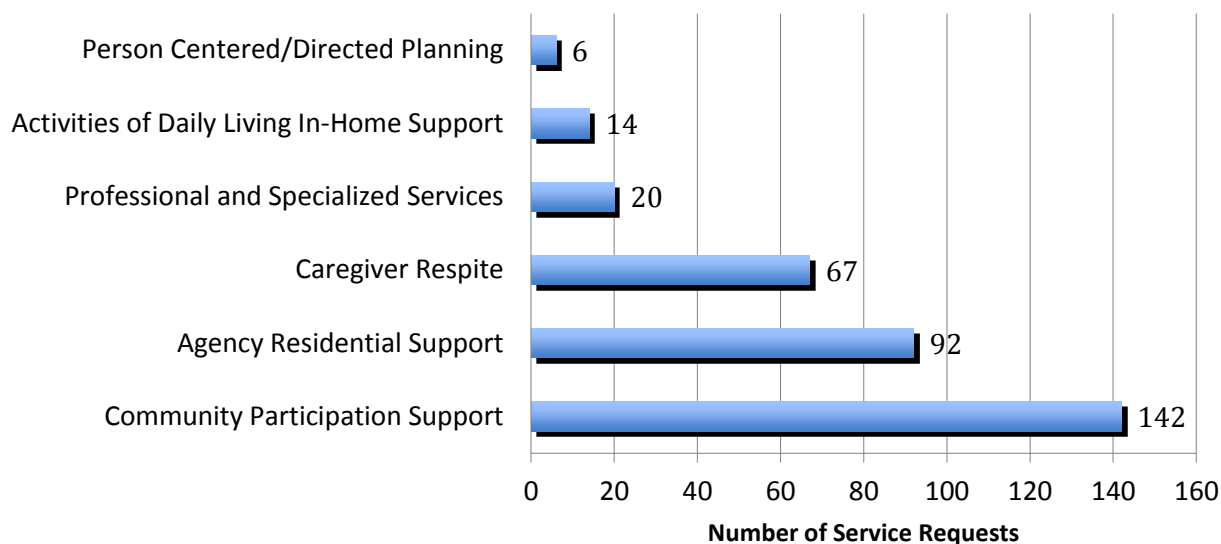
Individual Characteristics

As shown in Figure 7, parents of older adults (35 years and older) were less likely to request community participation supports and though not statistically significant, a trend is observed for the relationship between request for agency residential supports and increasing age of the child. Parents of the younger individuals (20 years and younger) were more likely than other parents to request professional and specialized services. The individual with IDD's sex was only associated with request for community participation supports with requests being more likely for males (Figure 8). Interestingly, parents whose sons or daughters had mobility impairments were less likely to request community participation supports (Figure 9). Parents of individuals with ASD were more likely to request caregiver respite (Figure 10). Dual diagnosis status was associated with the request for professional and specialized services; however proportionately fewer parents of individuals with a dual diagnosis requested caregiver respite (see Figure 11).

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Figure 7: *Service Requests* by Age of the Person with IDD for whom Service is Requested* (n=207 persons with IDD) [# indicates statistical significance]

% of Parents Requesting the Service

*Note: Service categories are not mutually exclusive
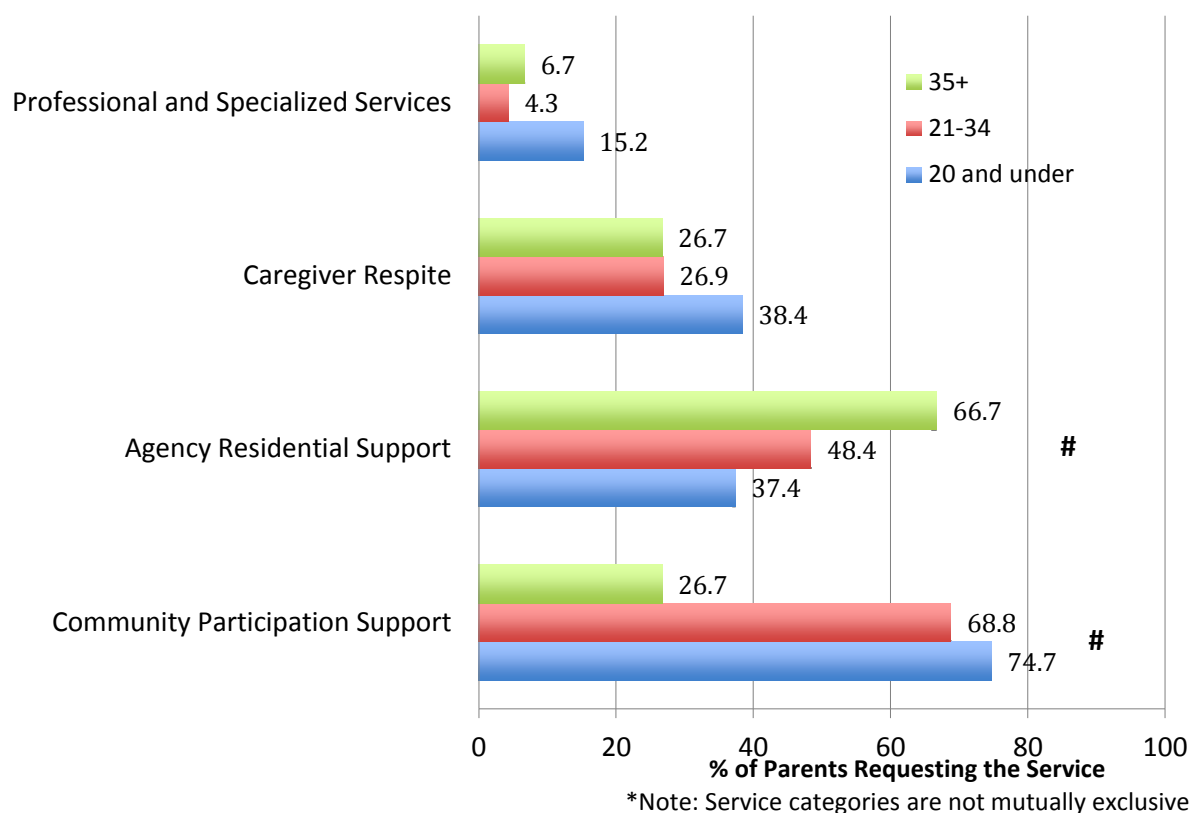
Figure 8: *Service Requests* by Sex of the Person with IDD for whom Service is Requested* (n=207 persons with IDD) [# indicates statistical significance]

