



# A Snapshot of Social Support Networks Among Parental Caregivers of Adults with Autism

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## Abstract

This study provided a description of types and dimensions of informal and formal social support among aging parental caregivers of adult children diagnosed with autism spectrum disorder (ASD). Parents participated in a web-based survey regarding use of and satisfaction with social support services for parents or their adult children. Results indicated that many parents participated in autism support groups (27.5%), with psychiatric services (48.8%), counseling (40.6%), and financial assistance (39.7%) the most commonly used formal social supports. Emotional support (88.8%) and informational support (67.5%) were the most common informal social supports used. Professionals who are working with parental caregivers and their adult children diagnosed with ASD should be aware of available social support services to help them find needed services.

**Keywords** Aging parental caregivers · Adults with autism · Informal social support · Formal social support · Caregiver burden

## Introduction

The prevalence of autism spectrum disorder (ASD) has increased substantially in recent decades (Blumberg et al. 2013; Braun et al. 2015; Zablotsky et al. 2015). Of the estimated 6.6 million individuals who are diagnosed with ASD worldwide, 80% are adults and 20% are children (Nightingale 2012). As individuals with ASD enter adulthood, they often continue to require some form of support, frequently from parental caregivers (Chamak and Bonniau 2016; Hines et al. 2014; Kuhn et al. 2018; Lunsky et al. 2017; Marsack-Topolewski and Graves 2019). The length and duration of caregiving can be challenging for parents who often assume these responsibilities across their lifespan (Marsack and Perry 2018; Namkung et al. 2018).

Social support services for adults with ASD and their caregivers may be available through formal or informal networks. Formal support services have a cost attached and are available in the community. Formal support services can be accessed through government, nonprofit agencies,

or community groups (Roux et al. 2017). In comparison, informal supports are unpaid supports that are provided by family and friends through the family's personal network. This study provides a description of the informal and formal social supports used by aging parents and their adult children diagnosed with ASD. This study is important in examining perceptions of parental caregivers of adult children with ASD on the use of and satisfaction with social support networks.

The United States Government Accountability Office (GAO 2015) indicated that from 2008 to 2012, the least funding was allocated for ASD lifespan issues (e.g., adult service needs, transition services, etc.), with this amount decreasing by 3% during this period. A study by Lai and Weiss (2017) found that 30% of individuals with ASD had their priority service needs met, with this percentage decreasing with age. Most published research has focused on children with ASD and their parents, with less research published on adults with ASD and their aging parents (Wallace et al. 2016; Wright et al. 2013). According to Baker-Ericzén et al. (2018), a paucity of research has been published on transition-aged youth and adults with ASD. Approximately 20% of published literature on autism has focused on adult populations with ASD, with 2% of funding for autism research earmarked for transition-aged youth and adults

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with ASD (GAO 2015; Interagency Autism Coordinating Community 2016). While some research (Dudley et al. 2019; Gerhardt and Lainer 2011; Griffith et al. 2012) has focused on social support service needs of adults with ASD, additional research is needed to determine if these service needs are being met and the level of satisfaction parental caregivers have for the services they are receiving.

## Formal Social Support Networks

Formal social supports include paid services, such as speech therapy, social work, and respite care. For this study, formal social supports include services relevant to the adult child with ASD, as well as the parental caregiver. Research by Turcotte et al. (2016) found statistically significant differences in service utilization among four age groups (preschool, elementary, middle/high school, and adult), with a lower percentage of adults receiving services than the other three groups. Some of the services in their study included: mental health counseling, speech/language therapy, occupational therapy, physical therapy, social skills training. As indicated in the Turcotte et al. (2016) study, the least used services by adults were physical, occupational, and speech and language therapy. Dudley et al. (2019) examined formal support service usage by adults with ASD. As reported by caregivers, adults with ASD accessed services, including mental health (53%), transportation (45%), in-home supports (40%), employment supports (36%), and independent living skills (34%). For a variety of reasons, parents of individuals with ASD may benefit from a number of caregiving and disability-related formal social supports. Despite the many benefits that can be derived from formal social support networks, many parents reported a number of barriers to accessing these types of support (Marsack and Perry 2018).

