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Moving Toward Neurodiversity-Affirming Occupational Therapy for Autistic People: Key Questions and Next Steps

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Abstract

With the rise in popularity of neurodiversity-affirming practices in occupational therapy, specifically with the autistic population, there is a need to establish a more robust theoretical underpinning for this work. A neurodiversity framework is different from the prevailing medical model that informs current practice in much of Westernized health care, and interested occupational therapists are now asking questions about how to apply it to their work. Occupational science is well-suited to generate research outside the medical model that can serve as a basic science foundation to inform practice. The purpose of this Opinions in the Profession paper is to suggest three needed areas of research in occupational science, to address occupational therapists' unanswered questions regarding (a) autistics' preferred methods of participation, (b) experiences of occupational injustice, and (c) the impact of autistic neurology on occupational engagement. These opinions are based on our experiences as both autistic and non-autistic occupational scientists and occupational therapists working with the autistic population. While these are not comprehensive, they serve as a starting point for identifying opportunities to move the profession toward neurodiversity-affirming standards of care. As we move forward, we stress the need to continue prioritizing research based on autistic input and under autistic leadership.

Comments

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Artificial Intelligence (ChatGPT and Bard) were used to periodically check for grammatical errors or suggest revised wording. All of the ideas contained within the manuscript were generated by the authors.

Keywords

neurodiversity-affirming, autism, capabilities, justice, embodiment, emplacement

Cover Page Footnote

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With the publication of a special issue on neurodiversity in the *American Journal of Occupational Therapy* (Kornblau & Robertson, 2021) and a recent publication in this journal aiming to provide more practical guidance on neurodiversity-affirming therapy with autistic people (Dallman et al., 2022), the momentum for neurodiversity-affirming therapeutic approaches is growing in occupational therapy. This momentum is underscored in the 2022 Eleanor Clark Slagle lecture, where Kristie Patten described the importance of a “paradigm shift” in occupational therapy toward a strengths-based model of care for autistic persons (Patten, 2023). Patten poignantly asks, “Do our current models of practice support flourishing?” (p. 1) as she encourages occupational therapists to be curious enough to explore what best practices for the care of autistic persons might look like tomorrow. The authors of this paper have carried this curiosity forward into our occupational therapy practices, leading us to ask how we, too, can adopt a strengths-based model of care that more aptly supports the well-being of autistic persons.

We believe that the principles of the neurodiversity-affirming movement align with the core professional values of the occupational therapy profession and may serve as a useful guide for supporting the well-being of autistic individuals. These core values have spawned decades-long work for leaders in the field (e.g., Bagatell, 2012; Case-Smith & Arbesman, 2008; Peloquin, 1989; Schaaf et al., 2011) who have advanced occupational therapy practice for autistic individuals. Standing on the shoulders of these giants, we recognize that some occupational therapists may not be so easily convinced that occupational therapy is experiencing a paradigm shift to neurodiversity-affirming practices. However, as educators and clinicians, we have also seen how low-value and non-affirming approaches continue to infiltrate occupational therapy practice with autistic clients. We do not mean to imply that occupational therapists are intentionally harming the autistic community. Still, well-meaning occupational therapists have inadvertently implemented practices that are non-affirming for decades despite drawing from a person-centered model of care. Occupational therapists were directly involved in the eugenics movement, making decisions about the value of some lives over others (Turcotte & Holmes, 2024). Occupational therapists have targeted “teaching more appropriate affective and behavioral responses” (Richards, 1963, p. 349), a non-affirming goal area. More recently, occupational therapists have aimed to reduce restricted and repetitive patterns of behavior (Patriquin et al., 2020), a treatment goal that was recently cautioned in the most recent American Occupational Therapy Association’s *Choosing Wisely* guidelines (AOTA, n.d.) and by autistic self-advocates (Kapp et al., 2019). In presenting this limited review, we do not intend to anachronistically critique the previous scholars of occupational therapy whose work has laid a foundation for our field. Moreover, we do not aim to alienate the occupational therapists who have been practicing with autistic clients before the neurodiversity-affirming movement. Rather, we argue that our field’s return to our core values is a paradigm shift away from low-value practices and that the person-centered model of care our profession espouses alone does not ensure one operates from an affirming model of care.