% of Parents Requesting the Service

*Note: Service categories are not mutually exclusive
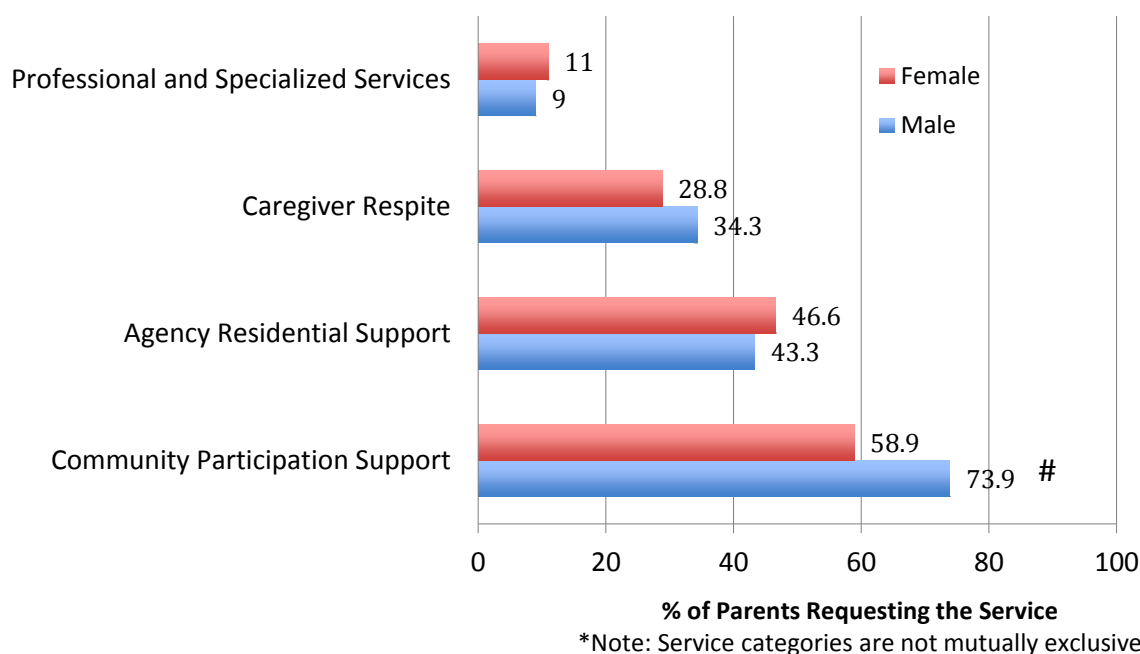
Figure 9: *Service Requests* by Mobility Impairment Status of the Person with IDD for whom Service is Requested* (n=207 persons with IDD) [# indicates statistical significance]

*Note: Service categories are not mutually exclusive
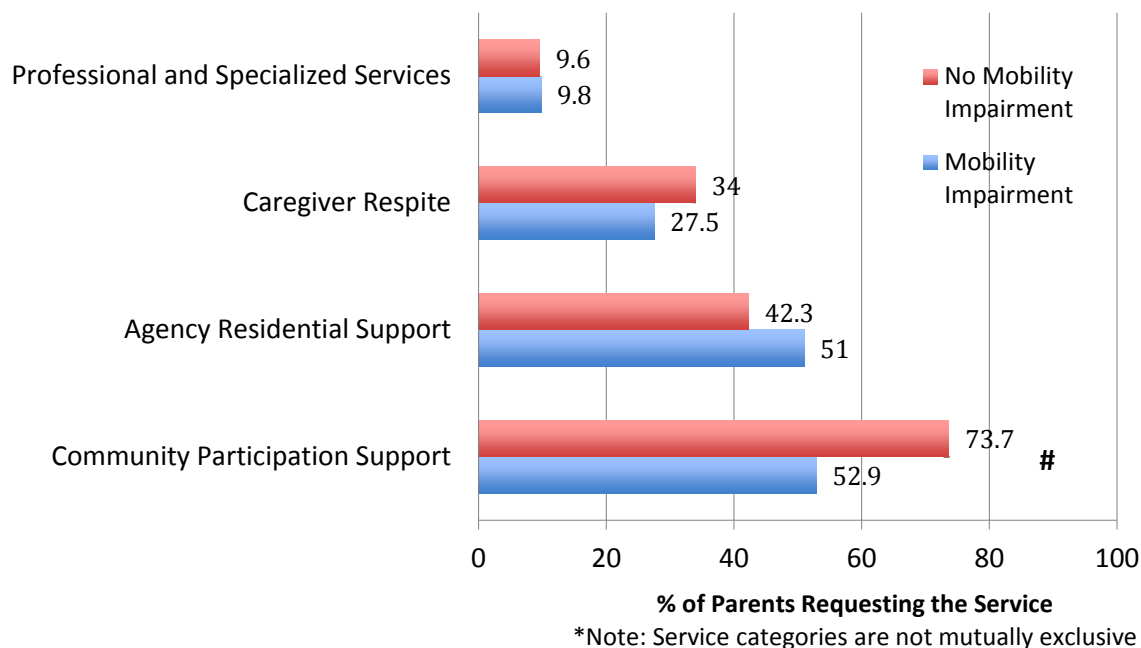
Figure 10: *Service Requests* by Autism Spectrum Disorder Status of the Person with IDD for whom Service is Requested* (n=207 persons with IDD) [# indicates statistical significance]

