Special Issue on Occupational Therapy With Neurodivergent People

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The neurodiversity movement presents a significant opportunity for occupational therapy practitioners to meet the needs of neurodivergent people across the life course. The term neurodiverse includes autistic people and people with intellectual disabilities, attention deficit hyperactivity disorder, obsessive-compulsive disorder, and several other mental health conditions. Research shows that neurodivergent people continue to need occupational therapy beyond the end of high school, when most supports and services end for them. Despite research showing that the needs of neurodiverse populations continue throughout the life course, research also shows that services for this population seem to taper as they progress through the public school system. The studies in this issue add to the body of literature supporting the role of occupational therapy practitioners in meeting the needs of neurodiverse people for services and supports through all stages of life.

This editorial introducing the American Journal of Occupational Therapy Special Issue on Occupational Therapy With Neurodivergent People presents the perspectives of two researchers in occupational therapy. One of the authors is an occupational therapy professor, a lawyer, and a parent of two adult sons who are autistic.¹ The other author is an autistic adult who conducts health and social science research and advances policies, practices, and improved services to increase access and opportunities for autistic people.

Increasingly, clinicians and researchers are exploring new approaches to enhance services for people who learn, think, perceive, and process information in ways that can diverge sharply from society’s norms and expectations. These clinicians and researchers frequently aim to expand access, participation, inclusion, and opportunities for youth and adults who identify as neurodivergent. Service providers also increasingly promote and support efforts to foster neurodiversity at schools and in health care settings, workplaces, recreational facilities, and other places in the community (Chapman, 2021).

Evolving Perspectives on Neurodiversity

Autism, a neurological developmental disability, exemplifies what neurodiversity is and how it can shape divergent ways for the brain to think, learn, perceive, and process information from the senses. Its prevalence is about 2% throughout the U.S. population, according to recent research (Dietz et al., 2020). The service and support needs of autistic children, youth, and adults can vary widely, both from person to person and throughout the life course. However, all autistic people do experience atypical thinking and its associated strengths, talents, and challenges in four basic domains:

¹Standards for social science recommend that researchers call people by their preferred identification. Most youth and adults who identify as autistic prefer identity-first language (e.g., autistic people) over person-first language to describe their autism (see Kapp et al., 2013, and Kenny et al., 2016).

Other common forms of neurodivergence include attention deficit hyperactivity disorder, obsessive–compulsive disorder, intellectual disability (ID), and mental health conditions such as generalized anxiety and depression (Gillespie-Lynch et al., 2020). New paradigms for viewing these cognitive disabilities and driving greater empowerment can and should lead clinicians and other providers of services to challenge the status quo. That status quo often reflects an outdated deficit model, which emphasizes actions to “fix” disabilities and conform to normative expectations for school, work, health care, and life in the community (Chapman, 2021; Gillespie-Lynch et al., 2020; Robertson, 2010).

In her article “What Can Physicians Learn From the Neurodiversity Movement?” Christina Nicolaidis (2012), a physician and parent of an autistic young adult, wrote that most physicians “have been trained to think about autism using a deficit model” (para. 3). Nicolaidis noted that this clinical worldview “ultimately leads us to see autistic individuals as broken people who are ill and . . . need to be fixed” (para. 3). This troubling outlook parallels similar concerns about services in the occupational therapy world. Historically, many occupational therapy practitioners have focused on efforts to “fix” deficits of autistic children and pre-teenaged youth rather than on cultivating strengths and enhancing self-determination, inclusion, and participation for success throughout the life course.

A recent clinical study examined treatment patterns for autistic children in the United States by surveying more than 5,000 caregivers (92% identified as mothers; Monz et al., 2019). The vast majority of participants (96%) reported that their children (M age = 9.1) received nondrug therapy; most participants’ children (80%) received speech-language therapy or occupational therapy, and about half (52%) received both. The young age of the participants’ children reflects the norm rather than the exception in the occupational therapy world. The broader autism research literature suggests that few occupational therapy practitioners provide services for adults and teenaged youth. This situation persists despite studies that support the continuing service needs of autistic youth and adults and the benefits of long-term access to occupational therapy services throughout the life course (Ohl et al., 2020).

The moment has now arrived for occupational therapy, as a profession, to shift its service paradigm toward efforts to expand inclusive support for autistic people and other neurodivergent populations across the full life course—early childhood through teenage and adult life. Occupational therapy practitioners must also begin to view autism and other disabilities from a neurodiversity framework rather than through a human disorder model. The neurodiversity framework recognizes that variations among all humans in thinking, learning, perceiving, and processing information are natural because all brains and peripheral nervous systems differ. No “average” brain exists in human society.

