

Expanding the Implementation of the Americans With Disabilities Act for Populations With Intellectual and Developmental Disabilities: The Role of Organization-Level Occupational Therapy Consultation

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The Americans With Disabilities Act (ADA) provides standards and guidance for accessibility and accommodations that remove barriers to facilitate community social participation for individuals with disabilities. However, ADA implementation does not yet fully address the diverse access needs of people with intellectual and developmental disabilities (IDD), who continue to face barriers to community social participation. This article explores the potential for occupational therapy practitioners to provide organization-level consultation as a means of maximizing community social participation among people with IDD. Case examples of occupational therapy practitioners working with community organizations are presented to illustrate organization-level consultation that addresses access needs across diverse community contexts. The relevance of supporting community social participation within the context of health equity is discussed, and key next steps, including developing population-based outcome measures, addressing reimbursement considerations, and developing best practices for organization-level consultation, are outlined.

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Given health care reform's growing emphasis on health promotion and client outcomes, including well-being and quality of life, rich opportunities to expand the scope of occupational therapy in community-based practice have emerged (Braveman, 2015; Mroz, Pitonyak, Fogelberg, & Leland, 2015). Consultation with community organizations is a growing area of practice that demonstrates occupational therapy's established role in supporting accessibility to public spaces for people with disabilities. It also illustrates the profession's unique and valuable contributions to promoting community social participation for all members of society. Although physical accessibility to public spaces helps facilitate community social

participation for people with disabilities, unrecognized environmental barriers remain in the social and built physical environment that prevent true social inclusion for some of these people.

In this health policy brief, we recognize the contributions of the Americans With Disabilities Act of 1990 (ADA; Pub. L. 101–336) in moving toward accessible environments and social inclusion, identify persisting gaps in this policy's implementation, and discuss occupational therapy's role in closing these gaps. Specifically, we explore ADA implications for people with intellectual and developmental disabilities (IDD), because this population may experience access barriers as a result of sensory, behavior, and cognitive challenges. Through case examples of occupational therapy

partnerships with community organizations, we highlight the role of occupational therapy in supporting efforts toward maximizing community life access among people with disabilities in diverse contexts. Finally, we place these issues in the context of health equity initiatives and propose action steps to further these efforts and enhance health outcomes through social participation.

Implementation of the ADA for People With Intellectual and Developmental Disabilities

Over the past 25 years, the ADA has prohibited discrimination and required equal opportunity in employment, government services, public accommodations, commercial facilities, and transportation for people with disabilities. This landmark civil rights law was enacted in 1990, revised by the ADA Amendments Act of 2008 (ADAAA; Pub. L. 110–325), and incorporated updated standards for accessible design in 2010. In 2016, the U.S. Department of Justice issued a final rule (81 FR 53203) that revised the ADA Title II and III regulations to broaden the ADA definition of disability.

Although implementation of the ADA has been challenging, great strides have been made toward increasing the accessibility of public and private spaces for people with physical, vision, and hearing challenges. Ramps, curb cuts, braille labels, and accessible pedestrian signals promote community mobility for wheelchair users and people with visual impairments. American Sign Language or other interpretation at public talks and cultural arts venues increases access for people with hearing impairments. However, ADA implementation has yet to fully address formidable community access barriers that people with IDD often face.

The population of people with IDD is diverse, encompassing children and adults with a range of conditions, including genetic syndromes and neurodevelopmental conditions such as autism spectrum disorder (ASD; Schalock et al., 2010). The ADAAA (2008) defines *disability* as “a physical or mental impairment that substantially limits one or more major life activities” (§12102).

Although this definition, included in the original ADA legislation of 1990 (§3), was broadly construed to encompass people with IDD, several Supreme Court decisions effectively narrowed this definition in practice until the ADAAA. Implementation of the ADAAA is ongoing, and changes to regulatory language in Titles II and III took effect in October 2016 (U.S. Department of Justice, 2016). The clear inclusion of people with IDD in ADA regulations represents a critical step toward improving community access for this population.

