



NCI Commemoration of the 30th Anniversary of the Americans with Disabilities Act

On July 26, 2020, the disability world celebrated the 30th anniversary of the Americans With Disabilities Act (ADA). The civil rights law prohibits discrimination against people with disabilities in all areas of community and public life including employment, education and transportation. The ADA was a major milestone in the fight for the rights of people with disabilities.

National Core Indicators® (NCI®), which began 7 years after this civil rights milestone, was in many ways created to ensure that the rights guaranteed in the ADA and elsewhere were available to people with intellectual and developmental disabilities (IDD). By collecting information on a variety of related domains, including community living, rights and respect, safety, employment, and access to the community, NCI has provided state IDD public managers with the valid and reliable information they need to detect where progress is being made and where there is a need for improvement.

NCI began when 13 state developmental disabilities managers met to devise standardized ways to measure the performance of their systems. They all agreed that the best way to know whether rights were respected, and the missions of the ADA and their state systems were realized, was to ask people receiving services and supports and their families. Since then, 46 states and the District of Columbia have joined NCI, contributing data that shed light on the experiences, outcomes and challenges of people and families who receive services from state IDD systems.

Since the ADA was passed, IDD systems have continued to mount important systems change. Reforms have included the continued movement of people out of institutions, the adoption of person-centered practices and principles, and the promulgation of the Home and Community-Based Settings Rule that asserts that people receiving long-term services and supports should have the same degree of access to their communities as people not receiving federal Medicaid funding—an assertion that has echoes of the decades-old principle of normalization.



In terms of progress, NCI data have shown that more people are living in smaller residential settings and in their own homes with support. Most people report they can do things they want to do in their communities, and that they can vote if they want to. However, the number of people with a competitive job in the community has not increased significantly over many years, older adults report having trouble getting transportation to get out of their homes, and some families and

individuals report they do not receive all of the services they need.

The hallmark of the IDD system over many years has been a continuous search for ways to improve the lives of people with IDD. The data gained from individuals and families have made it possible for the NCI team to highlight areas where, as a field, we need to improve performance and move closer to the aspirations of the ADA—for example, in providing alternatives to guardianship, expanding the ability of people with IDD to self-direct, improving outcomes for people with autism, and supporting people to make and sustain friendships.

The ADA was a landmark law that gave many people with disabilities access to their communities and other opportunities previously denied to them. However, there is still work to be done. Looking ahead, NCI will continue to amplify the voices of people with intellectual and developmental disabilities and their families. The NCI team hopes this information will provide an impetus for further policy and programmatic advances as states take the aspirations of the ADA to the next level.