Finding adequate, accessible, affordable, and accommodating services has been a well-documented challenge for parental caregivers and individuals with ASD (Khanlou et al. 2017; Müller and Cannon 2016). Coordinating and navigating services primarily has been the responsibility of parents of adults with ASD (Anderson et al. 2018). This coordination and navigation can be exhausting and burdensome, with service challenges reported by many parents of young adults with ASD (Anderson and Butt 2018). Approximately 25% of parental caregivers indicated that needed services were either unavailable or at too far of a distance (Dudley et al. 2019). In addition, many caregivers (26%) were unaware of services that could benefit their child with ASD (Dudley et al. 2019). Parents reported they had to fight for services, as well as navigate challenging, complex, bureaucratic systems to find services for their adult children with ASD. Challenges with the formal service delivery system, such as inadequate wages, subpar training, and

high employee turnover, often negatively impact satisfaction with services. Some parents indicated that many programs were inappropriate for their adult children, requiring them to develop specialized activities or hire staff.

## Informal Social Support Networks

Informal social support networks include supports that are unpaid by aging parental caregivers, individuals with ASD, or through governmental funds and donations (Duggan and Linehan 2013; Marsack and Hopp 2018; Rutman and Hubberstey 2016). Support derived from personal networks (e.g., family, friends, and neighbors) are examples of informal social support networks. These networks may be helpful in alleviating demands, stress, and burden often associated with the provision of care (Hodgetts et al. 2017; Marsack and Samuel 2017). Previous research demonstrated the need and corresponding benefits of informal social supports for parents of individuals with ASD (Derguy et al. 2015; Marsack and Samuel 2017; Mendoza and Dickson 2010; Smith et al. 2012). Smith et al. (2012) indicated that mothers with larger social support networks had more positive psychological well-being outcomes, such as fewer depressive symptoms. Higher levels of depressive symptoms and poorer psychological well-being were more commonly seen in mothers who perceived negative social support. Given the complex care needs, behavior, and social-communication challenges typical for individuals with disabilities such as ASD, aging parents could experience social exclusion and have less time with their friends and relatives (Marsack and Perry 2018; Yoong and Koritsas 2012). The presence of informal social support is found to be inversely related to caregiver burden among aging parents of adults with intellectual and/or developmental disabilities, such as ASD (Robinson et al. 2016). Caregivers of adult children with ASD who received informal social support tended to have less caregiver burden and greater quality of life (QOL), while caregiving parents with a lack of informal social support were more likely to experience high caregiver burden leading to poor QOL (Marsack and Samuel 2017; Robinson et al. 2016).

For caregivers, informal social support can either help alleviate challenges or augment anxiety associated with the provision of care (Marsack 2016). A number of studies documented the importance of, and benefits associated with informal social support for families of individuals with ASD (Altiere and von Kluge 2009; Marsack and Samuel 2017). Parental caregivers of children with ASD experienced lower stress and positive well-being from informal social support (Mendoza and Dickson 2010). Despite the need for parental caregivers of individuals diagnosed with ASD, research supports shrinking social networks among this population, with caregiving demands requiring more time, resulting in social

exclusion (Altiere and von Kluge 2009; Marsack and Perry 2018; Yoong and Koritsas 2012).

The quantity and quality of informal social support was studied by Smith et al. (2012). Using a sample of 269 mothers of adolescents and adults with ASD, Smith et al. found the level of social support was related to changes in maternal mental health. For example, mothers who had more people in their social support networks experienced fewer depressive symptoms and greater emotional well-being.

Boehm and Carter (2016) conducted a systematic review to understand experiences of parents of individuals with ASD or intellectual disability (ID) with informal social support. Based on their review, the authors reported that parents' perceptions of the availability of informal social support were mixed. Helpfulness was a commonly cited perception of informal social support that varied among parents in their analysis. The authors suggested that informal social supports beyond familial networks may be particularly helpful for parents of individuals with ASD or ID.

## Study Rationale and Research Questions

Previous research demonstrated that social support networks can help ease the burden of caregiving that aging parents of adults with ASD often experience (Marsack and Hopp 2018). While the types of social support services have been discussed in the literature (Anderson et al. 2018; Boehm and Carter 2016; Derguy et al. 2015), a gap exists as satisfaction with formal and informal social supports has not been the focus of research on social support services. The purpose of this study is to add to the literature by providing a description of types of formal and informal and the format and satisfaction with dimensions of social support among aging parental caregivers of adult children diagnosed with ASD. The following research questions will be addressed:

1. To what extent are aging parents of adults with ASD using specific types of formal and informal social supports?
2. How do parents of adults with ASD view the availability of, and rate their satisfaction with formal and informal social support dimensions?