Our momentum for writing this paper came as a result of directly witnessing the “curiosity” described by Patten (2023) and an overwhelming hunger of occupational therapists to “do” occupational therapy differently than what they were taught in their occupational therapy education and workplaces. We daily encounter questions about whether certain intervention approaches are “okay,” whether the structure of their sessions is acceptable or harmful, or how to work toward skills they feel are valuable without overriding the needs and feelings of their clients. At their core, we feel these uncertainties repeatedly speak to a few similar themes: Am I truly supporting participation as it is self-defined? Am I inadvertently perpetuating occupational injustices towards autistic individuals? How can I shift my occupational therapy practice to better support their well-being?

These curious occupational therapists embody the humility needed to advance the profession's commitment to both evidence-based and ethically-based practices. In this paper, we will first present a brief overview of the principles behind neurodiversity-affirming and high-value care. We will then present our opinion that there are many unanswered, key questions about occupation for autistic individuals and that answering these questions is critical to developing the high-value care Patten (2023) alludes to for this population. Crucially, answering these questions will enable our profession to stay true to our core values and seek to deliver the most effective care to support the flourishing of our autistic clients.

Neurodiversity and Autism

The term neurodiversity represents the concept that there is not a singular standard for neurological functioning but that a variety of neurologies exist in society, all of which are valid and reflect diverse ways of experiencing and being in the world (Blume, 1998; den Houting, 2019). The neurodiversity movement generally espouses a social model of disability and rejects medical models that aim to “fix” or “change” individuals to operate according to an arbitrary definition of normality, instead proclaiming a sense of self and personhood rooted in one's unique neurology. Autistic self-advocates have suggested medical practitioners move away from a deficit-oriented model and toward a lens that considers autistic styles of functioning as a normal part of human neurodiversity (Kapp et al., 2013; Kornblau & Robertson, 2021; Robertson, 2010; Silberman, 2015). In this view, occupational therapy for neurodivergent people begins with the premise of respect for their natural modes of understanding, acting on, and experiencing the world. Occupational therapists operating from this framework reject a medical model of autism spectrum disorder (ASD) which defines ASD as a deficit in social communication and the presence of restricted interests and repetitive behaviors (including deficits in sensory modulation; American Psychiatric Association, 2013); instead, a neurodiversity-affirming occupational therapist would view the behaviors of autistic people as valid and reasonable differences in thinking, communicating, socializing, and moving rooted in their neurological wiring (Autistic Self Advocacy Network, 2024). With this foundation, it is time for the field to translate this perspective into a compatible approach to therapy that informs the clinical process.

High- and Low-Value Occupational Therapy Practices with Autistic People

The *Occupational Therapy Practice Framework* (AOTA, 2020) mandates that occupational therapists “must” create a supportive and inclusive environment in their therapy (p. 20). As occupational therapists seek to implement high-value occupational therapy, they must critically question their therapeutic practices (Bennett & Bennett, 2000) to evaluate if they are sufficiently creating an environment in their therapy that supports the flourishing of autistic individuals. Ultimately, even though some therapeutic practices may be heavily researched or receive the most funding, they may be of low value to autistic persons (Augustsson et al., 2021) and fail to create this imperative, safe therapeutic environment. Low-value interventions are ineffective, costly, or do not align with the preferences of the patient or client population (Verkerk et al., 2018) and, by definition, should be replaced with high-value care when one such intervention exists. For example, there is long-standing evidence that behavioral interventions effectively reduce repetitive patterns of behavior (see Boyd et al., 2012 for a review). However, autistic self-advocates have argued that behavioral interventions (formally provided through Applied Behavioral Analysis, although often incorporated into occupational therapy) are abusive (Shkedy et al., 2021) and that therapy that aims to reduce restricted and repetitive patterns in behavior that negatively impacts the well-being of autistic individuals (Kapp et al., 2019). We recognize that occupational therapy and applied

behavioral analysis are distinct fields. However, constant reflexivity in our field is an important and necessary step to avoid the potential trap of low-value and status-quo therapeutic care.