People with IDD experience decreased community social participation compared with people without disabilities (Bedell et al., 2013; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Solish, Perry, & Minnes, 2010) and face multifaceted access barriers to community activities (Bedell et al., 2013; Bedell, Khetani, Cousins, Coster, & Law, 2011; Little, Sideris, Ausderau, & Baranek, 2014). The complex yet often invisible cognitive, behavioral, and sensory symptoms of many people with IDD can substantially affect their function in community settings. For example, some children with ASD experience auditory and visual hypersensitivities, making activities ranging from visiting museums to accessing public parks or playgrounds challenging for them and their families. In addition, children with IDD may lack adequate attention and behavioral regulation to remain silent in a movie theater or to stay seated when dining out. Thus, community access barriers for people with IDD extend beyond features of the physical environment to those of the social environment, including public attitudes and behavioral regulations and expectations (Anaby et al., 2013). Other barriers include emotional and psychological factors, cognitive and behavioral demands of activities, inadequate resources for people with disabilities, and inadequate training and education of staff in community settings (Bedell et al., 2011, 2013; Little et al., 2014; Solish et al., 2010).

ADA implementation to date has not fully addressed these hidden access and participation barriers. New services, programs, and policies are needed to expand the ADA’s reach and further dismantle these

barriers as well as support the desire of people with IDD for community social participation alongside peers and with their families (Bedell et al., 2013; Rimmer et al., 2004).

Occupational Therapy’s Role in Expanding ADA Implementation

Occupational therapy practitioners have a long history of supporting people with IDD in community social participation and are well positioned to influence ADA implementation. Using established conceptual frameworks and practice models, including Person–Environment–Occupation–Performance (PEOP; Baum, Bass, & Christiansen, 2015), Ecology of Human Performance (Dunn, Brown, & McGuigan, 1994), and the World Health Organization (2001) *International Classification of Functioning, Disability and Health* to guide intervention, practitioners have teamed with people with IDD and their families to maximize occupational engagement. Emerging population-level and community-based approaches to occupational therapy service delivery have potential to promote more comprehensive ADA implementation and maximize community life access for people with IDD.

Organization-level service delivery provided through consultation is an emerging approach that occupational therapy practitioners can use to improve community access for people with IDD. Organization-level intervention is described by Scaffa and Reitz (2013) as community-based practice that influences population health by modifying social, cultural, or environmental factors. *Occupational therapy consultation* is defined by Jaffe and Epstein (2011) as “the interactive process of helping others, including individuals, organizations, or populations, solve existing or potential problems by identifying and analyzing issues, developing strategies to address problems, and preventing future problems from occurring” (p. 522). Here, we define *organization-level consultation* as a collaborative community-based occupational therapy service that supports capacity building in client organizations to meet the occupational needs of target populations and promote their health and well-being.

Maximizing the alignment between community organization features and population needs requires breaking down access barriers and promoting meaningful engagement for people with a range of needs and abilities, including those with IDD. In addition, promoting and improving the health of people with disabilities by addressing access barriers in the built and social environments is a prominent component of national health promotion initiatives and is listed as a key objective of *Healthy People 2020* (U.S. Department of Health and Human Services, 2014).

Organization-Level Consultation

Occupational therapy practitioners have used organization-level consultation in community settings across the nation. Examples are provided of occupational therapy partnerships with community cultural arts and science organizations that aim to promote community access for people with IDD. Consultative processes and specific interventions used to reduce sensory, cognitive, and behavioral barriers within community organizations are highlighted. The examples also demonstrate how occupational therapy practitioners applied professional knowledge and skills to help community organizations better meet the complex needs of children with IDD and their families and reduce barriers to their full participation. In addition, involvement of occupational therapy also demonstrates how PEOP perspectives and practices were applied to shift organizational culture and practices.

The Arts

Organization-level consultation in the arts began in an early childhood learning center in Philadelphia, where occupational therapy practitioners used arts-based activities to engage children with autism and other developmental disabilities (Ideishi, Willock, & Thach, 2010; Lorenzo-Lasa, Ideishi, & Ideishi, 2007). The skills and tasks identified in the children's individualized education programs moved from the classroom to the community through visits to art institutions to reinforce the cultural arts experiences in the classroom. The practitioners

collaborated with school and community personnel and wrote public and private grants to support these activities. This arts program began as a local effort and grew nationally and internationally.

Community Partnerships. Partnerships between the learning center and local cultural institutions aimed to address identified social participation challenges in the community such as overstimulating sensory input; unpredictable situations; and unsupportive social environments in which families reported feeling judged, criticized, and isolated (Ideishi & Mendonca, 2013). Therefore, the occupational therapy practitioners partnered with cultural institutions such as the Walnut Street Theater and the Pennsylvania Ballet in Philadelphia as well as the New Jersey Center for Aquatic Sciences in Camden to explore strategies to support children with diverse sensory and cognitive abilities in the community.

