



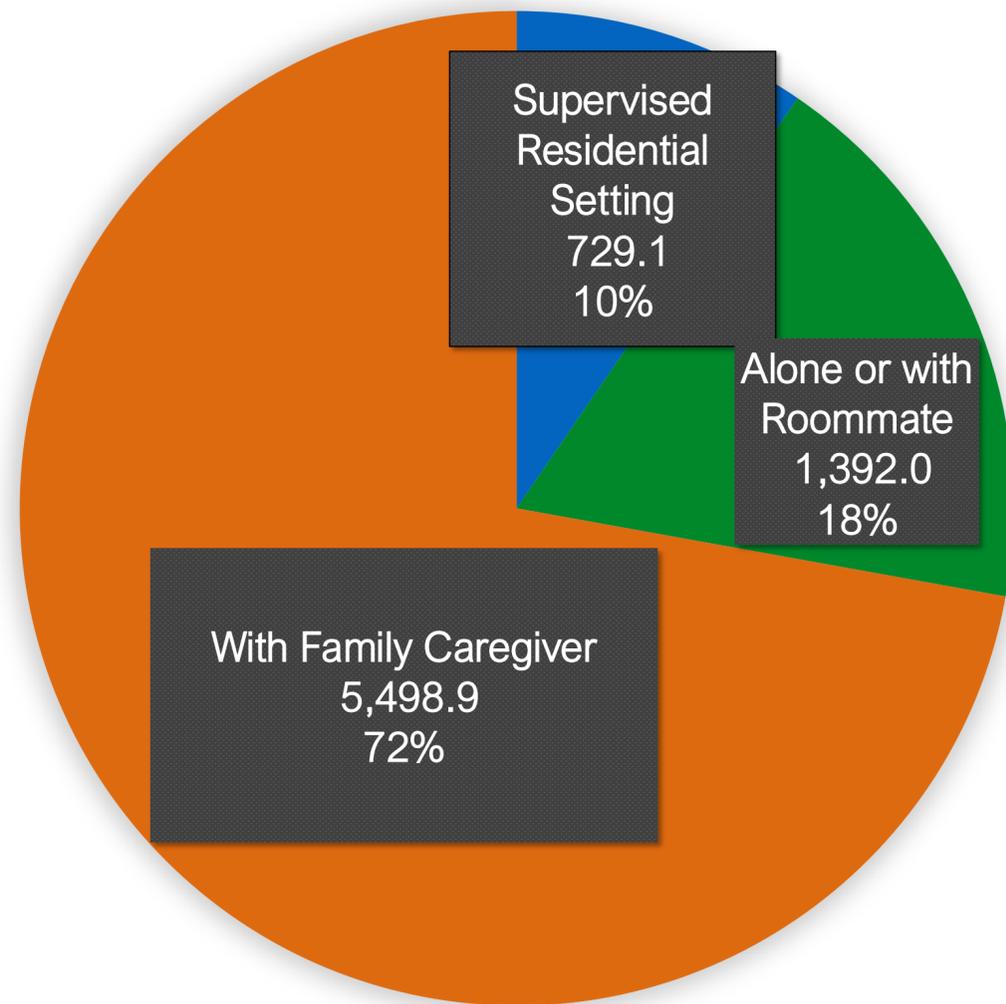
TOGETHER FOR CHOICE

**The Impact of the HCBS Settings Rule on Individuals
with Intellectual and/or Developmental Disabilities (I/DD)**

Estimate of I/DD Living Arrangements

Fiscal Year 2023

(in thousands)

