

Interventions That Foster Self-Determination in Autistic Individuals (2013–2021)

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Systematic Review Briefs provide a summary of the findings from systematic reviews developed in conjunction with the American Occupational Therapy Association's (AOTA's) Evidence-Based Practice Program. Each Systematic Review Brief summarizes the evidence on a theme related to a systematic review topic. This Systematic Review Brief presents findings from a systematic review that examined interventions to support and improve self-determination for autistic¹ individuals.

Patten, K., Murthi, K., Chen, Y.-L., Onwumere, D., & Shore, S. (2023). Systematic Review Brief—Interventions that foster self-determination in autistic individuals (2013–2021). *American Journal of Occupational Therapy*, 77, 7710393120. <https://doi.org/10.5014/ajot.2023.77S10012>

Full Systematic Review Question

This systematic review addressed the question “What interventions in the scope of occupational therapy support or improve self-determination for autistic individuals?”

Current Theme Reported

The main theme of the studies included in this systematic review brief is interventions to develop and enhance self-determination for persons on the autism spectrum.

Clinical Scenario

The development of self-determination and advocacy skills are critical for students and adults with and without disabilities. Self-determination is the process by which individuals demonstrate control over their own lives, make choices, and demonstrate mastery and competence (Deci & Ryan, 1985; Patten Koenig & Shore, 2018). For autistic adolescents, there is a need to specifically teach self-determination and advocacy skills as they transition to adulthood, as their access to accommodations and parental advocacy is restricted or changes after high school (Hotez et al., 2018). These skills allow autistic individuals to achieve competency,

become aware of their strengths, and master their interest areas, augmenting their self-efficacy and self-determination (Gordon et al., 2015; Martin et al., 2020). As more autistic students are in inclusive classrooms, they often are required to advocate for their sensory, academic, and social needs as they study alongside their nonautistic peers in these inclusive spaces (Onwumere et al., 2021). There is a need for creating spaces and evidence-informed programs where self-determination and advocacy skills can flourish, enhancing social competence and executive functioning, and potentially reducing mental health challenges. The focus on self-determination is often secondary to sensory and motor needs but is critical to successful participation in meaningful occupations. This systematic review brief presents the strength of evidence of interventions that focus on improving self-determination with subthemes on developing self-advocacy skills and autistic individuals gaining mastery and competence.

Summary of Key Findings

Of the 30 studies included in a larger review with additional mental health outcomes, five studies (16%) met the inclusion criteria and had self-determination as their primary outcome. The five articles were further divided into two subthemes: self-advocacy and competence and mastery. The risk of bias ranged from low to high in the five studies. We used the Oxford Centre for Evidence-Based Medicine (2009) levels of evidence for this review. The strength-of-evidence

¹This paper will use the identity-first language, “autistic individuals.” This nonableist language describes their strengths and abilities and is a conscious decision. This language is favored by autistic communities and self-advocates and has been adopted by healthcare professionals and researchers (Bottema-Beutel et al., 2020; Kenny et al., 2016).

Table 1. Evidence Table for Interventions to Support and Improve Self-Determination Skills in Autistic Individuals