This tension between effective/low-value care and neurodiversity-affirming/potentially high-value therapy has led some researchers to develop manuals and guides for neurodiversity-affirming care. For example, the Neurodivergent Nexus (Carlson-giving, n.d.) indicates that some occupational therapy approaches have a high grade of incorporating affirming intervention characteristics (e.g., approaches guided by Dunn's Ecological Model of Sensory Processing, Learn Play Thrive, and the SCERTS model) and others have a low grade of affirming intervention characteristics (e.g., astronaut program, social stories, and Ayres Sensory Integration). Similarly, in a previous paper, we presented general guidelines for occupational therapists aiming to implement affirming interventions (Dallman et al., 2022). However, these resources provide only early guidance for occupational therapists to implement neurodiversity-affirming practices, and they require additional empirical and theoretical support to justify their claims. In our opinion, there are three key questions at this time that need to be addressed to generate the foundational knowledge needed to guide clinical practice.

Key Question 1: What are the Preferred Methods of Participation for Autistic Individuals?

Currently, societal expectations and some clinical therapies promote “proper” ways of functioning that lead many autistic individuals to mask their autistic traits to operate in accordance with neurotypical norms (Kapp et al., 2019). Examples of masking include making eye contact even if it feels uncomfortable, refraining from discussing special interests, resisting the impulse for self-stimulatory behaviors, and mimicking non-verbal communication and body language (Miller et al., 2021). Some therapists impose their assumptions of the “correct” ways of sensing, moving, or communicating on autistic clients without stopping to reflect on whether those behaviors are actually in alignment with their neurology and whether that person can or wants to do them differently. This may lead occupational therapists to overlook the capabilities of autistic individuals in favor of ideas about what participation should “look like” in various occupations. For example, autistics’ capability to communicate non-verbally may be devalued in favor of a therapist’s interest in developing verbal communication. While masking can be a useful tool to decrease the contextual consequences of being neurodivergent (and may be a meaningful target of therapy if expressly desired by the client), indirectly promoting masking through neurotypical-oriented goals can lead to negative self-perception, depression, shame, exhaustion, and burnout (Pearson & Rose, 2021), all of which are antithetical to the core values of occupational therapy (Peloquin, 2007).

Occupational science is well-positioned to contribute detailed descriptions of occupations for autistic people that can expand awareness of autistic capabilities. Elucidating the unique ways that autistic people participate in various occupations, the adaptations they may organically make to those performances, and the ways that participation may or may not align with neurotypical styles of occupation is a necessary starting point for occupational therapists to appreciate the potential needs and preferences of their clients. It may also be important for helping those therapists identify which goals and treatment approaches may be in alignment with or detrimental to autistic ways of being. Scholarship rooted in occupational science may help identify current aspects of therapy that normalize masking, decrease the occupational possibilities of autistic individuals, and perpetuate a system of oppression. Ultimately, research into the occupations and meaning behind actions performed by autistic people will bolster opportunities for validating autistic styles of engagement and supporting these styles in therapeutic practice.

Key Question 2: What Occupational Injustices Continue to Impact the Lives of Autistic Individuals?

As occupational therapists seek to understand and enable the capabilities of autistic individuals, they will inevitably identify occupational injustices that hinder autistics' meaningful participation and how individuals or groups are either supported or restricted by external conditions (i.e., political, social, and cultural contexts). The fact that many autistics experience occupational injustice is not a new concept, as autistic self-advocates, such as Robertson (2010), have identified injustices in the treatment of autistic individuals for many years. However, the efforts of these self-advocates have largely been ignored, which is evidenced by, in part, the fact that shock therapy is still a recommended treatment in the care of autistic children in the United States (Wachtel et al., 2018). As an agent of change against the dominant forces in society that perpetuate the marginalization of certain groups (Gerlach, 2015), occupational scientists and therapists can leverage their position to translate many of the injustices raised by autistics into language and actions that others in society can understand. However, the field needs a more in-depth understanding of the injustices faced by autistic individuals; in turn, this may also help catalyze a shift by occupational therapists and other medical professionals toward treatments that prioritize caregiver education on the meaning behind certain behaviors as opposed to targeting the reduction of particular behaviors themselves. In addition, occupational therapists can help elucidate the importance of medical practitioners' positioning in health care systems and treatment decision-making, including how systems create situations that disempower and limit clients' participation (Bailliard et al., 2020).

