

4-1-2019

Occupational Therapy Practice with Adults with Intellectual Disability: What More Can We Do?

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Recommended Citation

Johnson, K. R., Blaskowitz, M., & Mahoney, W. J. (2019). Occupational Therapy Practice with Adults with Intellectual Disability: What More Can We Do?. *The Open Journal of Occupational Therapy*, 7(2). <https://doi.org/10.15453/2168-6408.1573>

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Comments

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

Keywords

occupational therapy, intellectual disability, adults, participation, occupation

Credentials Display

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DOI: 10.15453/2168-6408.1573

With recent celebrations to commemorate the 25th anniversary of the Americans with Disabilities Act (ADA) and the centennial of the American Occupational Therapy Association (AOTA), it is timely to take stock of the profession's involvement in the intellectual disability (ID) community. There are observable deficiencies in occupational therapy practice with adults with ID; however, occupational therapists are well positioned to assist members of the ID community by enhancing, enabling, and advocating for participation in daily life (Bathje, Lannoye, Mercier, & Panter, 2017). Individuals with ID are a disadvantaged group who have not come to their circumstances by chance. They have endured a history of isolation in state-operated facilities with limited supports and services and have confronted policies and professional practices that have, at times, reproduced their marginalization by perpetuating custodial care (Johnson & Bagatell, 2017). Although access to community-based services has increased since the passing of the ADA and the Olmstead Decision (Dean, Dunn, & Tomchek, 2015), barriers that restrict the spectrum of opportunities for occupational participation continue to put adults with ID at significant risk for occupational alienation and a decreased sense of occupational competence (Mahoney, Roberts, Bryze, & Kent-Parker, 2016). This has resulted in disparities in health care, community housing, transportation, secondary education, gainful employment, and social inclusion, to name a few.

In this *Opinions in the Profession* paper, we explore how occupational therapists can better address the occupational needs of adults with ID. We describe the facilitators and barriers to occupational therapists' work with this population, and we provide recommendations that align with broader efforts of national, state, and community-based organizations aimed at improving the lives of adults with ID.

Occupational Therapy with Adults with Intellectual Disability

ID is a developmental disability that is diagnosed before the age of 18 and expected to last throughout life. It involves significant limitations in intellectual functioning and adaptive behavior (American Association on Intellectual and Developmental Disabilities, 2017). The prevalence of ID is usually estimated at 1%; however, because the definition of ID has shifted, the actual prevalence may be less than 1% (McKenzie, Milton, Smith, & Ouellette-Kuntz, 2016). The recent diagnostic emphasis on adaptive behavior, defined as the coordination of conceptual, social, and practical skills learned and performed in daily life, provides a clear link between ID and occupational therapy. Individuals with ID require varying levels of support in occupations throughout life, and when they experience environmental changes, they may benefit from occupational therapy services to address their needs.

Occupational therapists provide services to adults with ID in practice settings such as state health facilities (e.g., intermediate care facilities for individuals with ID), residential programs, community transition programs, day treatment or vocational programs, and college readiness programs. The number of occupational therapists who practice with adults with ID is unknown. Although almost 20% of occupational therapists work in schools where they likely provide services to children and adolescents with ID, less than 5% of occupational therapists work in community or mental health settings where adults with ID may receive services (AOTA, 2015). As adults with ID age, they receive occupational therapy services for comorbid conditions in settings where they are not the typical clients, such as in primary care, mental health, rehabilitation, or skilled nursing facilities (Mahoney, Ceballos, & Amir, in press). Therefore, occupational therapists have the opportunity to address the needs of individuals with ID across the life span through direct services, consultations, or advocacy.

Occupational therapists can address the occupational concerns of adults with ID through basic activities and instrumental activities of daily living (IADLs) training, community reentry programs, vocational training and employment coaching, and health management skills intervention (Bathje et al., 2017; Friedman & VanPuymbrouck, 2018). However, there remain ongoing funding barriers to occupational therapy intervention for community-based ID services (Friedman & VanPuymbrouck, 2018). Traditional health care reimbursement mechanisms reward interventions that “fix” impairment, leading the occupational therapy profession to limit its involvement with particular disability communities, such as adults with ID (Brown, 2014). The inclusion of habilitation services as part of the essential health benefits under the Patient Protection and Affordable Care Act (PPACA), consistent with the scope, duration, and amount as with rehabilitative services (Brown, 2014), affords therapists potential funding to provide services beyond traditional settings to include innovative community-based interventions.

