



April 2020

A Survey of Occupational Therapy Services Provided for Adults with Autism Spectrum Disorder

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Recommended Citation

Ohl, A., Schelly, D., Brown, D., Schulze, N., Smith, M., & Davies, B. (2020). A Survey of Occupational Therapy Services Provided for Adults with Autism Spectrum Disorder. *The Open Journal of Occupational Therapy, 8*(2), 1-13. <https://doi.org/10.15453/2168-6408.1620>

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A Survey of Occupational Therapy Services Provided for Adults with Autism Spectrum Disorder

Abstract

Background: We examined the services provided to adults with autism spectrum disorder (ASD) by occupational therapists across the United States.

Method: This cross-sectional study used an online survey, with a combination of structured and open-ended questions, to collect data from a nonprobability sample. Descriptive, inferential, and nonparametric statistics were used to analyze data.

Results: In our sample ($N= 57$), the majority of the participants spent less than half of their workweek intervening with the adult ASD population. Caregivers were instrumental in both referral and discharge, and Medicaid was the most common payer source. The Adult Sensory Profile was used by more than half of the participants and sensory integration was the most influential model underlying practice (77%). The participants advised new occupational therapists to pursue high quality continuing education courses and formal mentorship from senior colleagues.

Conclusion: This study suggests that working with adults with ASD remains a niche area of practice. Further research is needed to examine the pathways to receiving occupational therapy for the adult ASD population.

Comments

The authors report that they have no conflicts of interest to disclose.

Keywords

autism spectrum disorder, national survey, practice trends

Cover Page Footnote

We thank the occupational therapists who filled out our survey and the individuals who helped us by advertising our survey.

Credentials Display

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DOI: 10.15453/2168-6408.1620

For children with autism spectrum disorder (ASD), occupational therapy is the third most frequently provided service in the United States, following speech-language pathology and social skills training (Zablotsky et al., 2015). In contrast, occupational therapy services along with speech-language pathology, one-to-one support, and social skills training are the most common areas of unmet need for adults with ASD (Turcotte et al., 2016). The proportion of adults with ASD receiving occupational therapy services after high school ranges from almost none (Laxman et al., 2019) to 15% (Cidav et al., 2013; Gotham et al., 2015; Turcotte et al., 2016).

Examining the existing service use patterns of individuals with ASD and how they change over time will inform the design of future occupational therapy services (Turcotte et al., 2016). The purpose of the present study was to examine the breadth of services provided for adults with ASD by occupational therapists in the United States. In particular, we focused on practice setting, caseload and workload characteristics, intervention and evaluation practices, payer source, and occupational therapist self-reported expertise. By establishing a profile of current practices, we provide a baseline for international comparisons and the monitoring of practice trends over time.

Review of the Literature

Transition and adulthood services for individuals with ASD. From birth through high school graduation, individuals with ASD are eligible to receive early intervention, special education, and related services (e.g., occupational, speech, and physical therapies) under the Individuals with Disabilities Education Act (IDEA, 2004). Before exiting high school, all students receiving special education under IDEA are entitled to a transition plan, beginning no later than when they are 16 years of age (IDEA, 2004). Transition plans are unique to the individual student's needs and may include instruction, related services, and community experiences to improve academic and functional achievement to facilitate the movement from school to postschool activities (IDEA, 2004). Postschool activities may include further education, a continuum of living arrangements (e.g., living with family, independent living, partially-supported living, or fully-supported living), employment opportunities (e.g., sheltered workshop, supported employment, or competitive employment), and community participation in recreation and leisure activities. According to the National Longitudinal Transition Study-2 (NLTS2), most young adults with ASD have employment related transition goals, further broken down into competitive employment (22%), supported employment (39%), and sheltered employment (39%) (Cameto et al., 2004). Independent living goals (28%) are also common among young adults with ASD, followed by goals to transition to either a 2- or 4-year college (23%) (Cameto et al., 2004).

As individuals with ASD age, they tend to experience a decline in the receipt of most services in the school system (Cidav et al., 2013; Laxman et al., 2019; Taylor & Henninger, 2015; Turcotte et al., 2016). After high school, when the entitlements associated with IDEA are no longer available, this decline is more dramatic (Laxman et al., 2019; Shattuck et al., 2011; Turcotte et al., 2016) and is often referred to as the service cliff (Turcotte et al., 2016). For parents of young adults with ASD, the loss of entitlements has been described as a jarring and overwhelming experience for which they are ill prepared (Anderson et al., 2018).

The lack of service receipt by adults with ASD has been attributed to numerous barriers, starting with the transition process itself. Individuals with ASD attend and participate in their individualized education program (IEP) meetings at lower rates than individuals in any other disability category (Shogren & Plotner, 2012). Hetherington et al. (2010) found that the students with ASD who do attend

their transition-focused IEP meetings largely describe the process as ineffective, leading the authors to conclude that “being present for an IEP meeting does not necessarily suggest engagement with the transition planning process” (p. 166). The social interaction and communication deficits characteristic of ASD (American Psychiatric Association [APA], 2000) and the common comorbid diagnosis of anxiety (Bellini, 2006) may also present obstacles to participation in the transition process.