*Note: Service categories are not mutually exclusive

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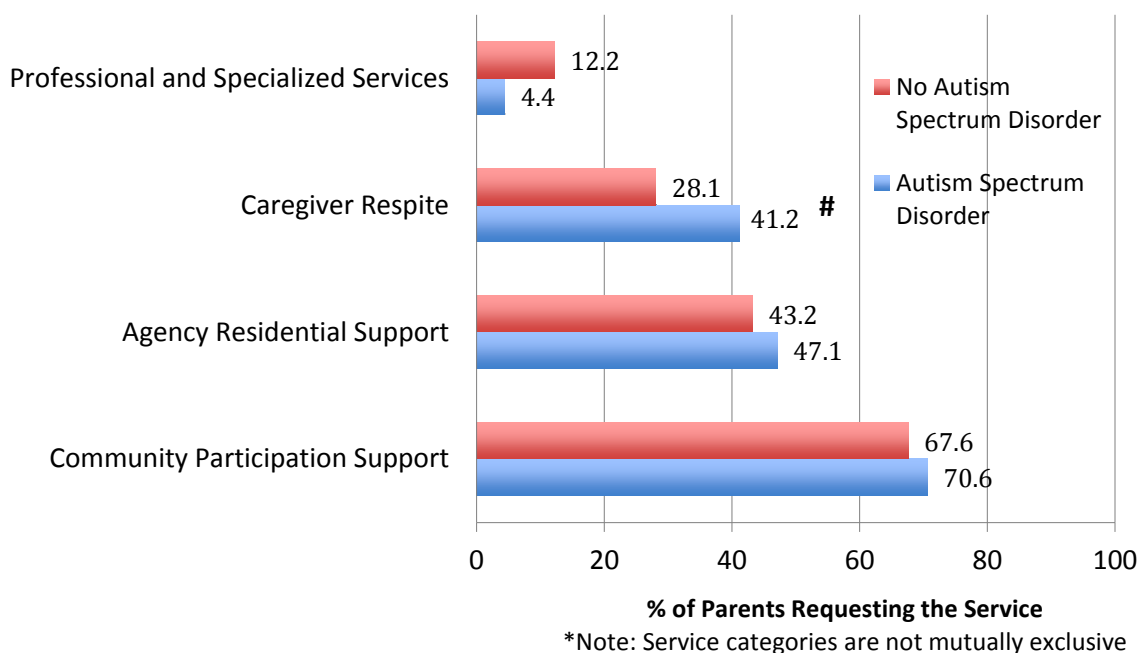
Figure 11: *Service Requests* by Dual Diagnosis Status of the Person with IDD for whom Service is Requested* (n=207 persons with IDD) [# indicates statistical significance]
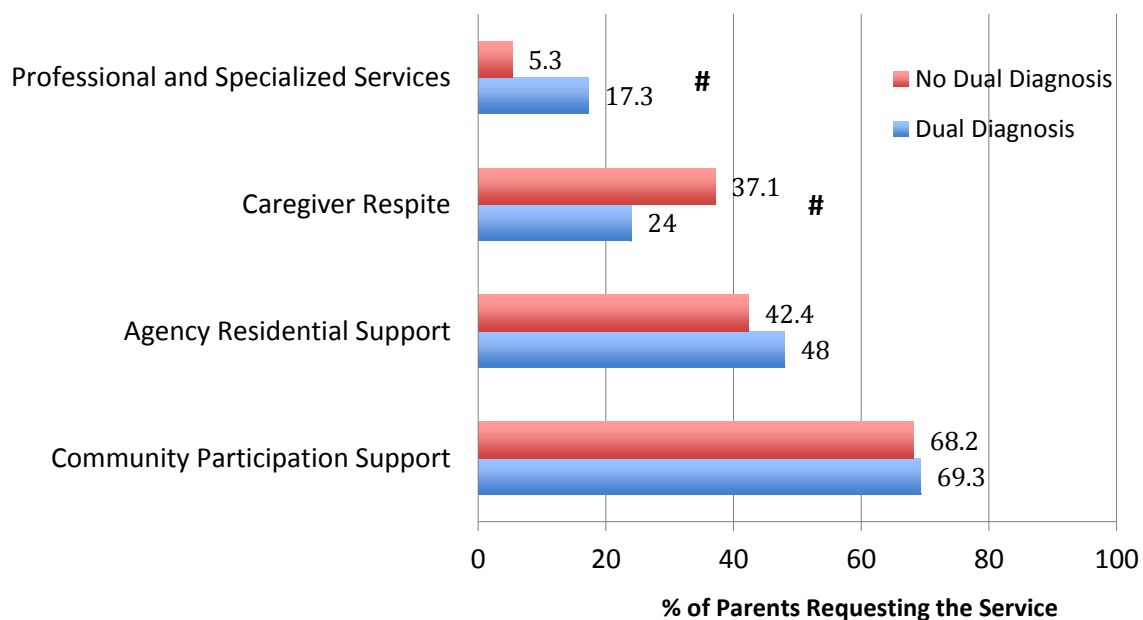
% of Parents Requesting the Service
*Note: Service categories are not mutually exclusive

Parent and Family Characteristics

Younger parents were significantly more likely to request 'community participation supports'; as were those with post-secondary education and those married to the child's other parent (Figures 12 to 14). Parents who were not working, were more likely to request professional and specialized supports (Figure 15). Parents who reported having significant mental health problems themselves were more likely to request professional and specialized supports for their sons and daughters (Figure 16); as were those who reported greater caregiver burden (Figure 17). Caregiver burden was also associated with the request for agency residential supports. Finally, we also found that as crisis rating increases so does the request for residential supports while a non-linear relationship was found between caregiver burden and request for in or out of home respite (Figure 18).

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Figure 12: *Service Requests* by Responding Parent's Age* (n=202) [# indicates statistical significance]

% of Parents Requesting the Service

*Note: Service categories are not mutually exclusive

Figure 13: *Service Requests* by Responding Parent's Level of Education* (n=201) [# indicates statistical significance]