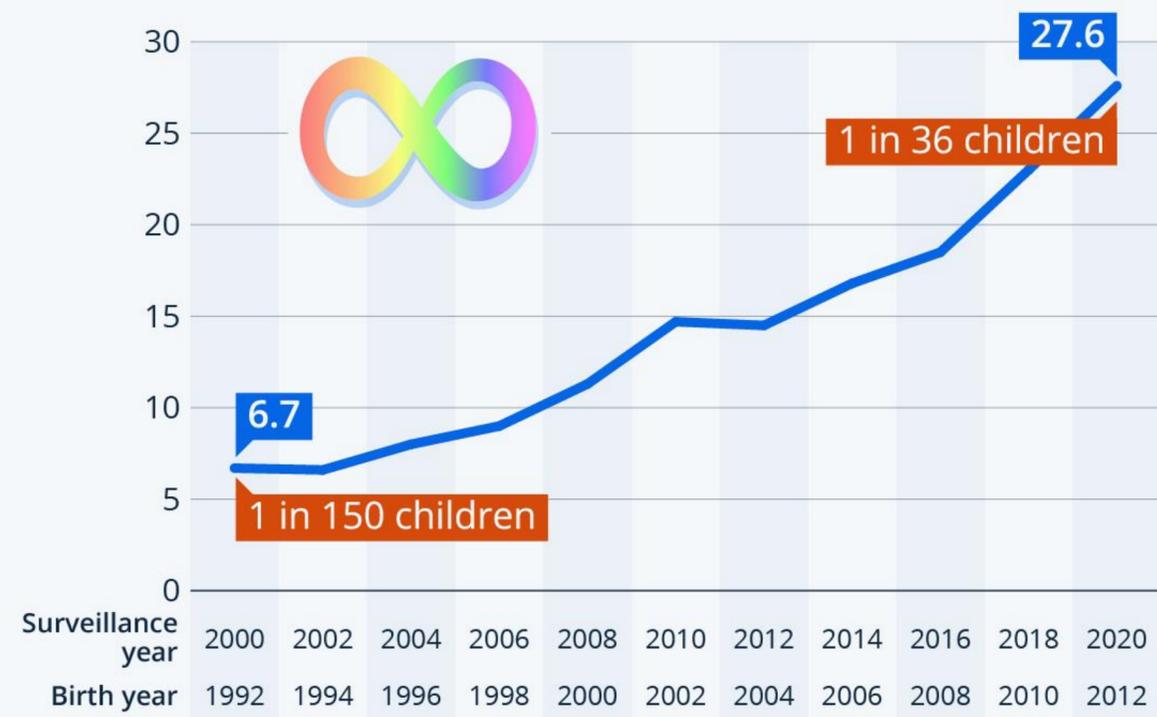


- About 72% of individuals with I/DD are living at home.
- Many are living with aging parents.
- The reliance on aging parents is an unsustainable model as parents face their own age-related challenges.

Source: Tanis, E.S., et al. (2025). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Disabilities, The University of Kansas. <https://stateofthestates.ku.edu>

The Rising Prevalence of Autism

Identified prevalence of Autism Spectrum Disorder (ASD) per 1,000 children in the U.S.



Source: Autism and Developmental Disabilities Monitoring Network via CDC



statista

- The rising rate of Autism is driving a wave of individuals in need of residential and vocational services.
- At age 22, comprehensive care under Medicaid's mandatory EPSDT benefit ends, and individuals with I/DD must transition into HCBS programs where access to services is more limited.
- Medicaid is a vital link to residential and vocational programs for adults with I/DD.
- Currently, there are over 700,000 adults with I/DD on state waiting lists for residential and vocational programs.
- The needs and preferences of adults with I/DD are diverse and they need a wide range of residential and vocational options.
- The Settings Rule unnecessarily restricts these options.

HCBS Prior to 2014

- Section 1915(c) of the Social Security Act, enacted in 1981, authorized states to implement Home and Community-Based Services (HCBS) waivers, enabling them to provide home- and community-based alternatives to hospitals, nursing facilities, and intermediate care facilities for Individuals with Intellectual Disabilities (ICF/IID) (institutional settings).
- CMS permitted Medicaid funding for HCBS in any setting that is not a hospital, nursing facility, or ICF/IID.
 - CMS's position reflected the congressional intent underlying Section 1915(c) to permit individuals to choose the service setting that best meets their needs.
 - Medicaid funding was available for a broad range of settings, including campus settings, farmsteads and intentional communities.
 - State Medicaid programs were not permitted to dictate the setting in which an individual lived or received services; individual choice of setting was required.

2014: The “Settings Rule”

In 2014, during the Obama administration, CMS changed its long-standing position by narrowly defining the types of settings that qualified as “home” or “community-based.”

- The Rule prohibits HCBS funding for individuals in campus settings, farmsteads, and other intentional communities that were uniquely designed to serve individuals with specific needs, like adults with autism; these settings are presumed to be “too isolating,” though the presumption can be overcome if states are willing to engage in a lengthy federal approval process (called “Heightened Scrutiny”). As a direct result, some states stopped funding HCBS at these non-institutional settings.
- The Rule is overly prescriptive and intrusive, and prevents facilities from adapting settings to the unique health and safety needs of residents. It places unnecessary burdens on states and severely limits the types of settings in which people with disabilities can choose to live or receive services.
- Many high-quality, disability-specific settings that are presumed to have “the effect of isolating” are not allowed to expand to meet the growing demand; development of new, innovative residential communities has stalled.
- Individuals who have happily lived in disability-specific settings have been forced to move to small group homes they did not choose, and where they often do not thrive. Living at home with aging parents has become the only option for many.