From caregiver perspectives, additional barriers to effective transition planning include: being inundated with too much information about complex state and federal programs (Anderson et al., 2018; Schall & Wehman, 2009), poor communication with school-based providers (Hetherington et al., 2010), generic IEP goals (Hetherington et al., 2010), and insufficient time in school for working on appropriate postsecondary skills (Hetherington et al., 2010). After graduation, families are responsible for navigating multiple systems for which eligibility, availability, and funding create additional barriers to services. Most state and federal programs for adults with disabilities do not begin until they are 21 years of age, creating a gap for individuals graduating from high school prior to that age (Anderson et al., 2018). After meeting age requirements, adults with ASD must further qualify for services based on criteria specific to the program to which they are applying. According to Anderson et al. (2018), adults with ASD with high IQs do not qualify for many programs, while their counterparts with intellectual disabilities (ID) and problem behaviors are hard to place. Finally, after finding and qualifying for a particular program, families have to navigate various funding streams, including Medicaid, private insurance, and Supplemental Social Security Income (SSI).

Cost of services for individuals with ASD. The average prevalence of ASD in the United States is between 1% and 2% (Centers for Disease Control and Prevention [CDC], 2018). The total annual economic cost of children with ASD is estimated at \$66 billion, while the total cost for adults with ASD is estimated to be substantially higher: \$196 billion (Buescher et al., 2014). For children, the largest contributors to the total cost are direct nonmedical services, such as special education (including early intervention services) and indirect costs like parental productivity loss (Buescher et al., 2014). For adults, the total cost is largely accounted for by accommodations (including support staff in accommodation settings), followed by direct medical costs and individual productivity loss from unemployment (Buescher et al., 2014). Assuming an increasing prevalence rate, the total economic burden of ASD (across all ages) is forecasted to more than double by 2025 to \$461 billion (Leigh & Du, 2015).

Private insurance coverage for ASD related therapies has historically been limited (Baller et al., 2016), with Medicaid-enrolled children with ASD receiving many more services than those enrolled in private insurance (Wang et al., 2013). For example, Medicaid-enrolled children with ASD attend 6.4 outpatient occupational and physical therapy visits to every 0.9 visits attended by children with ASD and private insurance (Wang et al., 2013). In response to the limitations of private insurance, as of 2017, 46 states and the District of Columbia have enacted laws requiring many private health plans to cover ASD-specific services (National Conference of State Legislatures [NCSL], 2019). Depending on the state, this mandated coverage is limited to specific age groups, a number of annual visits, or an annual spending cap. Although these mandates intend to benefit individuals with ASD, the evidence of their effectiveness is limited and mixed (Baller et al., 2016; Chatterji et al., 2015; Parish et al., 2015). In states where autism mandates have been perceived to improve autism services for children, increased demand for service use has outpaced the supply of services (Baller et al., 2016).

Adult ASD services are also funded by Supplemental Social Security Income (SSI), a federally administered program that provides cash to low income individuals who qualify by age or disability status (Duggan et al., 2015). After the age of 18, financial need is based on the individual's ability to earn an income, and SSI benefits operate on a sliding scale, adjusting according to the individual's actual earned income. In many states, SSI is tied into Medicaid health insurance; thus, qualifying for SSI also presumes eligibility for the Vocational Rehabilitation (VR) program administered by the Rehabilitation Services Administration (RSA) (U.S. Department of Education, 2017).

The VR and other services offered by the RSA are provided to assist individuals with disabilities to maximize their employment outcomes, independence, and integration in the community and competitive labor market (U.S. Department of Education, 2017). Funded by a combination of federal grants and state funds, state VR agencies provide services directly to people with disabilities through an extensive network of local VR offices and community rehabilitation providers (Roux et al., 2018). According to the most recent Workplace Innovation and Opportunity Act (WIOA) annual report, nearly one million individuals with disabilities receive services through the RSA (Montana Department of Labor & Industry, 2017). Of the individuals with disabilities using VR services, approximately 18% are transition-aged youth with ASD (Roux et al., 2018).

Adult outcomes and the need for occupational therapy. Evidence suggests that although individuals with ASD may experience improvements in many symptoms and behaviors as they age, impairments in adaptive functioning, defined as the skills necessary for age appropriate independent living (Mathews et al., 2015), persist well into adulthood (Billstedt et al., 2011; Farley et al., 2009; Gray et al., 2014; Mathews et al., 2015; Shattuck et al., 2007). Using latent growth curve modeling, Smith et al. (2012) found that individuals with ASD experience a plateau in their adaptive functioning in their 20s and a decline in their 30s. Adaptive functioning is often found to be a strong predictor of adult outcomes among individuals with ASD (Farley et al., 2009) along with IQ and verbal functioning (Magiati et al., 2014). Studies of more cognitively and verbally able adults with ASD generally report more positive results than those sampling from adults with ASD and ID (Howlin & Magiati, 2017); however, the outcomes of adults with ASD and average IQs are more variable and less predictable than adults with ASD and ID (Marriage et al., 2009).