## Method

The present study used a quantitative research design to examine the types of formal and informal social support used by aging parents of adults with ASD. In addition, using eight dimensions of social support, parents indicated if the dimension was formal, informal, both, or none and their degree of satisfaction with each of the eight dimensions.

Prior to the start of this study, the principal investigator (PI) obtained Institutional Review Board approval from Wayne State University (IRB#: 012615B3X). Various local, state, and national agencies and organizations throughout the United States were instrumental in recruiting potential participants through the use of email, newsletters, flyers, websites, and/or word of mouth. The organizations included national autism support groups and organizations such as: (a) Autism Alliance of Michigan, (b) Autism Society of Macomb/St. Clair, Michigan, (c) Autism Society of Oakland County, Michigan, (d) Autism Society of Wisconsin, (e) Judson Center, Michigan, (f) Milestones Autism Resources, Ohio, (g) Shelby County Regional Special Education PTA, Tennessee, (h) SRVS Tennessee, (i) the Autism Program of Illinois. The PI used face-to-face recruitment strategies to distribute study information at various places (e.g. local support groups). Professionals who were employed in school districts and in private practice and interfaced with adults with ASD and/or their parental caregivers helped distribute study information. These professionals included public school teachers, teacher consultants, transition coordinators, school administrators, social workers, vocational specialists, and psychologists. Participants also were recruited using snowball sampling, with the help of parents and others who were aware of this study.

## Sample

To be eligible to participate in this study, parents were required to be at least 50 years of age and caring for an adult child (18+ years) diagnosed with ASD. To respond to the web-based survey, parents needed to have access to a computer and be able to read and comprehend English. Survey respondents submitted a total of 353 self-administered surveys through the Qualtrics' website. All participants read and agreed to the information sheet on the first page of the online survey. The PI eliminated a total of 33 surveys as participants either did not meet study inclusion criteria ( $n = 10$ ) or surveys were incomplete ( $n = 23$ ). The sample for this study included 320 parents, with a majority of female participants ( $n = 259$ , 80.9%) who were between 50 and 59 years of age ( $n = 212$ , 66.3%). Most participants had more than one child, with some indicating other children had been diagnosed with ASD or other conditions. The largest group of parents reported relatively high family income levels (over \$100,000 annually;  $n = 103$ , 32.1%), with many parents indicating they had completed either baccalaureate ( $n = 100$ , 31.3%) or graduate ( $n = 123$ , 38.4%) degrees. (See Table 1.)

The adults with ASD ranged in age from 18 to 62 years, with most between 18 and 25 ( $n = 190$ , 66.9%). Similar to current demographic and diagnostic trends, most parents

**Table 1** Frequency distributions: parents' demographics ( $N=320$ )

Parents' demographics	<i>N</i>	(%)
Parents' age		
50–59	212	66.3
60–69	95	29.7
70 and over	13	4.1
Gender of parent completing survey		
Male	57	17.8
Female	259	80.9
Missing	4	1.3
Ethnicity		
African American/Black	5	1.6
American Indian/Alaskan Native	1	.3
Caucasian/White	289	90.2
Hispanic	12	3.8
Multiethnic	6	1.9
Other	5	1.6
Missing	2	.6
Marital status		
Single, never married	6	1.9
Married	252	78.8
Divorced	41	12.8
Widowed	11	3.4
Co-habiting	2	.6
Separated	6	1.9
Missing	2	.6
Educational level of respondent		
Less than high school	1	.3
High school/GED	10	3.1
Some college	42	13.1
Associates degree/technical school	44	13.8
Bachelor's degree	100	31.3
Master's degree	90	28.1
Doctorate/professional degree	33	10.3
Annual family income		
Less than \$20,000	14	4.4
\$20,001 to \$40,000	24	7.5
\$40,001 to \$60,000	42	13.1
\$60,001 to \$80,000	45	14.1
\$80,001 to \$100,000	37	11.6
More than \$100,000	103	32.1
I would prefer not to respond	48	15.0
Missing	7	2.2

indicated that they had sons with ASD ( $n=257$ , 80.3%; Christensen et al. 2016). The largest group of adults with ASD were attending extended programs in public schools ( $n=86$ , 26.9%) or were enrolled in educational/vocational training programs (e.g., college, workshops, etc.;  $n=69$ , 21.6%). Forty-five (14.1%) parents reported their adult children with ASD had graduated from college. The majority of

adults with ASD ( $n=248$ , 77.5%) were residing with their parent(s), with few adults living independently ( $n=16$ , 5.0%). (See Table 2.)