Recommendations for Occupational Therapy Practice and Advocacy

The following sections provide recommendations for occupational therapy interventions, including advocacy, with adults with ID. Although this list is not exhaustive, it focuses on critical and evolving areas of practice, including educational and vocational training, support and coaching for direct care staff in congregate settings, building social capital, and client- and policy-level advocacy.

Education and Vocational Training

Addressing the needs of adults with ID begins when they are children or adolescents and accessing services to prepare for adult life (Berg, Jirikowic, Haerling, & MacDonald, 2017). Occupational therapists can play a critical role, beginning with early transition planning, by focusing on IADLs, social skills training, vocational skills training, independent living skills, and community mobility and integration. Occupational therapists may educate families in ways to engage their child with ID in daily home chores and family activities through consistent, structured tasks in which the child or adolescent can participate (AOTA, 2013). Transition services, including occupational therapy, should work with youth to determine the strengths, needs, interests, and specific preferences of the adolescent with consultation from the family. This is an ongoing process that often starts with conversations with adolescents with ID and their families about their concerns and future goals, as few individuals with ID are asked what they want in life, compared to individuals without ID (Dean et al., 2015). Occupational therapists may also consult with group homes and developmental centers by designing and implementing special training courses focusing on cooking, homemaking, personal care, leisure activities, and other areas of interest for adults with ID (AOTA, 2013).

The unemployment rate for adults with ID is more than twice as high as those without disabilities, with only 44% of adults with ID aged 21 to 64 years participating in the labor force (Siperstein, Parker, & Drascher, 2013). Having a job in high school is a key predictor of work for adults with ID, but only 8% to 10% of young adults with ID are currently employed (Erickson, Lee, & von Schrader, 2017). Occupational therapists can work to create customized employment opportunities that meet the needs of both employers and youth and adults with ID, as well as provide community education and training to business and community members about sensory sensitivities and communication strategies for individuals with diverse learning needs (Riesen, Morgan, & Griffin, 2015). In addition, occupational therapists can educate business owners, public policy legislators, and community developers about universal design principles, customized job development and supports, inclusion, and access to services (Riesen et al., 2015).

Staff Training and Support

Community inclusion and engagement have been well-documented as indicators of quality of life, and adults with ID, especially those with more significant impairments, are at high risk for participation restrictions and limited occupational engagement (Mahoney et al., 2016; Qian, Tichá, Larson, Stancliffe, & Wuorio, 2015). Research indicates that adults with ID in group homes and day programs spend large amounts of time unoccupied (Qian et al., 2015). Staff members in these settings often struggle to provide the adapted activities and graded assistance necessary for many adults with more severe ID to participate in desired and necessary occupations; nevertheless, training can effectively address this barrier (Qian et al., 2015). Occupational therapists may develop and/or provide training and support to staff members and others to ensure they have the necessary skills to support the participation of adults with ID or serve as organizational consultants for community and/or ID service organizations to enable access and support for community participation (Umeda et al., 2017).

Building Social Capital

Adults with ID often experience disparities in social participation, community engagement, and social capital, or the benefits and resources individuals receive through their social networks, when compared to their peers without disabilities. Whereas adults have an average of 124.9 social connections (Hill & Dunbar, 2003), people with ID have far fewer, averaging 3.1 social connections (Verdonschot, deWitte, Reichrath, Buntinx, & Curfs, 2009). These social connections are rarely with non-disabled community members and often involve others with ID, family, or paid staff. Social connections are vital for this population and have been linked to increased community and civic participation, increased health, and lower rates of depression and loneliness (Amado, Stancliffe, McCarron, & McCallion, 2013). Occupational therapists can support adults with ID to build social capital by brokering connections with people, communities, and organized groups that match their strengths, interests, and needs (Brucker, 2015). In addition, occupational therapists can use assessments (e.g., the Bridging Social Capital Questionnaire) to get a baseline measure of an individual's civic, community, and social engagement to inform interventions to enhance social capital (Villalonga-Olives, Adams, & Kawachi, 2016). For example, for an adolescent with ID who seeks greater civic engagement, an occupational therapist can facilitate activities, such as finding community voting stations and attending community activist groups, that align with the adolescent's interests.