Compared to adults with other developmental disabilities, adults with ASD are more economically, educationally, and socially disadvantaged (Roux et al., 2013). A systematic review and meta-analysis of the overall outcome of children with ASD followed up during adolescence and adulthood found that almost 48% of the participants had poor or very poor outcomes (i.e., they required a high level of support) (Steinhausen et al., 2016). Studies examining more specific adult outcomes have consistently found poor vocational engagement (Chen et al., 2015; Gotham, et al., 2015), restricted community inclusion and living skills (Gotham et al., 2015; Gray et al., 2014; Hewitt et al., 2017), and low rates of college attendance (Shattuck et al., 2012), even controlling for IQ.

The needs of an adult population with ASD, which includes acquiring and enhancing independent living skills to participate at home, school, work, and in the community, are not only well within the scope of occupational therapy practice (AOTA, 2014) but are the very essence of the profession. With a wide range of health related expertise, occupational therapists are primed to play a key role in helping adults with ASD achieve positive health and quality of life outcomes. To better understand the current state of occupational therapy services provided for adults with ASD, we surveyed occupational therapists practicing in the United States.

Method

Research Design

We collected quantitative and qualitative data using a nonexperimental descriptive online survey. This method was chosen for its rapid turnaround and low cost (Fowler, 2014). This study was approved and conducted in accordance with the guidelines of the Clarkson University institutional review board. Participants demonstrated consent by completing the survey.

Sample

Participants were required to meet the following inclusion criteria: (a) practice as either an occupational therapist or occupational therapy assistant and (b) currently work with adults with ASD. Participants who did not meet both criteria and who did not complete at least 80% of the survey were excluded from data analysis.

Procedures and Data Collection

A postcard advertising the study and containing a link to the online survey was mailed through the U.S. Postal Service to a random sample of 1,000 occupational therapists who belonged to the following AOTA Special Interest Sections: Developmental disabilities, mental health, physical disabilities, home and community health, sensory integration, and work and industry. A follow-up postcard was mailed 8 weeks after the original mailing. To expand the sampling frame, additional participants were recruited by contacting adult ASD service centers, social media groups with occupational therapist members, and all 50 state occupational therapy professional associations. A paper version of the survey was available upon request.

Survey Instrument

After a comprehensive review of the literature, including occupational therapy practice trend articles (e.g., Cahill et al., 2014; Rodger et al., 2005), we developed a 38-item survey to assess current trends related to occupational therapy services provided to adults with ASD. The first author (Ohl), an occupational therapist with over 15 years of clinical experience, developed the first draft of the survey in collaboration with the second author (Schelly), a sociologist with experience in survey development and a background studying expertise. The survey was reviewed for content and understandability by the remaining authors. The survey, which included both open- and closed-ended questions, consisted of four sections (35 items): demographic information and background (11 items), caseload and workload (5 items), intervention and evaluation practices (11 items), and expertise (8 items).

Demographic information and background. Eligibility was established with the following two questions: (a) Are you currently working as an occupational therapist or occupational therapy assistant? and (b) Have you worked with individuals with ASD? The participants were also asked to provide the following demographic information: age, gender identity, state of practice, practice setting(s), hours at each practice setting, years at primary practice setting, total years as an occupational therapist, highest degree earned, and certifications held.

Caseload and workload. The participants were asked to identify the number of adult ASD clients with whom they worked each week. Further information was gathered on the amount of time spent on various service activities (i.e., consultation, evaluation, family training, group intervention, and one-to-one intervention) each week, the average length of intervention sessions, location of services, and the frequency of their collaboration with other health professionals.

Intervention and evaluation practices. The participants were asked to identify the referral and payer sources for their adult ASD clients, assessment information (i.e., assessment schedule and

assessments used), intervention information (i.e., frequency of occupations addressed during intervention and methods for monitoring outcomes), average length of total services provided to their adult ASD clients, rationale for discharge, and theoretical models and frames of reference used.

Expertise. The participants were asked to estimate the total number of adults with ASD with whom they had worked during their careers and to indicate their level of expertise with ASD on a 5-point Likert scale (1 = *novice*, 2 = *advanced beginner*, 3 = *competent*, 4 = *proficient*, 5 = *expert*). The participants were also asked to discuss how they achieved their current level of expertise and to provide recommendations for occupational therapists new to working with adults with ASD.