Three items were included to determine the severity of ASD, communication, behavior, and socialization. Frequency distributions were used to provide information on the functional ability of the adults with ASD. The three items were independent and were used for descriptive purposes only. These areas are the often used to determine functional capacity among individuals with ASD (DaWalt et al. 2017; Hull et al. 2017; Kanne and Mazurek 2011; Leung et al. 2018). The largest group of parents ( $n=124$ , 38.7%) indicated their adult child communicates a wide variety of topics meaningfully, with 112 (35.0%) reported their adult child communicates a limited range of topics meaningfully. Fourteen (4.4%) adult children with ASD, had typical age appropriate adult behavior, while 160 (50.0%) required minimal prompting, direction, or redirection. Forty-three (13.4%) of the parents indicated that their adult child had a group of friends and goes out with others in the community, and 82 (25.7%) reported their adult child socialized only with family. (See Table 2.)

## Instrument

A web-based survey was developed using Qualtrics© (2019), an online survey software platform. The online survey combined (a) researcher-created demographic survey, (b) ENRICH Social Support Inventory (ESSI; Mitchell et al. 2003), (c) three subscales; time dependence, developmental, and emotional burden domains; from the Caregiver Burden Inventory (CBI; Novak and Guest 1989), (d) one subscale; impact on finance subscale; from the Caregiver Reaction Assessment (CRA; Given et al. 1992), and (e) one domain from the World Health Organization-Quality of Life-BREF (WHO-QOL-BREF; World Health Organization 1996). In addition, two researcher-developed sections were added for formal and informal social support. The survey was uploaded to Qualtrics online survey software to make it available nationwide. The present study uses two sections from the web-based survey to measure informal and formal social support. In addition, a demographic questionnaire was included on the web-based survey to obtain information about the personal characteristics of the parents and their adult children diagnosed with ASD. The parents who participated in the study were asked to refer to their oldest child with ASD when completing the survey.

## Types of Social Support

Research literature and discussions with professionals were used to determine the types of social support that parents

**Table 2** Frequency distributions: demographic characteristics of the adult child with ASD ( $N=320$ )

Adult Child's (with ASD) Demographics/Characteristics	<i>n</i>	(%)
Age of adult child with ASD ( $M=25.14$ , $SD=7.09$ )		
18 to 20	71	25.0
21 to 25	119	41.9
26 to 30	52	18.3
31 to 35	16	5.6
36 to 40	11	3.9
41 and over	15	5.3
Gender of adult child with ASD		
Male	257	80.3
Female	63	19.7
Living arrangement of adult child with ASD		
Live independently	16	5.0
Live independently with support	35	10.9
Live in a group home	11	3.4
Live with parents	248	77.5
College	6	1.9
Other	4	1.3
Educational status of adult child with ASD at time of study		
Attending university, college, or community college	55	17.2
Attending vocational training program	14	4.4
Attending public school (extended program for students 18-26)	86	26.9
Unable to attend educational program	27	8.4
Aged out of public school	59	18.4
College graduate	45	14.1
Dropped out of college/left college	6	1.9
Other	17	5.3
Missing	11	3.4
Communication		
Communicates a wide variety of topics meaningfully	124	38.7
Communicates limited range of topics meaningfully	112	35.0
Communicates needs and wants in some meaningful way	29	9.1
Communicates basic needs and wants	33	10.3
Very little meaningful communication	17	5.3
Uses device	4	1.3
Other	1	.3
Behavior		
Typical, age appropriate adult behavior	14	4.4
Requires minimal prompting, direction, or redirection	160	50.0
Requires substantial prompting, direction, or redirection	108	33.8
Engages in self-injurious behavior/dangerous behavior	19	5.9
Requires 24-hour supervision to manage behavior	16	5.0
Other	1	.3
Missing	2	.6
Social		
Has a group of friends, goes out with others in the community	43	13.4
Is part of a social group	88	27.5
Would like friendships, but has no friends	73	22.8
Is not able to make friends	32	10.0
Socializes with family only	82	25.7
Other	2	.6

and their adult children with ASD accessed. Fifteen types of formal social support and 6 types of informal social support were derived from the literature. Formal social support is assessed using a researcher-created checklist comprised of 15 specific types of formal social support, such as respite care, speech therapy, and social work. Formal social supports are provided by an agency or require payment of some type. To assess formal social support, parents checked items to indicate which social supports were either accessed by their adult child with ASD or themselves. Parents also could provide a response in an available text box to indicate other types of formal social supports that were obtained by either their adult child or the parent. In addition, parents also were asked if they received six types of informal social support that were typically unpaid and provided by family and friends. Parents were encouraged to indicate all that applied, allowing for multiple responses for both formal and informal types of social support.