% of Parents Requesting the Service

*Note: Service categories are not mutually exclusive
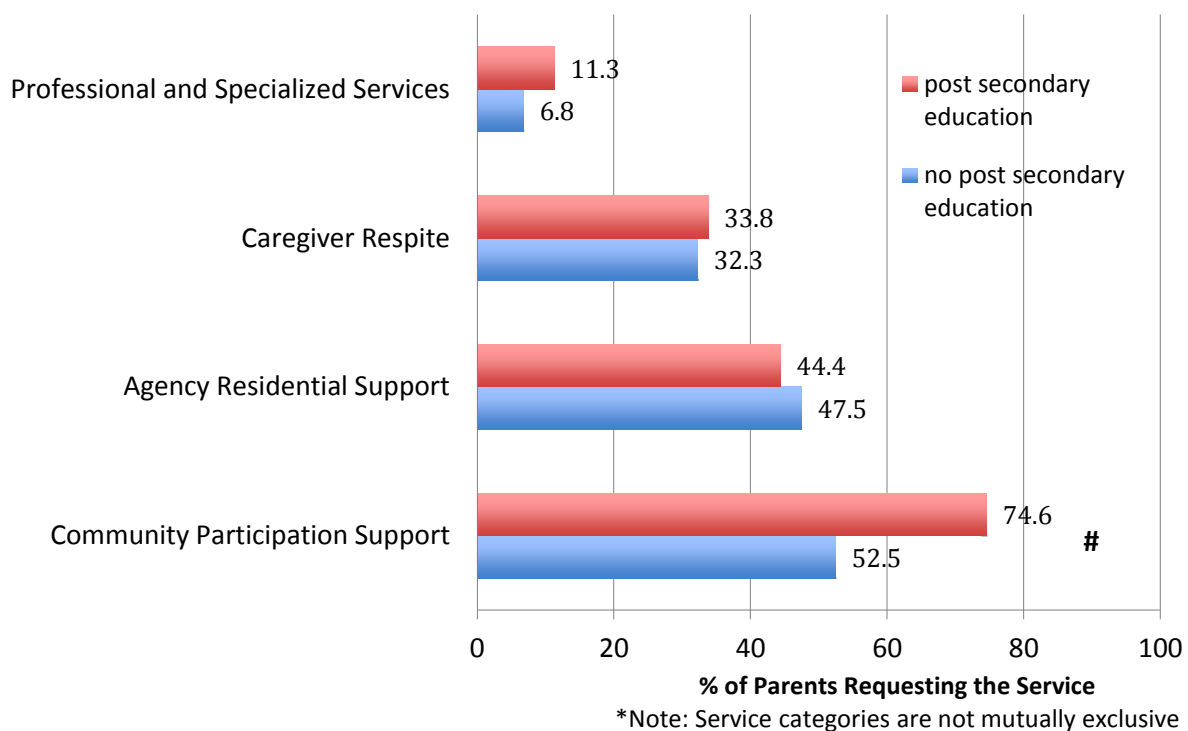
Figure 14: *Service Requests* by Responding Parent's Relationship to the Child's Other Parent* (n=201) [# indicates statistical significance]

Legend:
- Not married to child's other parent (red)
- Married to child's other parent (blue)

Professional and Specialized Services: 15.6 / 7.6
Caregiver Respite: 25 / 36.4
Agency Residential Support: 50 / 43.2
Community Participation Support: 57.4 / 73.5 #
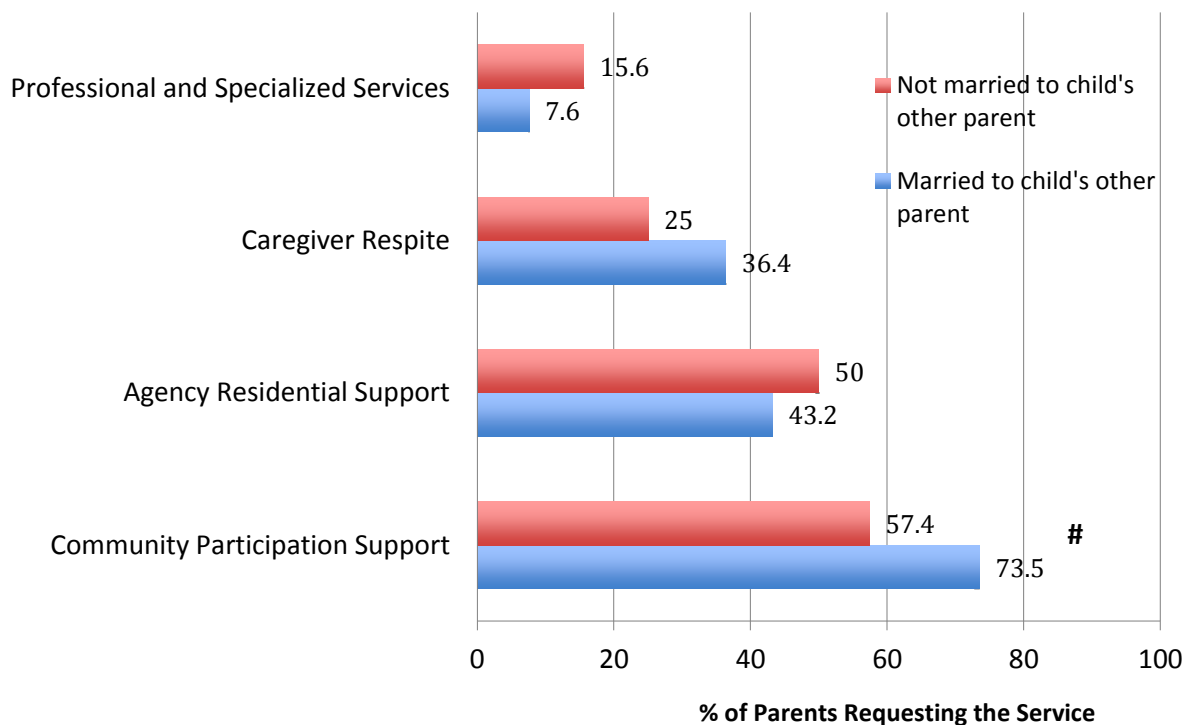
% of Parents Requesting the Service
*Note: Service categories are not mutually exclusive

Figure 15: *Service Requests* by Responding Parent's Employment Status* (n=200) [# indicates statistical significance**]**

Legend:
- Not Working (red)
- Working (blue)