Data Analysis

The survey results were analyzed using IBM SPSS Version 24 (IBM Corp., 2016). Quantitative data were first analyzed with descriptive statistics. Pearson Product Moment Correlation Coefficients were used to examine the relationship between self-rated expertise and two other variables: (a) the participants' total years of occupational therapy experience and (b) the total number of adults with ASD with whom they had worked throughout their careers. Qualitative text data from open-ended questions were analyzed using applied thematic analysis (ATA) (Guest et al., 2012), in which word counts were used to identify highly repeated key words and ideas, which were then identified as themes. ATA uses a positivist/interpretive epistemological approach to data analysis. The following steps were taken to ensure the trustworthiness (i.e., validity) and reliability of the qualitative data: (a) intercoder agreement was established between the first two authors, providing additional checks on individual biases and consistency of coding, and (b) verbatim quotes were used to directly connect the authors' interpretations with what the participants said.

Results

Participants

One hundred and forty surveys were initiated on SurveyMonkey. Nineteen surveys did not meet the initial inclusion criteria for the study (i.e., the participants were not occupational therapists), leaving 121 completed surveys for data analysis. Of these surveys, 64 were excluded because the participants did not have any adults with ASD on their caseloads. The participants ($N = 57$) were occupational therapists (89.5%) and occupational therapy assistants (10.5%) representing 22 states. The gender profile of the participant group was primarily female (87.7%). The participants ranged from 21 to 66 years in age ($M = 43$, $SD = 13.2$) and represented more than 15 practice settings. Table 1 provides additional demographic characteristics.

Table 1

Participant Demographics and Employment Characteristics (N = 57)

Characteristic	<i>n</i>	%
Gender identity		
Male	5	8.8
Female	50	87.7
Transgender	2	3.5
Practice setting		
Academia	6	6.9
Community setting/Day habilitation	14	16.1
Early intervention	5	5.7
Freestanding outpatient	14	16.1

Home care	8	9.2
Mental health	5	5.7
Hospital	5	5.7
Long term care/Skill nursing	4	4.6
School system	20	23.0
Other	6	6.9
Degree		
Associates degree	4	7.0
Bachelor's degree	14	24.6
Master's degree	31	54.4
Occupational therapy doctoral degree	4	7.0
Other doctoral degree	2	3.5
Ph.D.	2	3.5
Specialty certifications		
None	47	82.5
1 or more	12	17.5
<hr/>		
Years of clinical experience	<i>M</i>	<i>SD</i>
Current practice setting	13.3	9.8
Total clinical experience	18.0	12.5

Note. *Participants chose more than one option; therefore, sums do not add up to 100%.

Caseload and workload. The majority of participants who reported working with adults with ASD also reported working with children with ASD (82.5%). Over three-quarters (77.2%) of the participants worked with their adult ASD clients for a quarter or less of the work week, while a minority reported working with them between a quarter and one-half of the work week (19.3%) and more than half of the work week (3.5%).

Outpatient clinics (37.7%) and community practice settings (37.7%) were the most commonly identified locations for adult ASD services. On a weekly basis, three-quarters of the participants reported providing individual therapy sessions (>1 hr), while approximately one-third of the participants provided group sessions (>1 hr). Intervention sessions ranged in length from 15 min to more than 1 hr, with most of the participants (58.5%) seeing their adult ASD clients for 30 to 60 min per session.

Collaboration was infrequent between the participants and other professionals, with the most frequent mode of collaboration being less than once per month with other occupational therapists (18.5%), physical therapists (30.2%), speech therapists (27.8%), psychologists (32.1%), counselors (27.5%), social workers (35.8%), physicians (38.5%), and psychiatrists (26.0%). Table 2 provides additional caseload and workload information.

Table 2

Caseload and Work Characteristics of Occupational Therapists Working with Adults with ASD (N = 57)

Characteristic	<i>n</i>	%
Number of adults with ASD on weekly caseload (<i>n</i> = 52)		
0-10	46	88.5
11-20	5	9.6
More than 20	1	1.9
Time spent consulting per week (<i>n</i> = 47)		
0 hr	11	23.4

1-2 hr	22	46.8
3-5 hr	6	12.8
> 5 hr	8	17.0
Time spent performing evaluations per week (<i>n</i> = 45)		
0 hr	18	40.0
1-2 hr	14	31.1
3-5 hr	7	15.6
> 5 hr	6	13.3
Time spent providing family training and education per week (<i>n</i> = 45)		
0 hr	20	44.4
1-2 hr	17	37.8
3-5 hr	6	13.3
> 5 hr	2	4.4
Time spent providing group interventions per week (<i>n</i> = 44)		
0 hr	29	65.9
1-2 hr	6	13.6
3-5 hr	6	13.6
> 5 hr	3	6.8
Time spent providing 1:1 interventions per week (<i>n</i> = 49)		
0 hr	12	24.5
1-2 hr	21	42.9
3-5 hr	5	10.2
> 5 hr	11	22.4

Note. *The participants chose more than one option; therefore, sums do not add up to 100%.