### Dimensions of Social Support

Parents indicated if they or their adult children with ASD had accessed eight dimensions of social support (emotional, informational, physical relief, financial, housing, transportation, community-based activities, and community mental health). The dimensions were general, broad categories used to classify different sources of social support. (See Table 3 for a description of each of these dimensions.) For the purpose of this paper, formal social support had a cost attached to them. However, payment for the service might be through insurance, a grant, or community mental health services that was funded by tax dollars. While parents may not have to pay out-of-pocket for the social support service, there is a cost. Informal social support has no cost and is provided primarily by family, friends, and community members who

volunteer to help. Parents were asked to use a 4-point nominal scale, with 1 indicating received formal social support (paid), 2 informal social support (unpaid), 3 both formal and informal social support, and 4 received neither type of social support. They were asked to rate their satisfaction with each of these dimensions of support using a 4-point Likert-type scale used 1 for very dissatisfied, 2 for dissatisfied, 3 for satisfied, and 4 for very satisfied. Parents who received neither formal nor informal support indicated not applicable as their response to satisfaction with the dimension. The dimensions of social support were not tested as the responses were on a nominal scale. The satisfaction with social support services was tested by calculating the Cronbach alpha coefficient. The obtained alpha of .76 provided support that the scale had adequate reliability.

### Professional Feedback

After developing the web-based survey, the PI obtained feedback on the survey items, including lists of types of formal and informal social support and dimensions of social support, from various professionals (e.g. special education teacher, speech therapist, school social worker, school psychologist, teacher consultant, and transition coordinator) who worked with individuals with ASD and their parents. The experts made suggestions for minor changes to the survey items. Most of the comments indicated the survey was appropriate for the audience for which it was intended. Any suggestions they made were considered and made. The survey was not recirculated as none of the changes were major. After changing the survey items based on their suggestions, the final survey was uploaded to Qualtrics. The PI contacted the local, state, and national agencies and organizations who had agreed to distribute the survey link to their members

**Table 3** Dimensions of social support

Dimension	Description
Emotional social support	Support to provide help, guidance, or a listening ear/someone.
Informational social support	The offering of information/knowledge to connect. This support could entail information being shared regarding resources, services, understanding of ASD, etc.
Physical relief social support	A parental caregiver receiving help with the physical needs required to care for a loved one, such as respite care, watching a loved one, etc.
Financial social support	This type of support provides monetary assistance and can either be given through organizational and/or governmental support and/or support from family, friends, or others to directly or indirectly pay for goods or services.
Housing	Support with a physical space or housing supports. This may include support to live and maintain living in a shared living arrangement, apartment, or group home.
Transportation	Transportation includes ways to get from one place to another and may be offered either through community supports, such as public transportation, or through other means.
Community-based activities	Activities in the community that enable an individual to engage in leisure and learning experiences.
Community mental health	Services that provide preventative, diagnostic, psychological, and psychiatric services that address the mental health needs of an individual.

through email, newsletters, flyers, websites, and/or word of mouth.

## Data Analysis

Parents were given a list of types of formal social support and informal social support and instructed to indicate all that applied, with frequency distributions used to report which types of social supports were accessed. The formal social support services were categorized into five types: organizational groups, professional mental health, therapeutic services, caregiver relief, and financial support. The use of categories of types of social supports allowed comparisons among similar types of social supports. The eight dimensions of social support were answered twice: once to indicate the delivery form (formal, informal, both, or neither) and again to rate their satisfaction with the services using a 4-point Likert scale. The mean scores for satisfaction with dimensions were calculated by summing the numeric responses and then dividing by 8 to obtain the mean score. IBM-SPSS ver. 26 was used to complete the statistical analysis. To determine if satisfaction differed by the type of service delivery, Kruskal–Wallis one-way analyses of variance were used for each dimension of social support. All decisions on the statistical significance were made using a criterion alpha of .05.