Professional and Specialized Services: 15.6 / 5.7 #
Caregiver Respite: 35.1 / 31.7
Agency Residential Support: 49.4 / 43.1
Community Participation Support: 61 / 72.4
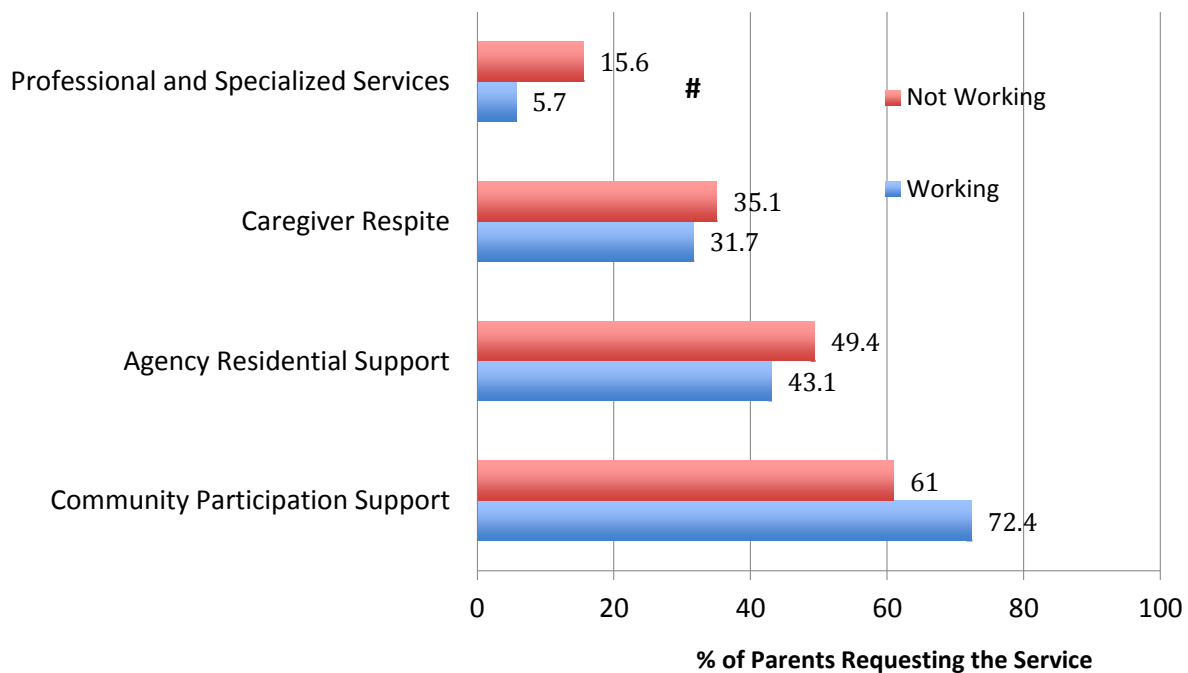
% of Parents Requesting the Service
*Note: Service categories are not mutually exclusive

Figure 16: *Service Requests* by Presence of Significant Mental Health Problem in the Responding Parent* (n=200) [# indicates statistical significance]

% of Parents Requesting the Service

*Note: Service categories are not mutually exclusive
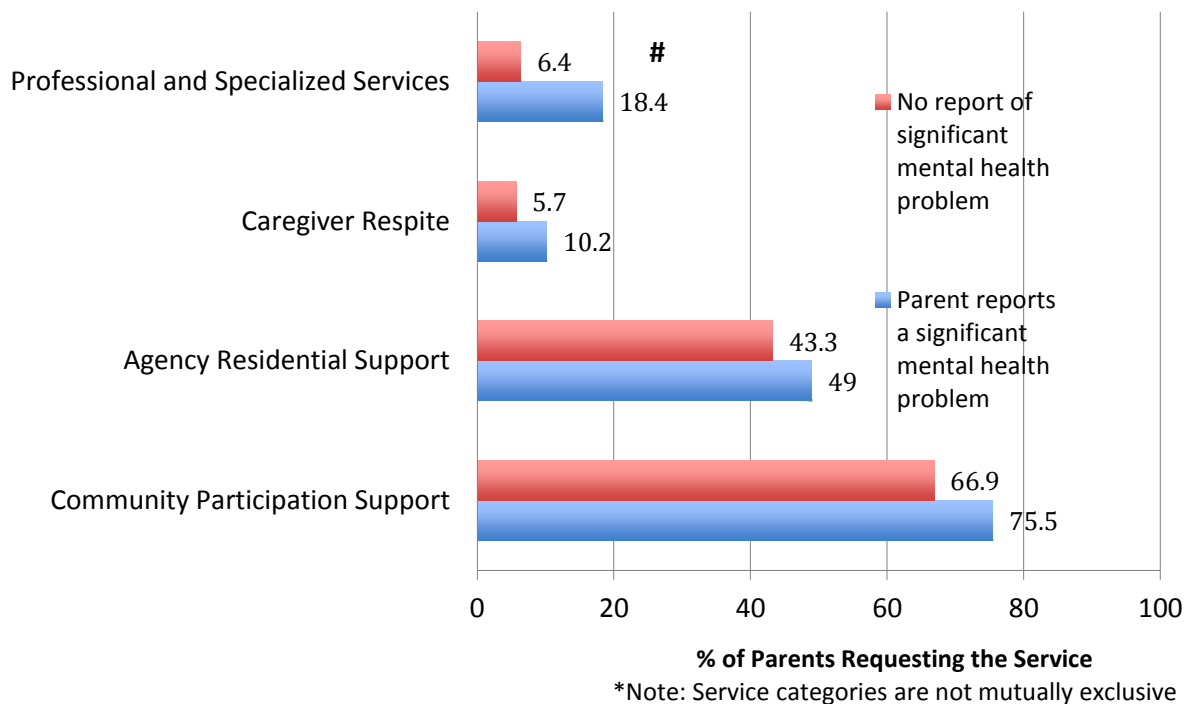
Figure 17: *Service Requests* by Responding Parent's Reported Burden Level* (n=200) [# indicates statistical significance]