Thus, neurodiversity reflects an analog to the forms of biological diversity seen throughout life on Earth, which enrich the planet and aid all species to prosper (Robertson, 2010). The neurodiversity framework also aligns with the long-term movement to adopt and foster a social and ecological model of disability. That model characterizes neurodivergence as a subset of the broader human neurodiversity. It calls for enacting actions to help empower neurodivergent children, youth, and adults, which can include work to

- Drive efforts to adjust environments, including physical and virtual spaces, to support neurodivergent people and integrate more affordances for diverse ways to think, learn, perceive, and process information;
- Enhance strengths, talents, and gifts to support success rather than striving only to fix perceived deficits and weaknesses;
Facilitate the use of adaptive strategies, tools, and technologies by children, youth, and adults to help mitigate their challenges and barriers; and

Emphasize and support the growth of self-determination and self-advocacy for children, youth, and adults throughout the whole life course (Kattari et al., 2017; Toro et al., 2020).

The neurodiversity movement stresses that all forms of thinking and learning, including neurodivergence, parallel the core aspects of diversity among humans, such as race, ethnicity, gender and gender identity, and sexual orientation (Robertson, 2010; Strand, 2017). This focus means that ongoing efforts to support diversity, equity, and inclusion should both consider and value neurodiversity. In lieu of the deficit model in the occupational therapy profession, practitioners should instead seek to embrace the goals of the neurodiversity movement.

Occupational therapy practitioners should also strive to adopt new and creative ways to provide their services, including in schools, but services should not end merely because a person graduates from middle school or high school. Practitioners should concentrate their efforts on ways to catalyze the strengths, talents, gifts, and long-term empowerment of children, youth, and adults. Likewise, occupational therapy researchers should conduct more studies to inform, shape, and expand their understanding of people who are neurodivergent across the life course.

As the studies in this issue show, occupational therapy has a key opportunity to play a significant role in long-range efforts to support and advance the life goals and occupations of neurodivergent youth and adults. Occupational therapy practitioners must now seize this opportunity to consider ambitious goals that can drive the integration of neurodivergent people into society by fostering their self-determination, inclusion, and full participation. Practitioners should also aim to refrain from making assumptions that rely on normative value judgments and presumptions about competence and capability to achieve life success and attain a high quality of life.

Raising Expectations
Advocate Micah Fialka-Feldman’s lived experience presents a real-life case study on how to adopt ambitious goals and presume competence of all people with intellectual and developmental disabilities (I/DD). Born in the 1980s “as a member of the ADA generation” (i.e., Americans With Disabilities Act of 1990 [Pub. L. 101-336]), Micah asserted in elementary school that he “wanted to go through the same door as all of the other students at a school”; he did not want to enter a door reserved for students with disabilities (Fialka-Feldman, 2021, para. 2). Micah tested at a lower range of cognitive ability on standard intelligence tests, and his scores on these tests drew unwarranted low expectations from clinicians about his potential for life success.

Despite these predictions, Micah’s parents advocated for his full inclusion at school so that he could access integrated educational experiences with his friends and peers as he desired—and attained—through high school (M. Fialka-Feldman, personal communication, January 16, 2021; Fialka-Feldman, 2021). After high school, Micah “sat in” on classes at Oakland University (OU) in Michigan through his school district’s transition program until the university opened its OPTIONS program, which enabled students with ID to take college courses (Fialka-Feldman, 2021).

Micah attended college classes with his same-aged peers, and he accessed a reasonable accommodation of oral exams—under the Americans With Disabilities Act and the Rehabilitation Act of 1973 (Pub. L. 93-112)—that enabled him to thrive in his studies. He also joined one of OU’s fraternities (M. Fialka-Feldman, personal communication, January 16, 2021; Fialka-Feldman, 2021). After growing tired of the need to take two buses to OU each way for his daily commute, Micah applied to live in a student dorm at OU. However, the university would not permit him to live in its student dorms because the school did not classify him as a “degree-seeking student.” Thus, Micah filed a successful lawsuit against the university, and the U.S. District Court for the Eastern District of Michigan affirmed his legal right to live in the dorms with other students at OU. Since completing his academic program at OU, Micah has also earned a...
certain in disability studies at Syracuse University (SU). He currently coteaches SU classes in inclusive education and disability studies in his role as a teaching assistant (Fialka-Feldman, 2021).

Significance of Continued Services and Supports Through The Life Course
Engaged leadership of efforts to embrace inclusive supports and services—including occupational therapy, of course—can help establish Micah’s story as the norm, rather than the exception, for students with I/DD and other forms of neurodivergence. Concerningly, services for neurodivergent students in K–12 frequently stop or diminish as youth progress through grade levels in school. A recent longitudinal study of more than 200 autistic students (59% with co-occurring ID) showed that each passing year of high school meant a decrease in services, particularly for autistic students without co-occurring ID (Laxman et al., 2019). Study participants in both groups experienced a “post high school service cliff” as the loss of services occurred beginning long before the end of high school.