## Results

Parents were provided with a checklist of formal social support services and instructed to indicate all that they or their adult child had used. Under organizational support, the largest group of parents were in autism support groups ( $n=88$ , 27.5%), followed by state organizations for caregivers of adults with ASD ( $n=41$ , 12.8%). Psychiatric services ( $n=156$ , 48.8%) and counseling ( $n=130$ , 40.6%) were the most used formal social supports under professional mental health. The therapeutic services included care for chronic illness ( $n=70$ , 21.9%) and speech therapy ( $n=33$ , 10.3%) as the most used services. Under the category of caregiver relief, 78 (24.4%) parents indicated they used paid respite care and 18 (5.6%) parents used adult day care for their adult children with ASD. Financial support from private or public sources was used by 127 (39.7%) parents. In addition to the formal social supports that were listed, parents were asked to write-in any formal social supports their adult with ASD received. Four parents reported their adult received support from social groups or recreational activities, such as Special Olympics. Two parents indicated their adult with ASD received employment support and one parent indicated a specialized college support program for students with ASD.

Parents were asked to indicate specific types of informal social support services they received. Informal social support typically is provided by family, friends, neighbors, and community residents at no cost to assist a family needing help. Emotional support ( $n=221$ , 88.8%) was the most indicated informal social support, followed by informational support ( $n=168$ , 67.5%). Seventy-four (29.7%) parents received physical assistance and 70 (28.1%) had help with respite care for their adult children. Help with chores/household activities ( $n=45$ , 18.1%) and financial assistance ( $n=42$ , 16.9%) were informal social support services used by aging parents of adults with ASD. (A complete list of formal and informal support services used by aging parents can be found in Table 4).

The parents' satisfaction with the eight dimensions of social support (emotional, informational, physical relief, financial, housing, transportation, community-based activities, and community mental health) were compared by the form of social support; formal (paid), informal (unpaid), both formal and informal, or neither formal or informal types of support using Kruskal–Wallis one-way analysis of variance. In terms of emotional support, most parents indicated receiving informal support ( $n=176$ , 56.2%), with 15 (4.8%) reporting they had formal emotional support. However, the mean scores for satisfaction found that those who received formal emotional support ( $M=3.20$ ,  $SD=.56$ ) were more satisfied than those who received informal emotional support ( $M=2.69$ ,  $SD=.70$ ), however this finding was not statistically significant ( $H[2]=4.64$ ,  $p=.098$ ). The greatest number of parents ( $n=211$ , 69.4%) received neither formal nor informal physical relief support, which included respite care. Among parents ( $n=36$ , 11.8%) who had formal physical relief, the mean satisfaction score was 2.36 ( $SD=1.25$ ). Forty (13.2%) parents had received informal physical relief, with a mean satisfaction score of 1.80 ( $SD=1.31$ ). The comparison of satisfaction across the three types of availability was not statistically significant ( $H[2]=5.10$ ,  $p=.078$ ). Parents reported participation in community-based activities ( $n=40$ , 13.0%) was formal, with 53 (17.3%) indicating informal participation in community-based activities. Nineteen parents indicated their adult child with ASD received both formal and informal support for participation in community-based activities. The comparison of satisfaction for community-based activities was statistically significant ( $H[2]=6.17$ ,  $p=.046$ ), with parents whose children participated in informal community-based activities having the lowest level of satisfaction. (See Table 5)

## Discussion

The purpose of this study was to examine informal and formal social supports used by aging parental caregivers and their adult children diagnosed with ASD. Parents indicated

**Table 4** Frequency distributions: use of specific types of formal and informal social support ( $N=320$ )

Formal and informal social support	<i>N</i>	(%)
<i>Formal social support</i>		
Organizational support	88	27.5
Autism support groups	41	12.8
State organizations for caregivers of adults with ASD	36	11.3
Community support groups for caregivers (regardless of disability)	9	2.8
National organizations for caregivers of adults with ASD	156	48.8
Professional mental health	130	40.6
Psychiatric services	74	23.1
Counseling	63	19.7
Social work	70	21.9
Community mental health	33	10.3
Therapeutic services	29	9.1
Care for a chronic condition	13	4.1
Speech therapy	78	24.4
Occupational therapy	18	5.6
Physical therapy	127	39.7
Caregiver relief		
Respite care (paid by parent or another source)		
Adult day care		
Financial support from private or public organizations/sources		
<i>Informal social support</i>		
Emotional support	221	88.8
Informational support	168	67.5
Physical assistance	74	29.7
Respite care	70	28.1
Help with chores/household activities	45	18.1
Financial assistance	42	16.9

which types of social support they accessed (e.g., psychiatric, physical therapy, social work, emotional support, etc.). The types of formal social supports were categorized into five domains: organizational support, professional mental health, therapeutic services, caregiver relief, and financial support from private or public organizations/sources. In addition, eight dimensions of social support (emotional, informational, physical relief, financial, housing, transportation, community-based activities, and community mental health) were used to determine if social support was formal, informal, both, or none; along with parental caregivers' satisfaction for these dimensions.

