Autism Spectrum News

September 15, 2025

Advancing Community Inclusion for Individuals with ID/DD: History, Challenges, and the Role of Caregivers

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Community-based living for people with intellectual and/or developmental disabilities (ID/DD) has improved since the mid-20th century, in the context of a broader civil rights movement. A more discrete focus on the rights of individuals with disabilities arose during the 1960s and 1970s under John F. Kennedy's presidency after he passed the Community Mental Health Act (CMHA) in 1963. The purpose of the CMHA was to provide more accessible and comprehensive mental health services in community settings, rather than in large institutions. Due to lack of funding, the CMHA did not effectively launch, nor was it sustained with funding over the long term. While the CMHA did not have the intended impact on support for people with a variety of special needs, including disabilities, the act did begin the process of closing large, dehumanizing, and often isolated communities and providing access to those communities.

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Our goal as caregivers is to support our individuals in the community environment and give them the opportunity to grow and flourish. Training staff in evidence-based practices that uphold these values and initiatives is imperative to ensuring that caregivers are able to provide the least restrictive and most inclusive support in the community. One of the most important trainings caregivers provide the individuals served is rooted in improving both the efficiency and clarity of communication. Often, people with ID/DD have deficits in communication, hindering their ability to communicate with others. The provider is responsible for teaching the person with ID/DD how to communicate their wants and needs effectively and appropriately, which is foundational to reducing challenging behavior and therefore enhancing independence (Carr & Durand, 1985; Tiger, Hanley, & Bruzek, 2008; Light & McNaughton, 2012). Due to these communication barriers, individuals with ID/DD may at times engage in challenging or disruptive behaviors such as yelling, tantrums, aggression, or self-injury. Caregivers are provided with additional training and support on how to best assist the person with ID/DD in these moments, prompting coping skills, communication, and ensuring safety of all involved.

When the individual served is at home or their day habilitation program, both the individual and caregiver are surrounded by other trained staff members in a familiar environment who can provide additional support, however, when in the broader community, different variables may arise that can present challenges to staff and the person being supported. In unfamiliar community settings like grocery stores, restaurants, or movie theaters, various sounds, smells, items, and people can contribute to sensory overload. All of these changes, combined with caregivers having access to a smaller pool of supporting staff, can factor in if an individual exhibits disruptive behavior in the community. Public reaction affects the individual's safety and dignity and has a significant impact on staff's comfort by accessing the community with individuals.

These reactions are often shaped by the visibility of disability, societal stigma, cultural attitudes, and a general lack of awareness about developmental disabilities (Gray, 2002; NCD, 2015). One factor that affects public perception is when the disability is not visibly apparent, leading to challenging behavior more likely to be misinterpreted. The visibility of a disability influences the public's attitude toward that person. McCoy and Banks (2012) found that children with emotional or behavioral disabilities/ multiple disabilities are perceived more negatively than children with a physical disability. Further, children with ID/DD are perceived more negatively than children with a physical disability (Nowicki, 2006; de Laat et al., 2013).

When these behaviors occur in the individual's home environment, trained direct support professionals (DSPs) are typically available to implement behavior support plans and assist the individual using evidence-based and functionally related practices. While in the community, a behavior can occur and people might think that the person is 'violent', suffering from substance abuse, etc., which can escalate the situation. In some cases, bystanders may call law enforcement, which introduces additional risk—particularly if the responding officers lack training in disability-specific de-escalation strategies (Ruderman Family Foundation, 2016; Perry & Carter, 2017). Such misunderstandings can cause harm to the individual, including the use of force (i.e. tasers) and could result in the individual being arrested and/or charges being pressed against them. This type of situation is not only extremely risky and harmful to the individual but also contributes to broader community fears and may reinforce ableist narratives about people with disabilities.

Federal legislative efforts over the last 35 years have been instrumental in ensuring that individuals with intellectual and developmental disabilities have equal opportunity and access to public accommodation, transportation, communication, and more, however the movement does not end there. Our role as providers is critical for not only the individuals we serve, but our highly skilled staff who provide compassionate care, and the broader community. Our goal is to ensure staff are adequately trained, and that the necessary support is provided within community settings so that the individuals we serve have full access to the community with the best outcomes. We continue to strive to positively impact the broader narrative about individuals with ID/DD in community settings by advocating for the rights of the individuals we serve and their families.