% of Parents Requesting the Service

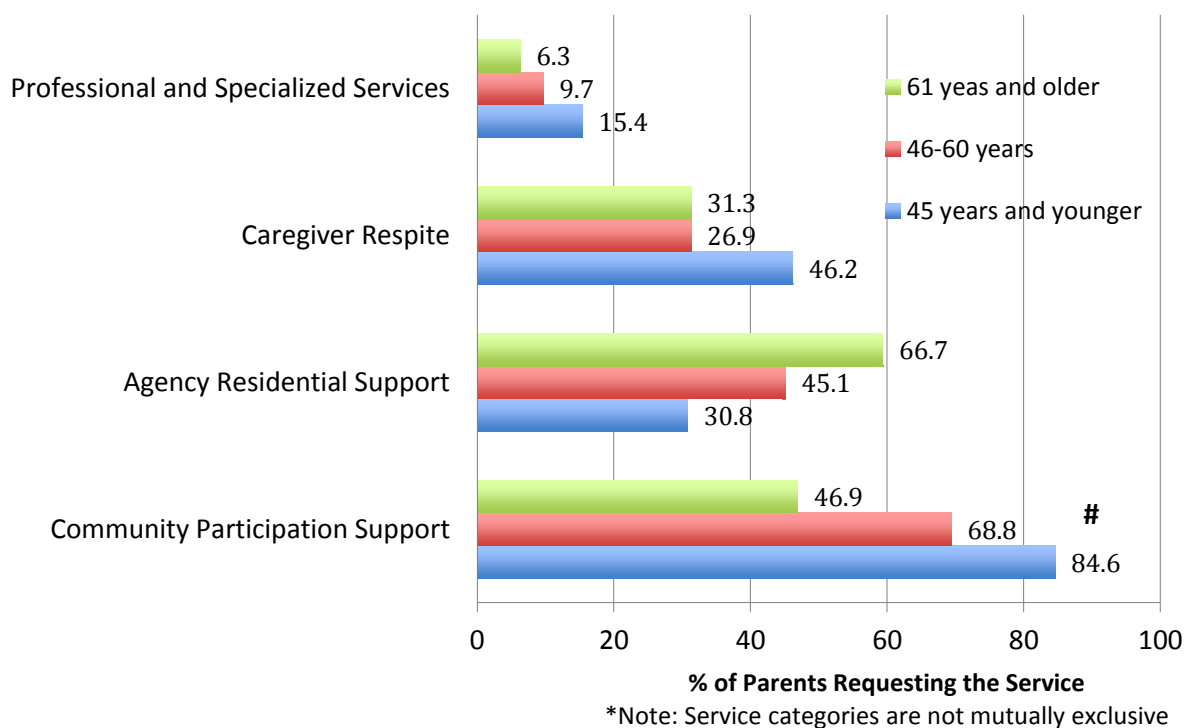*Note: Service categories are not mutually exclusive
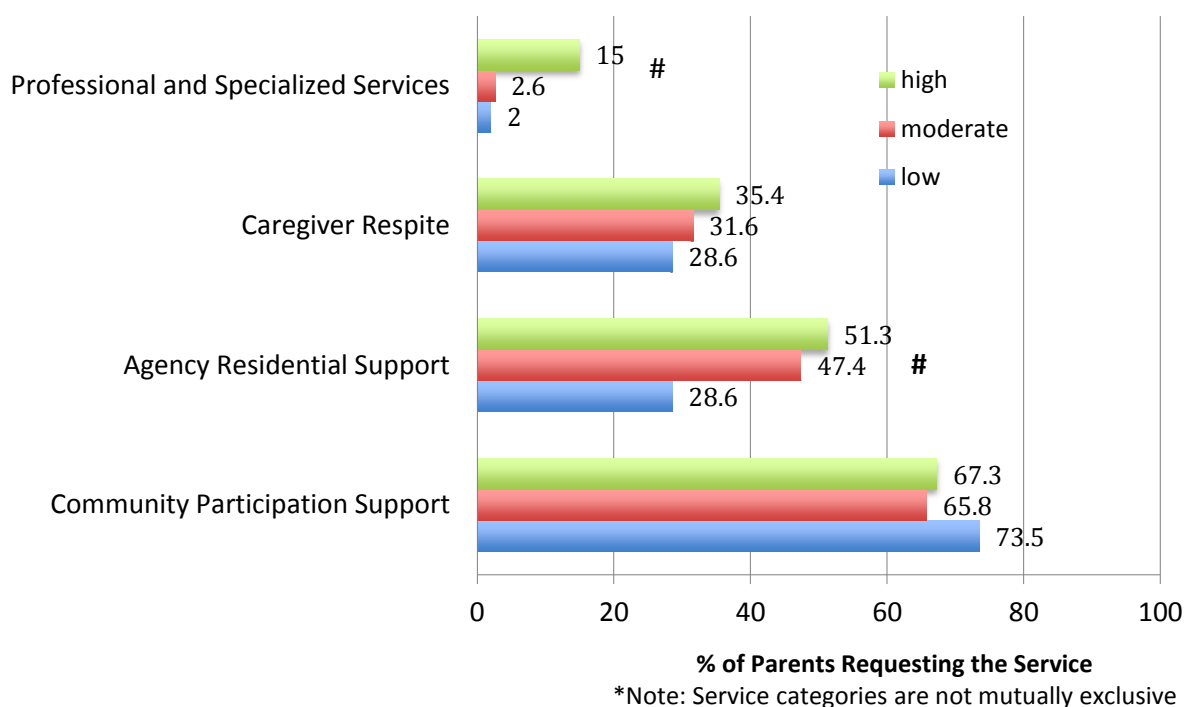
Figure 18: *Service Requests* by Responding Parent's Reported Level of Crisis* (n=200) [# indicates statistical significance]

% of Parents Requesting the Service
*Note: Service categories are not mutually exclusive
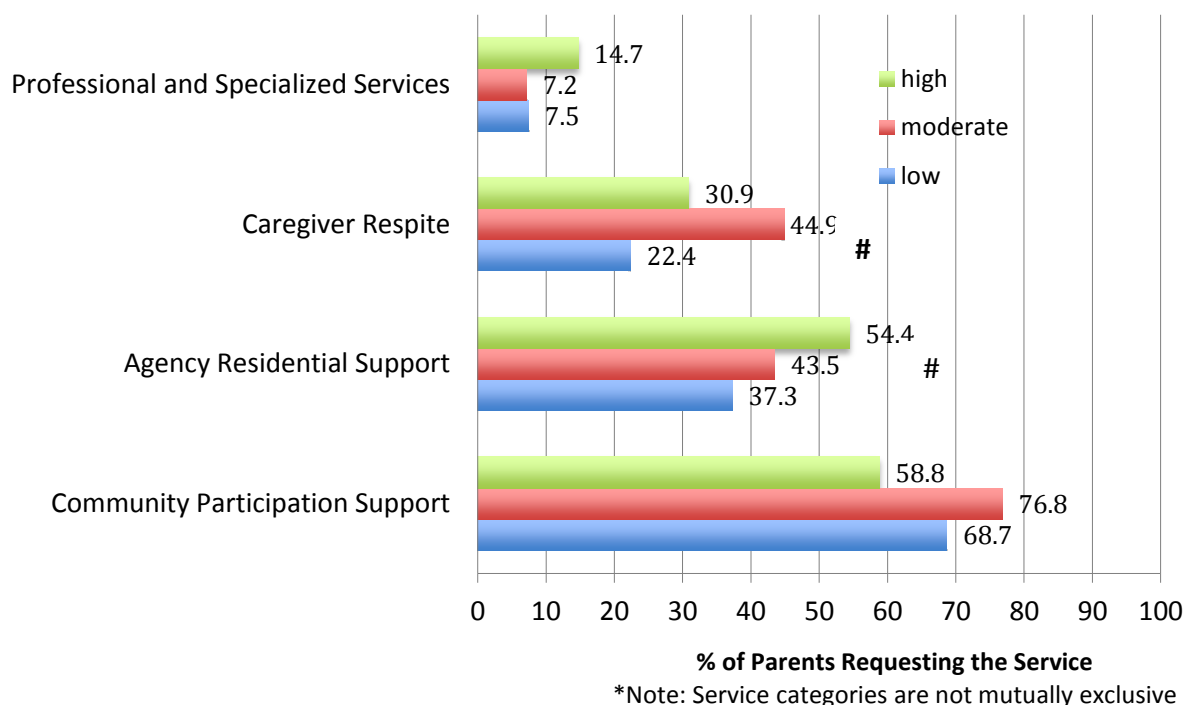
Combining the above findings, provides profiles of service requests for the three most common types of supports requested. Quotes from parents interviewed add further support for the results.