The research literature indicates that neurodivergent people need continuous and streamlined access to services to help guard against falling off the post–high school service cliff. A study from 2019 that examined 10 years of Medicaid claims data showed that the need for services for neurodivergent adults will grow and expand as more autistic youth turn 18 and age into adult systems. Rubenstein and Bishop (2019) examined Wisconsin Medicaid claims data and enrollment patterns for autistic adults with and without ID who were mostly younger than age 30. They “found a consistent influx of new young autistic adults without intellectual disability into the Medicaid system” (Rubenstein & Bishop, 2019, p. 1541). These researchers also found fewer health care visits and lower reimbursement amounts compared with people with other types of developmental disabilities.

Rubenstein and Bishop (2019) called attention to the need to drive and expand access to health care for autistic adults throughout the life course and the need to develop key strategies to ensure inclusive health care services. The changing enrollment patterns identified in their study suggest implications for delivering accessible health care services for the significant population of autistic youth and young adults entering the adult service system (Rubenstein & Bishop, 2019). This situation raises concerns about the need to support autistic youth with varying service needs as they age into adult-centered service systems. On the basis of this trend, Rubenstein and Bishop emphasized the priority to direct more research and resources toward innovative ways to identify effective strategies to support the health and health care needs of autistic adults.

Key Role for Occupational Therapy
The latest version of the Occupational Therapy Practice Framework: Domain and Process (4th ed.; OTPF–4; American Occupational Therapy Association, 2020) identifies health management as a significant occupation within the occupational therapy domain. The OTPF–4 defines health management as an occupation that focuses on “developing, managing, and maintaining routines for health and wellness by engaging in self-care” (p. 77). This definition further specifies the goal of health management as “improving or maintaining health, including self-management, to allow for participation in other occupations” (p. 77). These “other occupations” include access to postsecondary education. Supported by occupational therapy, the occupation of health management can help autistic adults meet long-term needs for mental and physical health, quality of life, and well-being.

A recent study investigated the experiences of autistic college students and their unique needs by conducting an online survey of 3,074 college students at 14 public institutions. McLeod and colleagues (2019) explored the academic, social, and health experiences of autistic college students compared with those of students with other disabilities and their peers without disabilities. They found few differences between the group of autistic students and the group of other students with disabilities. Both groups reported “significantly worse outcomes than neurotypical students on academic performance, social relationships and bullying, and physical and mental health” (p. 2320). These students can greatly
benefit from access to occupational therapy supports and services to help develop solutions to challenges and cultivate strengths.

Recently, occupational therapy research has applied a similar lens to explore access to gainful employment for autistic youth and adults. For instance, Scott et al. (2019) conducted a scoping review of 36 studies that examined factors that can foster employment opportunities for autistic adults. The researchers found that environmental factors, such as workplace trainings and the fit of the work environment, can play a key role in shaping the employment success of autistic workers. They also stressed the need for improved practices and supports and “the critical need for interventions which target contextual factors if employment outcomes are to be improved” (p. 869).

Scott et al.’s (2019) findings provide support for efforts to advance innovative practices, approaches, and strategies for occupational therapy in this area. As the OTPF–4 notes, occupational therapy focuses on contextual factors and uses them, in the form of “environmental factors” and “personal factors,” to promote participation. Scott et al. provided a welcome mat for occupational therapy professionals to target contextual factors through further research and enhanced practices. Occupational therapy practitioners can work together with autistic adults to develop, provide, and facilitate many potential workplace supports, services, and approaches that can make a difference in the lives of autistic adults.

Summary

The studies in this special issue show the need for enhanced practices, supports, and services through occupational therapy to increase access and life opportunities for all neurodivergent youth and adults with diverse support needs. This issue evidences the notion that the benefits of occupational therapy supports and services for neurodivergent youth do not stop merely because elementary school or middle school ends. In fact, the role of occupational therapy practitioners in empowering neurodivergent youth and adults continues throughout the lifespan, as this issue illustrates.

Occupational therapy practitioners can help facilitate the development of core skills and compensatory strategies, adaptive approaches, and tools and technologies to promote independent living and full participation in communication and social engagement. They can also support ways to enhance executive functioning and manage life tasks needed to access community living, school, work, health care, and transportation—including driving—as the articles in this issue and the OTPF–4 illustrate.

This issue informs occupational therapy about emerging evidence for ways to support neurodivergent youth and adults, such as strengthening occupational therapy services for adults with ID and fostering the driving skills of autistic young adults. Findings from studies in this issue also provide the basis for occupational therapy, as a profession, to sharpen its focus on driving self-determination, empowerment, and inclusion rather than focusing singularly on addressing impairments. Above all, this issue recognizes and emphasizes that the occupational needs of neurodivergent youth and adults extend into all stages of adolescence and then continue throughout the full life course of adulthood.

Challenges and barriers do not cease simply because an adolescent moves on from elementary school to middle school, completes middle school, and graduates from high school to pursue adult life. Crucially, occupational therapy can and must kindle efforts to enhance and expand supports and services for all aspects of adult life to meet the occupational therapy service needs of neurodivergent youth and adults throughout the lifespan.

References


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