Intervention and evaluation practices. The participants received referrals for their adult ASD clients from a variety of sources, with physicians (48.8%), caregivers (46.5%), and the education system (44.2%) in the form of IEP referrals being the three most common identified referral sources. Medicaid (56.8%) is the most common payer source for most occupational therapists, followed by services provided under IDEA in public schools (15.9%), SSI (9.1%), and private insurance (9.1%).

Half of the participants reported assessing their clients at least once a year, with the remainder assessing more frequently (e.g., every 6 months). The Adult Sensory Profile (56.3%) was the most commonly identified assessment, along with the Canadian Occupational Performance Measure (33.3%). Sensory integration (77.0%), the Model of Human Occupation (64.6%), Behavioral (58.3%), and ecological models (e.g., Person-Environment-Occupation) (54.2%) were the dominant models and frames of reference underlying intervention choices. When asked to identify the frequency of occupation-based interventions, 54.2% of the participants reported working on ADLs and social participation, followed by IADLs (47.8%), leisure (40.0%), work (31.9%), education (27.1%), play (25.5%), and sleep hygiene (15.2%). The most frequently identified method of monitoring outcomes and determining when to discharge was caregiver feedback (51.1%). Table 3 provides additional information on intervention and evaluation practices.

Table 3

Frequency of Intervention and Evaluation Practices of Occupational Therapists Working with Adults with ASD (N = 57)

Characteristic	<i>n</i>	%
Payer source (<i>n</i> = 44)		
Medicaid	25	56.8
Private insurance	4	9.1
SSI	4	9.1
Private pay	1	2.3
Non-profit/NGO	3	6.8
Public school/IEP	7	15.9
Referral source* (<i>n</i> = 43)		
Caregiver	20	46.5
Educational (IEP)	19	44.2
Medical doctor	21	48.8
Self-referral	6	14.0
Assessments* (<i>n</i> = 48)		
Adult Sensory Profile	27	56.3
Canadian Occupational Performance Measure	16	33.3
Independent Living Scale	10	20.8
Kohlman Evaluation of Living Skills	7	14.6
Leisure Interest Inventory	6	12.5
Frames of reference and Models* (<i>n</i> = 48)		
Sensory Integration	37	77.0
Model of Human Occupation	31	64.6
Behavioral	28	58.3
Ecological models (PEO/PEOP)	26	54.2
Psychosocial	17	35.4
Biomechanical	12	25.0
Method of monitoring outcomes* (<i>n</i> = 47)		
Caregiver feedback	24	51.1
Reassessing using non-standardized assessments	23	48.9
Client narrative	19	40.4
Goal attainment scaling	21	44.7
Reassessing using standardized assessments	14	29.8
Length of occupational therapy services (<i>n</i> = 48)		
< 1 year	22	45.8
> 1 year	26	54.2

Note. *The participants chose more than one option; therefore, sums do not add up to 100%.

Expertise. The participants reported working with anywhere from 1 to 100 adults with ASD throughout their careers, with the majority seeing 50 adults or fewer (72.7%). Self-rated expertise ranged from *novice* (4.2%) to *expert* (20.8%), with most of the participants reporting being *proficient* (41.7%). There were weak but statistically significant relationships between the participants' self-rated expertise and the number of adult ASD clients with whom they had worked ($r = 0.31, p = 0.03$) and between self-rated expertise and total years of experience ($r = 0.34, p = 0.02$).

When asked how they achieved their current level of expertise, most of the participants (77.2%) identified on-the-job experience as a source of knowledge, with recurring mention of learning through

trial and error, observation, and problem-solving. Approximately one-half of the participants reported learning about ASD during higher education, 61.4% received additional ASD-specific expertise through formal continuing education courses, and 32% received formal mentorship. An additional source of perceived expertise, self-directed learning, was described as a combination of reading books and/or research articles.

The participants were also asked to provide advice to occupational therapists new to working with a population of adults with ASD. The two most frequently mentioned recommendations were: (a) to educate oneself by attending high quality continuing education courses and by reading books and (b) to seek out mentorship and knowledge from more senior colleagues. The theme of respecting the individuality of each person with ASD also emerged. For example, the participants indicated: “No one person with ASD is the same,” and “remember that everyone is different even with the same diagnosis.” Further recommendations advocated for client-centered care: “Observe your client and adjust according to their response. Books are a great starting point, but the people you work with are the best reference.” Over a quarter of the participants emphasized the therapeutic relationship with both the client and the client’s family as a necessary component to developing meaningful goals. A smaller proportion of the participants (16.0%) discussed intrapersonal skills, recommending that occupational therapists confront their own biases, adapt, and problem-solve on their feet. Of interest is that many of the participants (12.9%) recommended that occupational therapists consider alternatives to sensory integration. One participant stated, “problem-solve, don’t use Sensory Integration, it won’t fix the problem. Spinning kids does not teach them fine motor skills, ADL’s, etc. ADL’s are most important.”