Author Year Level of Evidence Risk of Bias (RoB) Country Setting	Intervention	Statistically Significant Improvement Resulting From Interventions
<p><i>Subtheme: Self-Advocacy</i> Three Level 3b studies used self-advocacy interventions to develop and enhance self-advocacy skills in areas of transitions (i.e., schools to universities) where autistic individuals are expected to advocate for their accommodations. Moderate strength of evidence supports occupational therapy practitioners' use of these interventions.</p>		
<p>Gillespie-Lynch et al. (2017) Level 3b—single group pre/post</p> <p><i>RoB</i> Moderate</p> <p><i>Country</i> United States</p> <p><i>Setting</i> College</p>	<p><i>Population</i> N = 28, autistic college students provided pretest and posttest data (18 men and 10 women)</p> <p><i>Intervention</i> Development of a mentorship program through one-one and group collaborations with autistic students. Students also presented opportunities to take on leadership roles within the program. First semester focused on social skills, second semester on self-advocacy.</p> <p><i>Delivery method</i> Group and individual sessions</p> <p><i>Dose</i> 1 hr/wk, 9–10 wks group meeting and/or 1 hr/wk, 14 wk, one-on-one meetings</p>	<p><i>Between Groups</i> N/A</p> <p><i>Within Group</i> Decreased anxiety Increased social skills and communication Developing friendships within groups organically Increased self-efficacy in academics Organic inclusion of autistic students in the program</p>
<p>Hotez et al. (2018) Level 3b—single group, pre/post</p> <p><i>RoB</i> Moderate</p> <p><i>Country</i> United States</p> <p><i>Setting</i> College</p>	<p><i>Population</i> First year: N = 13 autistic college student participants age from 17 to 28 yr old (M = 19.07; SD = 2.76). The majority of the students were male (n = 12; 87.5%) and White (n = 10; 71.4%). Second-year: N = 10 autistic college student participants in the second transition program. Mentees ranged from 17 to 22 yr old (M = 18.8, SD = 1.58). Again, majority were male students (n = 8; 80%) and White (n = 5; 50%).</p> <p><i>Intervention</i> Students were invited to participate in individualized or group mentorship sessions with a structured curriculum that included student feedback and was appropriately modified each year. Opportunities to practice skills were provided through role-plays, social games, and the creation of leadership roles in the program. Students could transition from being mentees to mentors in the program. Furthermore, students who became mentors were provided additional support from experienced mentors who supported them during their meetings with mentees and gave individualized feedback.</p> <p><i>Delivery Method</i> Group and individual</p> <p><i>Dose</i> First summer transition 1 wk, 5 days, for 5 hr each day. Second summer transition was 1 wk, 5 days for 5 hr a day.</p>	<p><i>Between Groups</i> N/A</p> <p><i>Within Group</i> Improved self-advocacy-related knowledge and skills. Development of a program that uses autistic expertise integrally. Increased empathy and social skills</p>
<p>Onwumere et al. (2021)</p>	<p><i>Population</i></p>	<p><i>Between Groups</i> NA</p>

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Table 1. Evidence Table for Interventions to Support and Improve Self-Determination Skills in Autistic Individuals (Cont.)