Settings Rule is a Barrier to Growth & Innovation

- Uncertainty over meeting the Settings Rule requirements and overcoming the Rule's "Heightened Scrutiny" test prevents families, providers and communities from investing in and creating new and innovative models that meet the varied needs of people with disabilities.
- The Settings Rule greatly exacerbates the shortage of appropriate housing for those with I/DD and the long waiting lists for services.
- Individuals with disabilities have diverse needs, interests, and challenges. Some thrive in small group homes that meet the Settings Rule's strict "community integration" requirements. Others do not and, ironically, the group home setting makes them more isolated from friends, family and community because of safety concerns.
- Individuals that are not well-suited for the small, group home model often thrive in farmsteads, campus settings, and other intentional communities.

Impact of HCBS : Caroline (Kentucky)



- Level 3 Autism with complex challenges
- Non-verbal and dependent on others for toileting, bathing, dressing, food preparation
- She once lived happily in a HCBS waiver-funded community home, close to her family.
- Her home was located adjacent to a private intermediate care facility, which under the Settings Rule, was presumed institutional.
- As a result, she was forced out of a setting where she was truly flourishing.

Impact of HCBS: Caroline (Kentucky)



- She was moved to a Settings Rule compliant home 2 hours away from her family.
- Caroline has endured 134 unexplained injuries:
 - Many bruises to her hands, arms and feet
 - A one-inch gash to the back her head which required stitches
 - Deep scratches
 - Many urgent care visits and abandonment at the Emergency Room
- Stability, daily visits with her family, living without fear of abuse – all gone.
- **Video:** https://youtu.be/ObfBm0oTDQU?si=oS9J_O5_zugg1Vyi

Impact of HCBS: Samantha (Michigan)



- 28-Years old with autism with very limited expressive and receptive language
- High-level of Anxiety and OCD behaviors
- Since aging out of school, her days have been consumed by VHS tapes and DVDs of shows that she watched and loved when she was in preschool.
- She goes to an art class once a week for 2 1/2 hrs.

Impact of HCBS: Samantha (Michigan)

“Due to cameras being utilized, Deer Run Rehabilitation is determined to not be compliant with the HCBS [Settings] Rule and therefore not eligible to receive HCBS Medicaid funds.

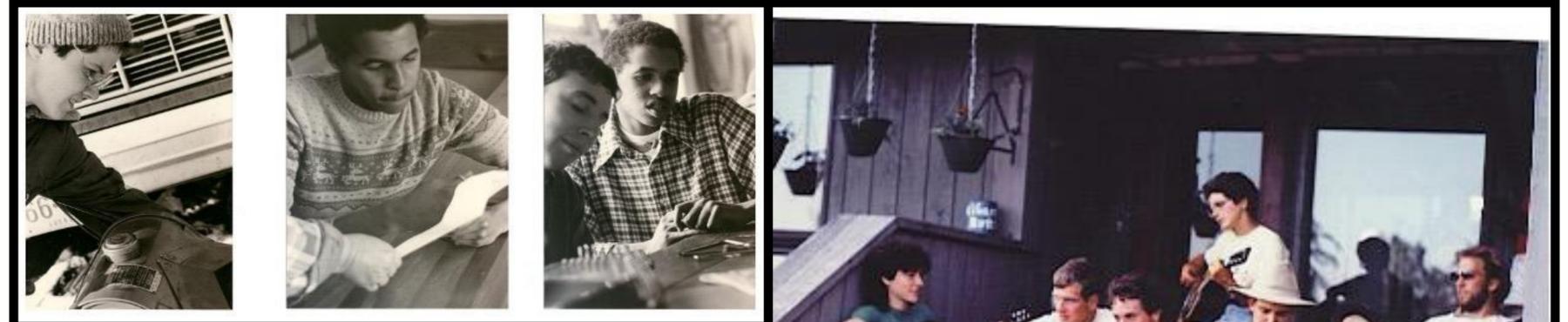
Community Mental Health for Central Michigan (CMHM) is therefore unable to authorize Medicaid funds to be utilized for placement at Deer Run Rehabilitation.”