One example of this is autistic styles of participation in Westernized school settings. Occupational science research may refute current practices that attempt to 'retrofit' each autistic child into a neurotypical classroom by concluding it is an impossible standard because of their neurology and an unfair burden for the child to bear. Occupational scientists may then provide the basic science necessary to inform the design of an educational system compatible with the child's needs in the school environment (Leifler et al., 2021). Another example of a neurodiversity-affirming research approach may entail supporting a shift away from the current view that autistic people lack social skills. Occupational science may help identify the needs for social participation at a systems level, ensuring all parties involved understand both autistic and neurotypical social communication needs and preferences. "Doing with" may mean being near or next to as opposed to sharing directly, or eye contact may not be made as a way to prevent sensory overload and allow individuals to continue participating (e.g., Bagatell, 2012) as opposed to the common view that absent eye contact is a sign that individuals are not participating or wanting to engage socially.

Key Question 3: How Does the Lived Experience of Being Autistic and Having an Autistic Neurology Impact one's Preferred Methods of Occupational Engagement?

Historically, repetitive or stereotyped behaviors have been the target for intervention as they were believed to prevent autistic people from the behaviors that were indicative of meaningful participation. However, from an embodied perspective, motor movements are meaningful expressions for the people performing them to actively direct and interpret their sensory experiences through bodily expression in the world (Bailliard et al., 2018). Self-stimulating behaviors, referred to as "stimming," have been described by the autistic population as serving a vast range of functions, such as self-regulation, filtering sensory input, and expressing enjoyment (Kapp et al., 2019). Theories of embodiment in occupational science may be used to further understand how self-stimulation supports the ability of autistic people to engage in occupation and generate evidence to further support this shift in clinical practice.

Just as self-stimulatory behaviors should be respected as embodied expressions of autistic neurology, further research into autistic play styles may also help occupational therapists understand their

value in self-expression and enjoyment. It is currently common for occupational therapists to target goals that promote neurotypical styles of play, such as stacking blocks instead of placing them in a line. However, through the lens of occupational science, health and well-being come from having the freedom to meaningfully engage in play activities as one sees fit (Moore & Lynch, 2018). Spitzer (2003) and Fahy and colleagues (2021) provide examples for occupational scientists and therapists about how to describe autistic styles of play (e.g., sensorimotor, freely structured, repetitive, and ritualistic) and appreciate their value in the enjoyment they create and their contribution to development for autistic children. These and future studies may help occupational scientists and therapists understand how to interpret autistic play styles and support these expressions by their pediatric clients.

Furthermore, the current prevailing medical model hyperfocuses on changing the individual, while many autistic self-advocates suggest that it is the environment that detracts from well-being and creates barriers to participation. The transactional perspective of occupation (Dickie et al., 2006) and emplacement theory (Bailliard et al., 2023) provide theoretical support for researchers and clinicians to take a more holistic and less individual-centered intervention approach. Humphry and Wakeford (2008) provide one example of using the transactional perspective in supporting autistic children in a school setting, in which their intervention focused on embedding various supports in the overall school environment that improved the quality of the children's engagement in activities. Expanding possibilities to broader environmental adaptations that support natural forms of participation for autistic people has great potential for the future of occupational therapy but will require a more extensive body of research on how to translate these philosophical perspectives into clinical intervention approaches beyond directly targeting the child.

Conclusion

With the increasing popularity of the neurodiversity movement in society, occupational therapists are looking to embrace neurodiversity-affirming practices when working with autistic clients (Kornblau & Robertson, 2021). Research in occupational science, which aims to understand occupation beyond the individual and outside the medical model, lends itself to a neurodiversity-affirming lens and can serve as an important foundation for practice. The three outstanding questions presented in this article are suggested starting points based on the priorities outlined by the autistic community and our experiences as autistic and non-autistic occupational scientists and therapists. However, these are certainly neither static nor comprehensive. We hope that answering these questions will help occupational therapists to develop high-value interventions that address some of the identified areas of importance for future research by the autistic community and occupational therapists (e.g., employment issues and intersectional disparities) (Damiano et al., 2014). As these questions are answered and new ones emerge, occupational therapists should continue to look to autistic people to identify new priorities for research and intervention development. Moreover, clinicians must continue to seek to understand autistic styles of functioning as a valid example of neurodiversity and, with respect to these styles, promote participation and inclusion as it is self-defined (Pellicano et al., 2014).

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