Discussion

This study establishes the first profile of practice patterns for providing occupational therapy to adults (18 years of age and older) with ASD. Despite using a comprehensive sampling strategy that included sending postcards to 1,000 AOTA members, twice; posting our survey link on social media; distributing the survey through state occupational therapy associations; and offering an incentive; our sample was small ($N = 57$). A small sample may be indicative of a poor response rate (possibly as low as 5%); however, because much of the sample was likely not eligible to complete the online survey (i.e., they did not work with adults with ASD) and multiple sampling methods were used, the true response rate is incalculable. Our small sample may be reflective of a combination of factors, including the practical difficulties associated with surveying a small target population and a practice area that is still emerging. Recall from the literature review, current estimates of occupational therapy service receipt by adults with ASD range from 0 to 15% (Cidav et al., 2013; Gotham et al., 2015; Laxman et al., 2019; Turcotte et al., 2016). Furthermore, excluding occupational therapists working in the school system, the second and third largest employers of our participants were outpatient clinics and other community practice settings, both of which account for a relatively small proportion of the total occupational therapy workforce (10.8% and 2% respectively) (AOTA, 2015).

Adults with ASD comprised a relatively small component of our participants’ caseloads, and none of the participants reported working solely with a population of adults with ASD. This finding is expected given the low estimated prevalence of ASD in the United States (i.e., averaging between 1% and 2% across studies) (CDC, 2018). In a small geographic area, there may not be enough adults with ASD to sustain a full occupational therapy caseload. Even with a sustaining population, caseloads may remain low because of the known barriers associated with accessing adult ASD services. Furthermore, there are potentially additional unexamined barriers specific to occupational therapy.

In our survey, excluding adults with ASD still receiving services in the school system, the most cited referral sources were medical doctors and caregivers. It should be noted that physician referrals may be at the behest of caregivers; therefore, caregivers may be the most influential driver of adult services. Provided that caregivers are largely responsible for procuring services for their adult children with ASD, one potential barrier to service receipt may be general poor awareness and lack of knowledge of the scope of occupational therapy practice. According to Kuhaneck and Watling (2015), although there is currently no research documenting general knowledge of occupational therapy services, in the context of ASD occupational therapists are most widely known as sensory integration experts. While this misperception can be addressed at a professional and grassroots level through a public relations campaign, research is first needed to determine how familiar families are with various occupational therapy practices. Lack of supply may present an additional barrier, given the relatively small proportion of the occupational therapy workforce employed in outpatient and community settings (AOTA, 2015). Further inquiry is needed to better understand the referral pathways and barriers to occupational therapy services for adults with ASD.

Congruent with current literature (Baller et al., 2016; Wang et al., 2013), we also found Medicaid to be the largest payer source for services, with less than 10% of our participants reporting payment from SSI or private insurance. It is unclear whether lack of private insurance funding is a function of the insurers refusing to pay for occupational therapy services or simply lack of insurance by adults with ASD. After the age of 26, adults with ASD are no longer covered under their parents' insurance (U.S. Department of Health and Human Services, 2017), and given their high rates of unemployment (Chen et al., 2015), they may not be able to acquire their own health insurance.

When considering the evaluation process, the Adolescent/Adult Sensory Profile (Brown & Dunn, 2002) was the most cited assessment. It is notable that none of the identified standardized assessments were specific to ASD and assessments were not commonly used as outcome measures, which may suggest a need for further assessment development unique to both ASD and occupational therapy. Sensory integration (Ayres, 1972) was also a commonly identified model underlying treatment decisions. Given that hypo or hyperreactivity are diagnostic characteristics of ASD (APA, 2000), the emphasis on sensory integration is to be expected; however, data from open-ended questions indicates that occupational therapists recommend additional approaches to meet the needs of their adult clients, such as focusing on more daily living skills acquisition. Aligning with the predominant needs of an adult population with ASD (Mathews et al., 2015), the most common occupation-based interventions focused on ADLs, IADLs, leisure, and work. More research is needed to better understand the effectiveness of these interventions.

Strengths and Limitations

While our study contributes seminal information on the practice patterns of occupational therapists working with adults with ASD, it is severely limited in generalizability by a small nonprobability sample. Further inquiry should employ mixed-methods to examine service provision for adults with ASD, including pathways and barriers to service receipt, the role of various intervention models, assessment development, and intervention effectiveness.

Implications for Occupational Therapy Practice

The results of this study have several implications for occupational therapy practice and future research. First, our sample of occupational therapists reported using assessments that are not specific to ASD or adulthood; therefore, we suggest inquiry into further assessment development. Second, our

finding that caregivers were the primary referral mechanism for occupational therapy services in adults with ASD suggests that caregiver education about the full scope of occupational therapy practices may improve access to adult services.