Activities were developed to reinforce supportive strategies not only in the classroom but also in the home and the community. For example, theater art and dance classes (offered to students through artist residencies) as well as museum outreach at the learning center embedded these strategies into learning curricula and therapy interventions. Community engagement occurred through visits to the theater, ballet, and aquarium. The school and cultural education staff created adaptive opportunities for children of all ability levels to meaningfully participate at each cultural institution. Parent engagement was facilitated through parent-child outings to these venues as well as afterschool programming such as parent-child yoga and jump rope workshops and an art show with children acting as tour guides for their parents. These parent-child outings and workshops were intended to build a common relationship between the parent and child around the concepts the children were experiencing at school. The teachers and practitioners reinforced these cultural themes in their educational and therapeutic planning for classroom activities.

Sharing. The theater, ballet, and aquarium shared their home-school-community initiatives within their industries. Around the same time, the Smithsonian

Institution and John F. Kennedy Center for the Performing Arts in Washington, DC, were inquiring about autism programming because these institutions were receiving increasing interest and inquiries from families to explore methods to support their children in these venues. The Smithsonian Institution and Kennedy Center reached out to the Philadelphia cultural institutions to explore how their initiatives were being created. The Philadelphia institutions connected the occupational therapy practitioners who worked on these programs with the Washington, DC, institutions. Through these collaborative partnerships, the practitioners began a dialogue with these national institutions.

Process. Reflecting on occupational therapy's role in a community institution, the occupational therapy practitioners used the statement of person, population, and organizational clients in the *Occupational Therapy Practice Framework: Domain and Process* (3rd ed.; American Occupational Therapy Association, 2014) to frame the scope of their work at an organizational level. They used an ecological perspective to establish potential change agents that fostered meaningful engagement through adapting, modifying, or creating activities and contexts that supported children with diverse abilities (Dunn et al., 1994). The goals of organization-level consultation included identifying organizational needs, fostering organizational social and policy changes, and enabling the organization to support a person's engagement in society. In partnering with two national institutions, the occupational therapy consultants were instrumental in developing new audience programming, materials and resources, and new pilot projects and research; training staff and students; disseminating information; and expanding partnerships.

Impact. The impact of supported community opportunities for children with autism and IDD included the families reporting that modified lighting and sounds made the experience easier to manage; the staff being better able to create a safe social environment, which reduced parents' anxiety and vigilance; and the children having more suitable environments to be who they are and experience arts in their own way.

Therefore, these opportunities allowed families to go into the community with increased satisfaction. The impact on cultural institutions included creating a new audience market, converting single ticket holders to season or multipass ticket holders, and deepening the institutional mission and values to benefit a wider swath of society.

The partnerships between the occupational therapy practitioners and the Smithsonian and the Kennedy Center provided a platform to disseminate program results to a national and international audience. Cultural institutions across the country have reached out to occupational therapy practitioners to provide arts access consulting. In 2014, the Kennedy Center held an international summit on relaxed, sensory-friendly experiences in theatrical and arts settings. The summit was an invitation-only meeting for 25 stakeholder participants, including disability self-advocates, families, art administrators, educators, and four occupational therapists. In addition, disseminating information and outcomes in the cultural arts industry creates another platform to share occupational therapy's contributions to arts accessibility. Many cultural institutions developing arts access initiatives for people with diverse sensory and cognitive abilities advocate for occupational therapy practitioners as a critical part of arts access teams.

Science

An example of organization-level consultation in science includes the collaboration between the University of Washington and the Pacific Science Center (PSC), an interactive science museum in Seattle. University of Washington master of occupational therapy (MOT) students provided organization-level consultation to PSC staff as part of their community-based capstone projects. Two projects were carried out over 2 academic years, emphasizing environment-level supports and staff training and development.

The PSC reached out to the University of Washington with the goal of being more responsive to the diverse needs of children with sensory, social, or other behavioral challenges. The PSC had

a yearly Autism Early Open Event for families on a Saturday morning before the museum opened to the public. Because this event was popular, PSC staff wanted to expand the program and develop more supports for children with ASD and their families.

MOT students worked with PSC staff by conducting a needs assessment that included a focus group with parents of children with ASD and a focus group with PSC museum and floor staff. An environmental scan was also completed in which students observed and evaluated the PSC's physical space, levels of sensory stimulation throughout the science center and exhibits, and museum information guides and materials. Results from the needs assessment were shared with PSC staff to make program recommendations and develop materials.