Source: Letter from Community Mental Health, May 14, 2024

- After an exhaustive search for an appropriate residential program that truly met her needs, Samantha’s parents discovered Deer Run—an adult foster care home.
- However, Samantha was denied for residential placement at Deer Run.
- Community Mental Health for Central Michigan (CMHCM) formally determined Deer Run Rehabilitation to be ineligible for HCBS Medicaid funds, citing the use of cameras as a violation of the Settings Rule.
- The video cameras were only in common areas because many residents were unable to communicate.
- CMHCM’s determination was in direct conflict with Samantha’s parents who requested a housing placement with video cameras in common areas to ensure Samantha’s safety.

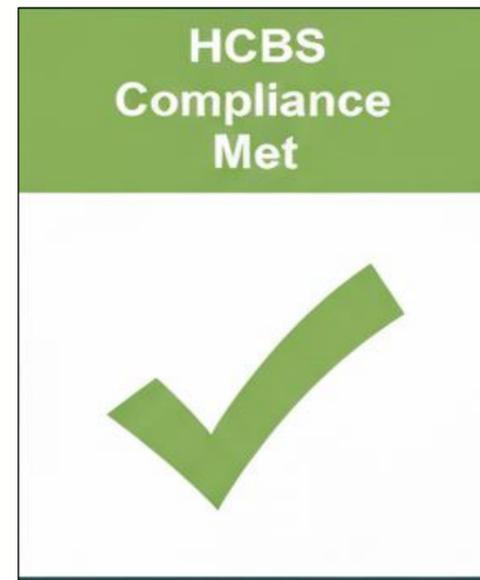
Impact of HCBS: Bittersweet Farms (Ohio)

- Founded in 1983, Bittersweet is the first autism farmstead community in America specializing in supporting individuals with high behavioral needs.
- Main campus is situated on 80 acres in Whitehouse, Ohio.



Impact of HCBS: Bittersweet Farms (Ohio)

- Residential services for 42 adults
- Adult Day Services for approximately 85 adults
- When the Settings Rule went into effect, Bittersweet was cited for being “too isolating” and co-located with an ICF, and was therefore subject to Heightened Scrutiny.
- After more than three years of rigorous compliance reviews, the farm was not only deemed fully aligned with the rule but also recognized for exceeding community integration standards compared to urban providers.
- Despite this, Bittersweet was prohibited from building additional residential housing because of the Settings Rule.
- This constraint is particularly concerning given the organization's waitlist of over 150 Ohioans.



Impact of HCBS: Benjamin's Hope (Michigan)



- A "Live, Learn, Play, Worship" Farmstead Community where 44 adults with autism and developmental disabilities live full lives with purpose and belonging in Holland, Michigan.
- It's one of very few communities that serve people with profound communication, behavioral and sensory needs in the U.S.
- A debt-free public-private partnership, Benjamin's Hope is an inspirational model for many families across the country.



Impact of HCBS: Benjamin's Hope

When common sense health and safety practices are labeled “restrictions,” people are put at risk.

TRANSIT VAN
SAFETY



Using a safety-approved device because a resident repeatedly unbuckles her seatbelt while the van is moving

✘ non-compliant with HCBS

BED-ALARMS FOR
FALL-RISK
RESIDENTS



Using a physician recommended bed-mat alarm to prevent dangerous falls

✘ non-compliant with HCBS

LOCKED PANTRY
FOR MEDICAL
SAFETY



Locking a pantry for residents with PICA or unsafe food-related conditions as clinically indicated

✘ non-compliant with HCBS

Executive Order 14219 and Rescission of the Settings Rule



- [President Trump's Executive Order 14219](#) requires all agencies to rescind rules that exceed the agency's statutory authority or that impose significant costs or burdens on private parties.
- The Settings Rule meets the criteria for rescission in EO 14219
- Section 1915(c) of the Social Security Act does not authorize CMS to regulate home and community-based settings. Recent Supreme Court precedent makes it clear that an agency cannot regulate without an express delegation from Congress.
- The Settings Rule's prescriptive provisions impose significant burdens on states and private individuals and organizations while interfering with the development of innovative service settings. Most important, the Settings Rule inhibits the individual's right to choose the setting that best meets his or her needs.
- [Over 80 organizations](#) serving individuals with I/DD nationwide support rescission.
- Rescission will unlock needed private investment in innovative settings, enhance individual choice, and go a long way toward meeting the shortage of residential and vocational settings needed by individuals with significant I/DD.



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different choices.

www.togetherforchoice.org