Summary

Community Participation Support

> *He's turned 18 and because we don't have anything set up they're happy to have him go back for a victory lap in school, but he needs his own life and I don't know how to give that to him. We're trying to guide him into finding his place in the community.*

Approximately 65% of the parents in our study indicated that they were requesting community participation support. These parents tended to be younger, to have completed post-secondary education and to be married to the individual's other parent. The individual for whom supports were requested also tended to be younger. They were more likely to be male and to be free of mobility impairments.

> *We have a child who was active and engaged during her years at school who left school at age 21 and now has no day programs so is now home with mother 24/7 and is becoming despondent and isolated.*

He is very social and absolutely wants to have a role to play in his community and feel useful. He needs a reason to get up and get out of the house - not to mention, I, too, need to get up and out of the house.

Agency Residential Support

I am on a waitlist for a residential placement for her but I was told it's going to be two years. It's hard; I'm a single caregiver. My other son has ADD and Tourette's. I can't do it all.

Approximately 44% of parents in our study indicated that they were requesting agency residential support services. These parents tended to be older and to have older children. The parents requesting residential services reported greater burden and were more likely to have children who had a dual diagnosis.

What happens if I die? He needs somewhere to be taken care of. I would rather graduate him to a setting like that while I am alive.

Respite services

I'm a single parent and not that well either so I'm not sure how long I can care for him. I'm so stressed out. My whole life is focused on him. We need respite.

Just under a third of parents (70; 32%) in our sample indicated that they were requesting respite support. Parents requesting respite support had higher crisis scores and were more likely to have a child with an autism spectrum disorder diagnosis. Our finding of a reverse association between dual diagnosis and request for respite services may be due to the imprecise measurement of dual diagnosis (parental report of a broad range of psychiatric and behavioural conditions) or that these parents request agency residential support in lieu of respite services. Further analysis is needed.

Professional and specialized services

When he decides he's going to have a meltdown he will search out a table to bang his head on, he will bite his wrists, push things, throw things. I actually had him in the local emerg a week ago because I couldn't control him.

Only 20 requests were for professional and specialized services (less than 10% of persons with IDD for whom supports were requested). The parents making these requests were more likely to report mental health problems of their own and to having higher burden scores. Their children tended to be younger and to have a dual diagnosis.

Number of Services Requested

Less than half of the requests for services for the 216 individuals with IDD in our study were for only one support (see Table 7). The maximum number of services requested was five. After the

single service requests for community participation support (21.8%), the most common request was for a combination of community participation and agency residential support (15.7%).

Table 7: *Service Request Combinations* **(n=216)**

Support(s) Requested	N	%
1 support requested	*99*	*45.8*
Community Participation Support	47	21.8
Agency Residential Support	31	14.4
Caregiver Respite Support	12	5.6
Professional and Specialized Services	6	2.8
Activities of Daily Living Support	3	1.4
2 supports requested	*79*	*36.6*
Community Participation Support + Agency Residential Support	34	15.7
Community Participation Support + Caregiver Respite Support	28	13.0
Other combinations of 2 service requests	17	7.9
Combinations of 3 to 5 service requests	*27*	*12.5*
Undecided/Not specified	11	5.1

Parents requesting 3 to 5 supports were more likely to have a significant mental health problem and reported greater perceptions of burden. Their son/daughter was more likely to have behavioural support needs.

Discussion

Lessons learned regarding parent recruitment and working with the DSOs

Phase 1 of the Parent Study required cooperation from all nine Developmental Service Ontario regions in order to reach every eligible family. Through the process, we learned about how to conduct collaborative research with the DSO's as well as what strategies appeared to work best with parents.

DSO collaboration was enhanced through on-going contact between them and the MAPS research team. We also held annual update meetings with DSOs using videoconferencing. During these meetings, we received input on how to improve the study and how to interpret our findings.

The first challenge faced by DSOs was to develop a mechanism to identify eligible families. Since the Developmental Services Consolidated Information System (DSCIS) does not clearly indicated if the person for whom services and supports are requested lives with parent, the task could not be automated. Some DSOs developed separate datasets to assist with this task but this was a time intensive activity that not all DSO's could implement.

Another challenge related to legal requirements making it impossible for the Ministry to share with us SIS and ADSS data entered into DSCIS once we had obtained the consent of parents. The DSO staff did not have the technical ability to share the data with us electronically so they had to photocopy and securely transmit the ADSS and SIS information to the MAPS research team to re-enter into the study database manually. This process was time consuming for DSO and MAPS staff and not yet complete (the MAPS team is still awaiting packages from 5 of the 9 regions).

The percentage of request for information forms received from parents by our team varied considerably by region from 1% to 56%, indicating that particular DSO regions were more successful at promoting the study than others. This may be due to the recruitment method (i.e. face-to-face contact allows more dialogue about the study whereas mass-mailing is a faster way to reach more individuals). It appears that email was not an effective method for making first contact with parents, although once parents agreed to participate, several preferred to be contacted by email. In general, once parents connected with members of the MAPS research team, they were quite keen to continue with the study, with high response rates on both the interview and survey component of the project. Many have indicated that this project is one that is very relevant to them and they are pleased that the issues are being studied.

In the following section, we discuss findings related to the 4 questions outlined in the introduction.

Who are the Parents and how are they coping?

Our sample consists mostly of mothers between 46 and 60 years of age. The sample includes a good cross-section of urban and rural families with parents having varying levels of education, and income. The parents are in a range of different relationships with their son or daughter's other parent (e.g. married, separated, widowed). Nearly half of parents reported having at least one significant medical, physical or mental health condition and just over a quarter of parents indicated that they were providing care for at least one more person with special needs, other than their son or daughter for whom they were requesting services. Even though most of our study participants would not be considered seniors, they are already reporting significant demands and health issues.