MOT students developed content and structure for patron and staff materials informed by emerging practices, strategies implemented by other programs nationally, and relevant literature. Families were invited to try the materials during a museum visit and were asked questions about how and when they used each of the materials, what they liked about the materials, and what suggestions they had on ways to make the materials easier to use. Materials were also reviewed by a group of pediatric occupational therapists and speech pathologists and the PSC director of science and education. The PSC approved and branded the final versions of the materials and made them available to the public on the PSC website and in print.

Patron materials included a sensory guide, two versions of an adventure planner, a visual schedule, and a tip sheet for parents, and staff materials included a training module and recommendations to enhance communication with families and children and museum inclusivity. Following are descriptions of these materials:

- *Sensory guide.* This guide highlighted areas that families may want to select or avoid on the basis of their child's sensory needs. The guide included visual indicators illustrating the levels and types of sensory stimulation for

each exhibit. For example, exhibits with minimal sound had one ear; loud exhibits were represented with four ears.

- *Adventure planner.* A series of 29 narratives, termed *adventure planners*, was created to illustrate social expectations for museum tasks and activities such as how to buy an entry ticket and what to expect at different exhibits. Adventure planners were developed for early and intermediate developmental levels.
- *Visual schedule.* A visual schedule along with images of all regular and special exhibitions was developed to enable families to plan their visit before their arrival. The PSC provided photos and images for the visual displays, and the images and templates were made available to the public on the PSC website.
- *Tip sheet for parents.* A tip sheet to help parents plan a successful visit to the PSC was created, highlighting available supports and materials, lower volume times to visit the museum, and strategies to support transitions between exhibit areas.
- *Staff development and training.* An ASD information sheet was developed that included general information about ASD and sensory processing difficulties, two case studies that illustrated how ASD and sensory processing difficulties may affect a child at the PSC, and tips for successful interactions with people with ASD. The training and materials were presented at a brief in-service for staff who were involved with the early open events and were added to the staff training manual for all museum staff.

Health Equity

Community social participation is associated with health and social outcomes across the life course (Fauth, Roth, & Brooks-Gunn, 2007; Harrison & Narayan, 2003; Jones, Kimberlee, Deave, & Evans, 2013; Renton et al., 2012). Cultural arts organizations, aquariums, zoos, and other community venues are examples of places that provide naturally occurring societal

activities; however, disparities in participation in these desired activities exist as a result of barriers in the environment. Access to these types of social activities at the neighborhood, local, community, state, and national levels is an important part of creating social capital and health equity. Srinivasan and Williams (2014) proposed five initial steps for moving from examining health disparities to creating health equity:

1. Consider the role of population health in research and intervention;
2. Understand complex, multidisciplinary, multilevel, and multifactorial interactions;
3. Improve research methodologies and statistical analytical techniques;
4. Build on community resiliency and partnerships; and
5. Develop the research and professional workforce.

The health-producing aspects of neighborhoods and communities are a growing focus in public health research and health policy, and occupational therapy has the ability to contribute to broader outcomes such as health equity by creating access to participation in societal activities.

Conclusion

Occupational therapy practitioners are providing organization-level services that improve community practices and organizational culture, yet barriers and challenges remain. Research to examine outcomes and the organizational features that support development, implementation, and sustainability of accessible programs developed through organization-level consultation is an important next step. Reimbursement, best practice features, actions to bridge policy and practice, and steps to expand this approach to a broad range of community contexts are also key considerations.

Examining outcomes to determine whether community initiatives contribute to participation, well-being, and quality of life of children with IDD and their families is critical. Outcomes must include meaningful person-centered measures and the perspectives of organizations as partners and

key stakeholders. Implementing these interventions requires commitment and buy-in from organizations. Therefore, organizational factors that contribute to the success of these collaborations include organization-initiated change, time and resource allocation to develop new programs, training, and branding of materials and resources. In addition, these factors must be understood as they relate to successful implementation, sustainability, and capacity building.

Reimbursement for consultation and services that are delivered outside traditional health care or educational systems remains a consideration. Organizational knowledge of the distinct value of occupational therapy practitioners to do this work is limited. Delivering services as a consultant requires a different skill set than direct service. A better understanding of professional preparation to provide consultation and advocacy in both entry-level and postprofessional programs requires attention to defining and refining best practices of consultation. ▲

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