Given that almost 67% of the adults with ASD in the present study were between 18 and 25 years of age and most living with parents, the need for services may vary. As children with ASD approach adulthood, the need for services and types of services may change. With age limits of special education varying across the United States, many adults with ASD (approximately 27%) in this study were receiving some form of public education. This reality may change types of services used by emerging adults with ASD and their parental caregivers (Anderson et al. 2018; Turcotte et al. 2016).

The largest group of parental caregivers indicated using professional mental health services followed by financial support. Consistent with findings from Dudley et al. (2019), caregivers in the present study reported their adult children with ASD commonly accessed mental health services. Parents were less likely to access therapeutic services, such as physical, occupational, or speech therapy. These services require referrals from medical professionals, but generally are not covered by health insurance because ASD is considered chronic, not acute. The costs involved with therapeutic services may be prohibitive or the service may not be available (Anderson et al. 2018). This finding was consistent with Turcotte et al.'s (2016) findings that illustrated that the least used services by adults with ASD were physical, occupational, and speech and language therapy. Because the parents were encouraged to indicate all types of support they accessed with their adult children, determining which specific domains were used most could not be established.

Parental caregivers most likely received emotional support followed by informational support as the most commonly used informal supports (typically unpaid). Given that challenges often present for parents of adults with ASD, it is



**Table 5** Use and satisfaction with dimensions of informal and formal support (*N* = 320)

Type of social support	Availability of social support								Kruskal–Wallis test		
	Received formal support (paid)		Received informal support (unpaid)		Received both formal and informal support		Received neither type of support		<i>H</i>	<i>df</i>	<i>p</i>
	<i>N/M</i>	<i>%/SD</i>	<i>N/M</i>	<i>%/SD</i>	<i>N/M</i>	<i>%/SD</i>	<i>N/M</i>	<i>%/SD</i>			
Emotional									4.64	2	.098
Frequency	15	4.8	176	56.2	28	8.9	94	30.0			
Satisfaction	3.20	.56	2.69	.70	2.89	.50	–	–			
Informational									.79	2	.673
Frequency	11	3.6	154	50.2	55	17.9	87	28.3			
Satisfaction	2.64	.67	2.70	.94	2.75	.87	–	–			
Physical relief									5.10	2	.078
Frequency	36	11.8	40	13.2	17	5.6	211	69.4			
Satisfaction	2.36	1.25	1.80	1.31	2.53	.80	–	–			
Financial									.51	2	.776
Frequency	63	20.8	15	5.0	15	5.0	210	69.3			
Satisfaction	2.56	.86	2.27	1.28	2.60	1.06	–	–			
Housing									3.10	2	.212
Frequency	18	5.9	3	1.0	1	.3	284	92.8			
Satisfaction	3.11	.96	2.33	1.12	4.00	–	–	–			
Transportation									3.38	2	.184
Frequency	36	11.7	7	2.3	7	2.3	258	83.8			
Satisfaction	2.64	1.25	2.43	1.40	1.71	1.38	–	–			
Community-based activities									6.17	2	.046
Frequency	40	13.0	53	17.3	19	6.2	195	63.5			
Satisfaction	2.55	1.20	2.08	1.12	2.68	.82	–	–			
Community mental health									.74	2	.689
Frequency	56	18.3	8	2.6	12	3.9	230	75.2			
Satisfaction	2.34	1.01	2.13	.84	2.42	1.08	–	–			

Frequency and percentages are based on actual numbers (*N*) and percentages (%). Satisfaction are means (*M*) and standard deviations (*SD*) based on a 4-point Likert scale ranging from 1 for very dissatisfied to 4 for very satisfied. A scale point of 0 was provided for not applicable and was not included in the mean scores. Kruskal–Wallis nonparametric analysis of variance compared satisfaction with each type of social support service by the availability of that particular service (formal, informal, and both formal and informal)

no surprise that emotional support from family and friends is commonly used. For these families, informational support may be needed to provide parents with insight on what to expect now and in the future from their adult children with ASD (D’Astous et al. 2016; Marsack-Topolewski and Graves 2019). The majority of parents in this study had adult children between the ages of 18 and 25 years, suggesting that the need for informational support may be high as their children with ASD transition from adolescence to adulthood.

