

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Connecticut– Pilot Program for Young Adults with Autism Spectrum Disorders

Issue: Supports for Adults with Autism Spectrum Disorders

Summary

Connecticut is operating a state-funded home and community based services pilot program to help adults with Autism Spectrum Disorders (ASD) gain the skills to become contributing members of the workforce. The program serves people with ASD who do not qualify for the State's Medicaid home and community-based services waivers. This pilot program targets individuals who need continued supports to pursue employment opportunities and improve their independent living.

Introduction

Autism Spectrum Disorders (ASD) are neurological disorders characterized by impaired communication, difficulty with relationships and social interactions, and repetitive behaviors. People with ASD have symptoms that range the full continuum from mild to severe. The majority of states provide services to people with ASD in Medicaid Home and Community-Based Services (HCBS) waivers for people with developmental disabilities. However, an individual's services may not fully address the social and communication challenges adults with autism face. In addition, many people with ASD are not sufficiently impaired to qualify for a waiver in their state, yet still need assistance to work and live independently.

The State of Connecticut is implementing a two-year, state-funded, pilot program: 1) to study the effect of home and community-based services on adults with ASD; and 2) to learn how to help adults with ASD develop functional skills for participating in the workforce. This report is based on interviews with state program staff and a co-chair of the pilot project's steering committee, as well as state documents such as the program's authorizing legislation.

Background

Adults with ASD that do not have a mental retardation diagnosis are typically ineligible for support services in Connecticut. The state serves people with dual diagnoses of autism and mental retardation in a Medicaid HCBS Waiver for people with mental retardation, but does not

have a waiver that includes other people with ASD.

Many of these adults received services as children, including services required by the Individuals with Disabilities Education Improvement Act (IDEA). In many instances,

Many adults with ASD performed well in school, but have difficulty obtaining employment.

these adults have done well academically and earned college degrees. However, without support

services in adulthood, individuals can quickly lose the self-help and socialization skills gained during the school years. Without these skills, and appropriate supports, it can be difficult for adults with ASD to initiate a job search, participate in interviews, and communicate their job expectations.

Intervention

In 2006 the Connecticut legislature authorized a two-year pilot program to address this gap in coverage. The pilot serves 25 adults in the Greater New Haven area who have ASD but are not eligible for the state's HCBS Waiver for people with mental retardation.

To include higher functioning adults with ASD, the pilot program uses different functional eligibility criteria than most HCBS waivers for people with developmental disabilities. These waivers typically serve individuals who require the level of care delivered in an intermediate care facility for people with mental retardation (ICF/MR). For people who do not have mental

retardation, ICF/MR level of care is defined as significant impairments in three of six functional areas: self-care, understanding and use of language, learning, mobility, self-direction, and capacity for independent living.¹ For the autism pilot program, Connecticut added a seventh functional area, economic self-sufficiency, to serve higher-functioning individuals who still need support. Connecticut's criteria reflect the definition of developmental disability used in the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000.

The program's services focus on helping people move toward employment. Some services focus on employment, helping adults with ASD identify potentially interesting jobs, promote their skills and abilities, interact with co-workers and supervisors, and understand employers' expectations. The program also offers social skills training on both an individual and group basis, and other services to help participants improve daily living skills.

Some services focus on improving job-related skills.

Implementation

Connecticut's Department of Mental Retardation (DMR) implemented the program, with considerable assistance from a Steering Committee comprised of many autism advocates, experts, and staff from several state agencies. The committee started meeting soon after the program's authorizing legislation was passed, and continued to meet through the first year of implementation. The Steering Committee defined a vision for the program and was instrumental in developing the pilot program's eligibility criteria, service package, service planning processes, a provider training curriculum, desired outcomes, and criteria for measuring these outcomes.

The program started serving individuals in October 2006. DMR's most successful outreach was through support groups for families of people with ASD. DMR also sent notices to municipal disability services directors, the Connecticut Bureau of Rehabilitation Services, several private agencies that serve people with autism, and local education agencies (for people leaving the school system). DMR also

publicized the program through the Department of Mental Health, since many people with ASD also have mental health diagnoses, and through local universities where many New Haven residents work or attend school.

Enrollment occurred more slowly than expected and the program did not reach its full capacity, 25 participants, until May 2007. The pilot's legislation authorized services for up to 50 people. DMR planned to provide services to 25 and to have an additional 25 participate in a control group. As part of the program's independent evaluation, DMR planned to assign people randomly into treatment and control groups. Because of modest enrollment, DMR recruited a control group from another geographic area, the Greater Hartford area. The reasons for slower than anticipated enrollment are unclear, but the nature of ASD may be a contributing factor. People who are isolated because of limited social or communication skills can be particularly hard to reach and concerned about a change in routine.

Developing a provider network knowledgeable about ASD has been an important implementation challenge. The state has a limited provider base with expertise in serving adults with ASD without a mental retardation diagnosis, since there had been no services targeted to this population.

DMR has worked with an autism educational contractor to develop a training curriculum for direct support staff. Topics included characteristics of ASD, the person with ASD's perspective, and strategies for working with people with ASD. DMR initially conducted several one-day, in-person training sessions to small groups of staff. DMR is now creating videos to make the training more accessible to

DMR developed a training curriculum for direct support staff.

staff who have other jobs and cannot easily attend a full day of training. The video training modules will include pre and post-tests to assess what providers have learned from the training. The videos include interviews with program participants who agreed to explain their perspective on camera.

¹ Title 42 Code of Federal Regulations, Section 435.1009

Impact

DMR has contracted with the University of Connecticut Center on Aging (UConn) to conduct an independent evaluation of the ASD pilot. UConn will compare participants to a control group of 25 adults with ASD in the Greater Hartford area, where services are not available. UConn will collect information from the Scales of Independent Behavior-Revised, an assessment of participants' needs and independence, and from interviews with participants and caregivers. UConn has collected baseline information and will obtain new data near the end of the pilot's two-year operating period. In addition, UConn will study the cost impact of the pilot, both the state's direct costs and the affect of the pilot on the cost

of other services such mental health services. The evaluator also will study the program's implementation and identify lessons that could apply to program expansion or to program development in other states. If the program proves successful, the state hopes to expand the program at the end of the pilot to the Greater Hartford area and eventually to the rest of the state.

Contact Information

For more information about Connecticut's pilot program for adults with ASD, please contact Kathy Reddington at (860) 418-6026 or kathryn.reddington@po.state.ct.us. Online information about the program is available at <http://www.dmr.state.ct.us/AutismPilot/>.

Discussion Question:

What are the advantages and disadvantages of a separate program focused on the people with autism spectrum disorders, compared to a program serving all people with developmental disabilities?

One of a series of reports by Thomson Healthcare for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series will be available online at CMS' Web site, <http://www.cms.gov>. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.