Author Year Level of Evidence Risk of Bias (RoB) Country Setting	Intervention	Statistically Significant Improvement Resulting From Interventions
Level 3b <i>RoB</i> Moderate <i>Country</i> United States <i>Setting</i> Middle school	<p><i>N</i> = 13 autistic middle school students (5th grade, 10–11 yr of age)</p> <p><i>Intervention</i> Occupational therapy group interventions focusing on instrumental activities of daily living (IADLs), social participation and interest, self-advocacy, community integration, executive functions, self-regulation, and strategies for learning</p> <p><i>Delivery Method</i> Group interventions</p> <p><i>Dose</i> Groups met for 40–45 min, one time per week during the academic school year</p>	<p><i>Within Group</i> Significant student improvement in reported self-determination 70% goal attainment in executive function tasks</p>
<p><i>Subtheme: Competence and Mastery</i> Two Level 2b studies used interest-based interventions to develop and enhance mastery and competence in areas of interests in an organic manner. Moderate strength of evidence supports occupational therapy practitioners' use of these interventions.</p>		
<p>Gordon et al. (2015) Level 2b—RCT <i>RoB</i> Low <i>Country</i> United Kingdom <i>Setting</i> Not Reported</p>	<p><i>Population</i> <i>N</i> = 48, High functioning autistic youth (40 M, 8 F), Ages (9–14 yr) Intervention group = 18/6; Control group = 22/2</p> <p><i>Intervention</i> Child and parent were invited to attend the PEGASUS program. Psychosocial education was provided on two levels: Level 1—awareness about autism diagnosis and Level 2—providing strategies to help young individuals to use knowledge of autism to gain an insight into their strengths and abilities and find ways to use their strengths. Parents' sessions included short presentations, discussions, and games. Children's sessions included fun activities, visual games, and "home tasks."</p> <p><i>Delivery Method</i> Parent and children separate, parallel group sessions</p> <p><i>Dose</i> Sessions are 1x/wk and last for 1.5 hr for 6 wk</p>	<p><i>Between Groups</i> Level 1: showed a significant effect of group on ASD knowledge postintervention, $b = 0.29, p < .001, 95\% \text{ CIs } [0.13, 0.44]$. A higher number of both ASD strengths ($b = 0.41, p = .002, 95\% \text{ CIs } [0.15, 0.67]$) and ASD difficulties ($b = 0.34, p = .001, 95\% \text{ CIs } [0.08, 0.60]$) listed by PEGASUS participants at postintervention assessment</p> <p><i>Within Groups</i> Significant improvement in both awareness of ASD and increase in understanding among participants about the number of ASD-related strengths and challenges.</p>
<p>Martin et al. (2020) Level 2b—cohort study <i>RoB</i> High <i>Country</i> United States <i>Setting</i> Middle-school</p>	<p><i>Population</i> <i>N</i> = 109, Full group (including nonautistic students), $n = 30$ Autistic middle school students (Grades 6–8). (15–20 students per club, ages 10–14)</p> <p><i>Intervention</i> Informal afterschool maker clubs that teach engineering activities in an inclusive setting. A specialized 12-activity curriculum was developed.</p> <p><i>Delivery method</i> Inclusive group program with autistic and nonautistic students. Two teachers facilitated each club session.</p>	<p><i>Between Groups</i> When the maker club group was compared with the control group, it demonstrated an increase in self-efficacy, interest in engineering, vicarious experiences, science appreciation and understanding the engineering design process. Benefits were seen more in neurotypical students possibly because autistic students potentially entered the program with higher knowledge of engineering and increased interest in STEM (Science, Technology, Engineering and Mathematics). The qualitative results demonstrated that autistic students could engage in their</p>

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Table 1. Evidence Table for Interventions to Support and Improve Self-Determination Skills in Autistic Individuals (Cont.)


Author Year Level of Evidence Risk of Bias (RoB) Country Setting	Intervention	Statistically Significant Improvement Resulting From Interventions
	<p><i>Dose</i> Sessions are weekly at either lunchtime or after school. 30–50 min/club for 12–14 wk.</p>	<p>interests, complete projects and effectively communicate with their peers. Teachers noted that they saw their students as more capable.</p> <p><i>Within Groups</i> 50%–100% increase in social skills demonstrated by spontaneous, reciprocal conversations from autistic students.</p>

Note. ASD = autism spectrum disorder; CI = confidence interval; IADLs = instrumental activities of daily living; PEGASUS = psychoeducation group for autism spectrum understanding and support; RCT = randomized controlled trial; RoB = risk of bias.

designations are based on the guidelines of the U.S. Preventive Services Task Force (2018). Subthemes are synthesized and reported in Table 1.

Bottom Line for Occupational Therapy Practice

When working with autistic adolescents, occupational therapy practitioners should consider the importance of the acquisition of self-determination and self-advocacy not only during transition planning but in other contexts (i.e., interest-based clubs, university programs). Interest-based activities can be introduced for younger children as well, with elementary (Onwumere et al., 2021) and middle-school students (Martin et al., 2020). Studies highlighted the need to develop self-advocacy and self-determination skills through developing curricula that focus on positive mental health skills and self-determination. Additional studies showed moderate evidence highlighting the efficacy of developing interventions that enhance and use the strengths of autistic individuals to achieve mastery in their interest areas, thus building the self-advocacy of their participants. Studies are also beginning to include authentic autistic involvement where collaboration and partnership are centered on creating a self-advocacy curriculum through authentic, collaborative partnerships with autistic students (Gillespie-Lynch et al., 2017).

There is a need to move away from deficit-focused interventions and build interventions that organically develop and enhance autistic individuals' self-advocacy by building opportunities within interventions where they can practice these skills and gain competence and mastery. Environments that are safe spaces for autistic individuals to develop self-advocacy will prepare them to advocate for themselves in real-world scenarios. 

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