Few parents accessed dimensions of social support that were available both formally and informally. Parents were somewhat satisfied with the support they received, with satisfaction for formal support generally rated higher than informal support. This finding was not surprising as formal types of services are provided by professionals who have

been trained to work with individuals with special needs, while informal services are offered by friends and families who want to be helpful, but may lack the background and time needed to provide the support. The largest number of parents reported receiving neither formal nor informal support for six of the eight dimensions of social support (physical relief, financial, housing, transportation, community-based activities, and community mental health). This finding is in alignment with previous research that suggested that access to services was limited because of location, failing to qualify due to income or severity of the condition. Parents often encountered difficulty in finding adequate, accessible, affordable, and accommodating services for their adult children with ASD (Khanlou et al. 2017; Müller and Cannon 2016). Coordinating and navigating these services typically

are tasks assumed by parental caregivers (Anderson et al. 2018) that can be difficult, time consuming, expensive, and burdensome (Anderson and Butt 2018).

Many parents and their adult children with ASD were not receiving social support services, although the reasons for this were not explored. These findings paralleled the Anderson and Butt (2018) study that indicated 42% of young adults with ASD were receiving no services. Anderson and Butt discussed the need for increased funding for adult services to meet the needs of both the caregivers and the adult with ASD. In addition, they called for increased funding for research on the needs of adults with ASD.

## Implications for Practice

Formal social support services may not be available for adults with ASD due to a lack of funding. According to the GAO (2015), research on lifespan issues (e.g., adult service needs, transition services, etc.) indicated that adults with ASD received the least amount of funding from 2008 to 2012 compared to other research areas (e.g., biology, interventions and treatments, causes, and diagnosis) for ASD. In addition to individuals with ASD moving from adolescence to adulthood, parents who provide care are aging and facing increased health issues that require support from professionals, as well as family and friends. Professionals who are working with parental caregivers and their adult children diagnosed with ASD should be aware of available social support services for adults with ASD and their aging parents to help them find needed services. This reality must be recognized by professionals and society at large to provide both informal and formal social support to these populations.

Qualitative research with a similar study indicated that parents and their adult children with ASD often experience difficulty in obtaining needed services depending on geographical location and financial positions (Anderson et al. 2018). Healthcare professionals, including doctors, social workers, or case managers, who are working with this population should help parents and adults with ASD locate and access needed services. Satisfaction with the services should be monitored through the use of surveys and follow-up telephone calls to assist parents and adults with ASD achieve the best possible experience with the needed services.

## Study Limitations and Directions for Further Research

The participants in this study were a relatively homogeneous group of aging parents of adult children with ASD. They were comprised mainly of individuals who are highly

educated, female, European Americans, with socioeconomic statuses above the national average. The recruitment procedures targeted individuals who were more likely to interface with support groups and organizations in the United States that were relevant to individuals with ASD and their family caregivers. The use of snowball sampling was used to recruit individuals who were similar to the referring parents. As a result, the sample in the present study was homogeneous and included aging parental caregivers with similar demographic backgrounds. The parental caregivers self-selected to be in the study. Participants were limited to those who had access to a computer and the Internet. As a result, the sample may be biased as those without computers unable to participate. It is unknown if they participated because they wanted their voices heard, as caregivers of adults with ASD form a largely unheard, vulnerable population. Parents may have misunderstood or misinterpreted the types of formal and informal support services included on the survey. In addition, the survey failed to determine who (parent or adult child) was accessing the social support. Future research should take these two factors into consideration when studying social support for caregivers and their individuals with ASD. The present study did not explore parental caregivers appraised need of services, nor how geographic location (e.g. rural, urban, suburban, or state of residence) influenced the use of and satisfaction with services. Future research is needed to understand what services are needed, the temporal importance of services, and the degree to which services are adequately offered. Additionally, as more individuals with ASD reach adulthood and continue to rely on parental caregivers who are aging, future research should examine service needs based on age and severity of the adult children with ASD and the age of their parents. As the age at which public school services terminate vary depending on the state, services that are needed may be affected. Future studies should focus on understanding the specific transition supports that are used and needed as individuals with ASD and their parents progress across the lifespan, as well as the satisfaction with these services. Despite the noted limitations, these research findings contribute to the limited literature examining service use and satisfaction for parental caregivers and their adult children with ASD.

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