Client-Level Advocacy

Advocacy on a client level begins with understanding each individual's unique strengths, needs, and priorities (Dean et al., 2015). Occupational therapists can use a variety of person-centered planning tools (e.g., Supports Intensity Scale-Adult Version [SIS-A]) to assist adults with ID in setting and monitoring individualized goals (Thompson et al., 2015). Results of these assessments are used to engage all stakeholders in the person-centered planning process and to advocate for services that support adults with ID to achieve their goals. In addition, occupational therapists can help adults with ID prepare for their Individualized Service Plan (ISP) meetings by creating an agenda or presentation highlighting their priorities and collaborating with the case manager to encourage their active participation in ISP meetings.

The ADA and Olmstead Decision created greater opportunities for community inclusion for individuals with ID. As a result, adults with ID have transitioned from living and working in institutional settings to community-based settings (Dean et al., 2015). However, provision of community-based services, including occupational therapy, do not meet current demand (Friedman & VanPuymbrouck,

2018). In order to adequately support adults with ID to live and work inclusively in their communities, occupational therapists must advocate to expand their role beyond traditional service delivery in congregate day and residential settings to that of community-based consultant, program developer, and evaluator (Umeda et al., 2017). For example, occupational therapists can consult with local churches, leisure groups, museums, or parks and recreation to improve the accessibility and inclusion of adults with ID by educating organizations on adaptations they can make to the sensory, social, or physical environments of their community spaces.

Occupational therapists can also facilitate greater inclusion for adults with ID by educating them on more flexible models of service delivery, such as self-directed services. A self-directed services model shifts control of an individual's health services and funding from provider agencies to individuals and families. Individuals who have decision-making authority report greater access to staffing resources and services, including occupational therapy, greater overall satisfaction with their staff and services, and increased involvement in their communities (Dean et al., 2015). Occupational therapists can support adults with ID to hire (and terminate) their own staff and provide training to manage their self-directed services budgets.

Policy-Level Advocacy

Friedman and VanPuymbrouck (2018) found that many Medicaid waivers did not provide occupational therapy services to adults with ID during the 2015 fiscal year, despite expanded coverage under the PPACA. It is imperative that occupational therapists are aware of the language used to describe habilitation services in their states and that they advocate, with their state-level occupational therapy associations, for a more comprehensive and inclusive definition to increase insurance coverage of habilitative occupational therapy services for adults with ID (Brown, 2014). An impending threat to repeal or replace the PPACA may underfund or defund occupational therapy services provided to people with ID in schools, homes, adult day programs, and clinics (AOTA, 2017). While it is still unclear what a final health reform bill will look like, occupational therapists have a professional obligation to advocate for individuals with ID, a population largely underserved and greatly impacted by social and health disparities. The AOTA Legislative Action Center can help occupational therapists gain a broad understanding of current health care bills under review by the Senate and House of Representatives (AOTA, 2017).

Conclusion

The occupational therapy profession is not sufficiently addressing the occupational concerns of adults with ID. We have argued that occupational therapists can be influential in planning and executing care and enabling participation of adults with ID through direct, consultative, and advocacy-based intervention. Although declines in specialization in ID and reimbursement have impacted practice, the profession must renew its commitments to address the individual and group needs of adults with ID. Continued inattention to adults with ID in occupational therapy is not only a missed opportunity for the profession, but an inadvertent perpetuation of their marginalization. As a profession whose distinct value is to enhance health and quality of life through participation in occupations, occupational therapists have a professional responsibility to address the needs of adults with ID to ensure their connections with and participation and inclusion in the fabric of everyday life.

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