As we do not have information on eligible parents who did not volunteer to participate in the study, we cannot comment on how representative they are to all parents requesting services through the DSO in the recruitment period whose sons or daughters live with them. Furthermore, our project does not represent the many parents who requested services prior to the implementation of the new service request process. We would expect these parents to be older and to have more health concerns.

Our study has found that 56% of parents seeking services feel high burden in their caregiving role, with more than half of parents (59%) likely to have an emotional disorder. A significant proportion of parents (1 in 3) report that their situation is approaching crisis or already a crisis, suggesting that it is critical that needed services be provided to them quickly. One way in which parents cope is through the receipt of support from professionals and from family and friends. In the absence of professional supports and services, informal support is that much more important. Unfortunately, the majority of parents reported that they either were not receiving very much informal support, or the support they were receiving was not particularly helpful. It is overly simplistic to assume that all "support" is beneficial. Help from others, such as extended family or friends, if it is not the right kind of help, can be another source of stress. Indeed in our study, parents are reporting that this is the case. The types of support most beneficial to parents are from their spouse, and their other children. This highlights the importance of being able to strengthen the capacity of immediate family to support one another in caring for their family member with a disability.

Despite significant caregiving demands, a lack of services and low rates of helpful social support, parents are continuing in their role as caregiver as best they can. This highlights the resilience of many parents in Ontario, who continue in their caregiving role until their young children become adults and continue to be their main source of support, after school ends, sometimes in the absence of any programs or services. Parents reported a number of positive coping skills in our study, including problem focused coping and acceptance.

Who are the individuals in need of services and supports?

The individuals in need of supports are mostly under 35 years of age. This is not to say that there are not some older adults waiting for services, but it does show that the group in need of

services whose parents consented to be in our project and who approached the DSO in its first nine months are primarily young adults. Our findings do not speak to the needs of those individuals who applied for services before July 2011 or those who have requested supports since July 2011 but who do not live with their parents.

More men than women are in our sample, which is expected given that IDD is more common in men than women. However, the rate of ASD (33.8%) found in our project is high. This may be a growing demographic with unique care needs, which has been highlighted in epidemiological research here and in the United States. Indeed, parents of those with ASD were more likely to request caregiver respite. Our results suggest it is important to capture information related to such subgroups in the application process, and to plan appropriately for services. There may be other causes of IDD which are decreasing. For example, although parents were asked about it specifically, none reported their son or daughter having a diagnosis of Fragile X syndrome. Regardless of the etiology of the disability, physical impairments and mental health and behavioural issues are relatively common in service applicants. Services and supports must take into account these additional complexities.

What Services and Supports Are Requested?

Parents are requesting a variety of services for their sons or daughters. Just over half of families would like to receive more than 1 service. Community participation support was the most frequently requested service category (68.6%), followed by agency residential support (44.4%) and caregiver respite (32.4%). Daytime supports tend to be requested by more parents than residential supports perhaps because not all families are ready for their son or daughter to leave home. However, all adults with IDD need some stimulation and meaningful activities during the day once they have completed school. Only a minority of individuals are able to find work or other activities without supports and services to help them do so. Respite services can help relieve stress experienced by parents who are struggling to support their son or daughter and can also serve as a good transition to residential care for the individual with the disability, when ready. It would be important to understand whether the 2/3 of parents who did not request respite, already have informal respite in place, have concerns that their child is not ready for respite, or are simply not interested.

What Predicts Specific Service Requests?

Our study found that both characteristics of the individuals with IDD and characteristics of the parents and family situation are associated with the types of services requested. It is important therefore to capture information beyond the child's needs in any planning efforts. In terms of characteristics of the individual with IDD, age may predict service patterns for several reasons. Younger people are more used to being in programs all day long (school), and so them and thei parents expect on-going involvement in activities hence the request for community participation supports. Older adults may have adjusted to being home during the day and the crucial support now required for them is somewhere for them to live. With increased age, it is harder to do things independently and it is also harder for aging parents to provide care, hence the need for residential supports in later life. Diagnostically, it can be more stressful to be

without services when there are comorbidities. Those with dual diagnosis are in greater need of professional supports, which we found. It is interesting that they have fewer requests for respite. It may be that parents are aware of how difficult respite may be for their son or daughter with psychiatric issues and that risks associated with respite in their unique situation may outweigh potential benefits. In contrast, parents of those with an autism spectrum disorder are more likely to request respite. This may be because of the unique challenges associated with raising a child with autism (general literature has shown that these parents are most stressed when compared to parents of those with other types of disabilities).

With regard to parent characteristics, age is relevant and that is likely related to the age of the child discussed above. Income is not a predictor of service needs, nor is marital status. The key parent characteristics predicting service requests concern the parent's psychological state. When parents are more stressed, they need more support, particularly respite and clinical services. This is why it is so important to get a sense from families of how burdened they feel and their overall level of distress. There was concern prior to our study that all parents would report equally high levels of burden not because they truly feel that way, but because they want to guarantee they will get services they would like. Our data demonstrate that this is not the case. Many parents report that they can still cope and that they can manage with their current level of distress. Families reporting greater burden are more likely to request respite, professional services and residential support. This underlies the need to really listen to parents and gauge their level of burden and distress when they enter the system.

Through the next phases of our project, we will be examining what coping strategies are used by parents in the 9 to 12 month period following the request for services and how effective they are.

Conclusion

Our study of 221 parents from across Ontario seeking adult developmental services for their sons and daughters demonstrates a range of presentations for both parents and their children. These resilient parents are managing with multiple caregiving roles, health problems of their own, and limited social support. Many of the adults with IDD in the study have physical and emotional difficulties beyond their cognitive disability. This puts both the parents and their children are at risk if they do not receive the services they are requesting.

The most commonly requested services are community participation supports. It appears that these supports are identified as a need first, in younger adults and parents. The need for residential support is more evident with aging parents, and among parents reporting higher levels of burden and distress. The type of disability the adult child has may also have some relevance with regard to degree of parental burden, distress and need for unique services. For example, parents of adults with an autism spectrum disorder are more likely to request respite. To best support adults entering developmental services who still live with their parents, the interplay between parent needs and those of the individual for whom supports are requested must be considered.

This project explores associations between parent and child needs at the time of service request but does not help us to understand what occurs over time. Phase 2 and 3 of the study will provide further detail on how parents cope over time. These phases of the project will offer both quantitative and qualitative approaches to study this important period in the lives of young adults with IDD and their parents.

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