



LIFELONG SUPPORTS

MAKING AN IMPACT ACROSS THE SPECTRUM AND THROUGHOUT THE LIFE SPAN

AUTISMSPEAKS.ORG

Lifelong supports include those that people with autism need to live happily, connected to their community and as independently as possible throughout their life span.

These supports and services are dependent on the person's needs and are often considered during the transition planning process. They may include supports for caregivers, housing and residential services, financial planning tools and meaningful day activities such as employment or non-employment day activities.

The types of supports available vary widely across and within states. Several federal policies, both regulations and legislation, shape lifelong supports for people with autism. The extent to which these federal policies promote change often depends on their implementation at the state level.

Financial Planning. Many children and adults with disabilities, including autism, have significant current or anticipated expenses. Planning for those expenses has often proven difficult.

The **Achieving a Better Life Experience (ABLE) Act** amended the federal tax code to allow families to set up tax-exempt 529A savings accounts for disability-related expenses. These accounts can be used by people with disabilities to save without losing their eligibility for Medicaid or Social Security.

As of December 2018, **\$171.7 million in assets had been invested in over 34,700 ABLE accounts.**

While all people with autism currently have access to ABLE accounts regardless of age, people with other disabilities may be limited. The **ABLE Age Adjustment Act** would increase the age threshold for ABLE accounts from 26 to 46. Increasing the number of people eligible to use ABLE accounts will help improve and sustain ABLE accounts overall.

Employment and Day Supports. Lifelong supports include employment programs that are funded by Vocational Rehabilitation, Medicaid and other sources. Medicaid also funds community-based, non-employment day programs. There is a **nationwide trend to move people with disabilities into integrated employment** where most employees do not have disabilities and employees earn at least a minimum wage.

The availability of competitive integrated employment is influenced by several federal regulations. The U.S. Department of Labor currently authorizes certain employers to pay people with disabilities less than minimum wage under Section 14c of the Fair Labor Standards Act. The use of these certificates is declining and subminimum wage is increasingly viewed as discriminatory. Other policies, such as the U.S. Department of Education's definition of competitive integrated employment within its vocational rehabilitation programs aim to increase the number of people with disabilities receiving competitive wages.

The lifetime cost of supporting one person with autism can range from

\$1.4 to \$2.4 M¹

In Drexel's 2017 National Autism Indicators Report, only

14% of adults with ASD

held a job for pay in the community.

1. Buescher AVS, Cidav Z, Knapp M, Mandell DS. Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA Pediatr.* 2014;168(8):721-728. doi:10.1001/jamapediatrics.2014.210



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In Drexel's 2017 National
Autism Indicators Report, only
**49% of adults
with ASD**
lived in the home of a parent
or relative.

HCBS Settings Rule

Over **75,000**
people
have received HCBS as a
result of the MFP Project.

EMPOWER Care Act

Home and community-based services (HCBS). The vast majority of long-term services and supports is funded by Medicaid, and HCBS is the Medicaid program that provides most people with autism the lifelong supports they need. HCBS provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than in institutions or other isolated settings. HCBS varies widely within and across states, and different services may be available to people based on their age, where they live and level of functional impairment. HCBS may include:

- Respite and in-home supports
- Group homes, independent living and supportive housing
- Day programs, supported employment and pre-vocational training
- Transportation, home modifications and adaptive aids

In 2014, the Centers for Medicare and Medicaid (CMS) announced new rules that would affect residential and day service settings funded through Medicaid home and community-based services. **The new rules support inclusion and integration of people with disabilities in the community** and require states to improve all HCBS settings in accordance with the new person-centered standards.

States were required to submit a transition plan to CMS by March 17, 2015 for review. Each state transition plan was to include:

- An explanation of how the state will update state policies to conform with the new rules;
- A process for assessing and remedying current settings for compliance with the new HCBS requirements;
- A timeline for when the state expects to achieve milestones in their transition plan process; and
- Responses to public comments on their state transition plan.

As of April 2019, 42 states had received initial approval of their state transition plans and 13 states (AK, AR, DE, DC, ID, KY, MN, ND, OK, OR, TN, WA and WY) had received final approval. All other states had received a letter describing the additional steps it must take to get final approval. Public input on state plans can be shared by advocates through state waiver agencies.

This bill would extend the Money Follows the Person (MFP) Demonstration Project which has served as a catalyst that enhances existing Medicaid transition and home and community-based services since 2005.

Forty-three states and Washington, D.C., receive funding through the project and use it to assist Medicaid recipients to live in the community. Each state decides how to use the funds, which they have used to expand and enhance HCBS programs, reduce waiting lists and fund housing projects. While a short-term extension of MFP was passed in January 2019, the EMPOWER Care Act would extend the program for five years.