References

- American Occupational Therapy Association. (2014). Scope of practice. *American Journal of Occupational Therapy*, 68, S34–S40.
- American Occupational Therapy Association. (2015). Work setting trends for occupational therapy: How to choose a setting. Retrieved from: <https://www.aota.org/Education-Careers/Advance-Career/Salary-Workforce-Survey/work-setting-trends-how-to-pick-choose.aspx>
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders, DSM-IV-TR*. American Psychiatric Association.
- Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics*, 141(Suppl. 4), S300–S305. <https://doi.org/10.1542/peds.2016-4300g>
- Ayres, J. (1972). *Sensory integration and learning disorders*. Western Psychological Services.
- Baller, J. B., Barry, C. L., Shea, K., Walker, M. M., Ouellette, R., & Mandell, D. S. (2016). Assessing early implementation of state autism insurance mandates. *Autism*, 20(7), 796–807. <https://doi.org/10.1177/1362361315605972>
- Bellini, S. (2006). The development of social anxiety in adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 21(3), 138–145. <https://doi.org/10.1177/10883576060210030201>
- Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*, 15(1), 7–20. <https://doi.org/10.1177/1362361309346066>
- Brown, C., & Dunn, W. (2002). *Adolescent/Adult Sensory Profile*. Pearson.
- Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics*, 168(8), 721–728. <https://doi.org/10.1001/jamapediatrics.2014.210>
- Cahill, S. M., McGuire, B., Krumdick, N. D., & Lee, M. M. (2014). National survey of occupational therapy practitioners' involvement in response to intervention. *American Journal of Occupational Therapy*, 68(6), e234–e240. <https://doi.org/10.5014/ajot.2014.010116>
- Cameto, R., Levine, P., & Wagner, M. (2004). Transition planning for students with disabilities: A special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2). SRI International.
- Centers for Disease Control and Prevention. (2018). Data and statistics on autism spectrum disorder. Retrieved from <https://www.cdc.gov/ncbddd/autism/data.html>
- Chatterji, S., Byles, J., Cutler, D., Seeman, T., & Verdes, E. (2015). Health, functioning, and disability in older adults—present status and future implications. *The Lancet*, 385(9967), 563–575. [https://doi.org/10.1016/s0140-6736\(14\)61462-8](https://doi.org/10.1016/s0140-6736(14)61462-8)
- Chen, J. L., Leader, G., Sung, C., & Leahy, M. (2015). Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Review Journal of Autism and Developmental Disorders*, 2(2), 115–127. <https://doi.org/10.1007/s40489-014-0041-6>
- Cidav, Z., Lawer, L., Marcus, S. C., & Mandell, D. S. (2013). Age-related variation in health service use and associated expenditures among children with autism. *Journal of Autism and Developmental Disorders*, 43(4), 924–931. <https://doi.org/10.1007/s10803-012-1637-2>
- Duggan, M., Kearney, M., & Rennane, S. (2015). The Supplemental Security Income (SSI) Program. In R. Moffitt (Ed.), *Economics of means-tested transfer programs in the United States, Volume II* (pp. 1–58). University of Chicago Press.
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., Block, H., Pingree, C. B., Ritvo, E. R., Ritvo, R. A., & Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, 2(2), 109–118. <https://doi.org/10.1002/aur.69>
- Fowler, F. J. (2014). *Survey research methods* (5th ed.). SAGE Publications.
- Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders*, 44(12), 3006–3015. <https://doi.org/10.1007/s10803-014-2159-x>
- Gotham, K., Marvin, A. R., Taylor, J. L., Warren, Z., Anderson, C. M., Law, P. A., Law, J. K., & Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*, 19(7), 794–804. <https://doi.org/10.1177/1362361315583818>
- Guest, G., MacQueen, K. M., & Namey, E. E. (2011). *Applied thematic analysis*. SAGE Publications.
- Hetherington, S. A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., &

- Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities*, 25(3), 163–172. <https://doi.org/10.1177/1088357610373760>
- Hewitt, A. S., Stancliffe, R. J., Hall-Lande, J., Nord, D., Pettingell, S. L., Hamre, K., & Hallas-Muchow, L. (2017). Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States. *Research in Autism Spectrum Disorders*, 34, 1–9. <https://doi.org/10.1016/j.rasd.2016.11.007>
- Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry*, 30(2), 69–76. <https://doi.org/10.1097/yco.0000000000000308>
- IBM Corp. (2016). IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp.
- Individuals with Disabilities Education Act (IDEA). (2004). Individual with disabilities education act. Retrieved from <https://sites.ed.gov/idea/>
- Kuhaneck, H. M., & Watling, R. (2015). Occupational therapy: Meeting the needs of families of people with autism spectrum disorder. *American Journal of Occupational Therapy*, 69(5). <https://doi.org/10.5014/ajot.2015.019562>
- Laxman, D. J., Taylor, J. L., DaWalt, L. S., Greenberg, J. S., & Mailick, M. R. (2019). Loss in services precedes high school exit for teens with autism spectrum disorder: A longitudinal study. *Autism Research*, 12(6), 911–921. <https://doi.org/10.1002/aur.2113>
- Leigh, J. P., & Du, J. (2015). Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of Autism and Developmental Disorders*, 45(12), 4135–4139. <https://doi.org/10.1007/s10803-015-2521-7>
- Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, 34(1), 73–86. <https://doi.org/10.1016/j.cpr.2013.11.002>
- Marriage, S., Wolverton, A., & Marriage, K. (2009). Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 18(4), 322–328.
- Matthews, N. L., Smith, C. J., Pollard, E., Ober-Reynolds, S., Kirwan, J., & Malligo, A. (2015). Adaptive functioning in autism spectrum disorder during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 45(8), 2349–2360. <https://doi.org/10.1007/s10803-015-2400-2>
- Montana Department of Labor & Industry. (2017). Workplace innovation and opportunity act (WIOA): Annual statewide performance report narrative. Retrieved from <https://www.doleta.gov/Performance/Results/AnnualReports/PY2017/reports/MT/MT.pdf>
- National Conference of State Legislators. (2019). Autism and insurance coverage: State laws. Retrieved from: <http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx>
- Parish, S. L., Thomas, K. C., Williams, C. S., & Crossman, M. K. (2015). Autism and families' financial burden: The association with health insurance coverage. *American Journal on Intellectual and Developmental Disabilities*, 120(2), 166–175. <https://doi.org/10.1352/1944-7558-120.2.166>
- Rodger, S., Brown, G. T., & Brown, A. (2005). Profile of paediatric occupational therapy practice in Australia. *Australian Occupational Therapy Journal*, 52(4), 311–325. <https://doi.org/10.1111/j.1440-1630.2005.00487.x>
- Roux, A. M., Rast, J. E., & Shattuck, P. T. (2018). State-level variation in vocational rehabilitation service use and related outcomes among transition-age youth on the autism spectrum. *Journal of Autism and Developmental Disorders*, 1–10. <https://doi.org/10.1007/s10803-019-03972-8>
- Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(9), 931–939. <https://doi.org/10.1016/j.jaac.2013.05.019>
- Schall, C., & Wehman, P. (2009). Understanding the transition from school to adulthood for students with autism. In P. Wehman, M. D. Smith, & C. Schall (Eds.), *Autism and the transition to adulthood: Success beyond the classroom* (pp. 1–14). Paul H. Brookes Publishing Co.
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129(6), 1042–1049. <https://doi.org/10.1542/peds.2011-2864>
- Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37(9), 1735–1747. <https://doi.org/10.1007/s10803-006-0307-7>
- Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum

- disorder. *Archives of Pediatrics & Adolescent Medicine*, 165(2), 141–146. <https://doi.org/10.1001/archpediatrics.2010.279>
- Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities*, 50(1), 16–30. <https://doi.org/10.1352/1934-9556-50.1.16>
- Smith, L. E., Maenner, M. J., & Seltzer, M. M. (2012). Developmental trajectories in adolescents and adults with autism: The case of daily living skills. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(6), 622–631. <https://doi.org/10.1016/j.jaac.2012.03.001>
- Steinhausen, H.-C., Mohr-Jensen, C., & Lauritsen, M. B. (2016). A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatrica Scandinavica*, 133(6), 445–452. <https://doi.org/10.1111/acps.12559>
- Taylor, J. L., & Henninger, N. A. (2015). Frequency and correlates of service access among youth with autism transitioning to adulthood. *Journal of Autism and Developmental Disorders*, 45(1), 179–191. <https://doi.org/10.1007/s10803-014-2203-x>
- Turcotte, P., Mathew, M., Shea, L. L., Brusilovskiy, E., & Nonnemacher, S. L. (2016). Service needs across the lifespan for individuals with autism. *Journal of Autism and Developmental Disorders*, 46(7), 2480–2489. <https://doi.org/10.1007/s10803-016-2787-4>
- U.S. Department of Education. (2017). Welcome to RSA. Retrieved from <https://www2.ed.gov/about/offices/list/osers/rsa/index.html>
- U.S. Department of Health and Human Services. (2017). Young adult coverage. Retrieved from <https://www.hhs.gov/healthcare/about-the-aca/young-adult-coverage/index.html>
- Wang, L., Mandell, D. S., Lawer, L., Cidav, Z., & Leslie, D. L. (2013). Healthcare service use and costs for autism spectrum disorder: A comparison between Medicaid and private insurance. *Journal of Autism and Developmental Disorders*, 43(5), 1057–1064. <https://doi.org/10.1007/s10803-012-1649-y>
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., & Blumberg, S. J. (2015). Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. *National Health Statistics Reports*, 87(13), 1–20.