

Availability of Intermediate Care Facilities in the State of Iowa, in Comparison to Individuals in Need

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Objective: The Community Health Act/Deinstitutionalization

On October 31st, 1963, President John F. Kennedy signed into law The Community Health Act (CHA) of 1963. This Act was the first of several federal policy changes that helped begin shifting resources away from large institutions and pulling toward community-based mental health treatment programs. The Act provided grants to states for the construction of community mental health centers or CMHCs. The centers were required to provide five services: consultation and education on mental health, inpatient services, outpatient services, emergency response, and partial hospitalization.

The general hope for The Community Health Act of 1963 was to get institutionalized persons back into their community to provide a better outcome for their life. In the 1950's institutions were often unsanitary, inhumane, neglectful, and housed an environment for abuse of the individuals who resided there. It is no wonder that we welcomed this act with open arms. President Kennedy can be directly quoted stating: "I am proposing a new approach to mental illness and to mental retardation. This approach is designed, in large measure, to use Federal resources to stimulate State, local and private action. When carried out, reliance on the cold mercy of custodial isolation will be supplanted by the open warmth of community concern and capability. Emphasis on prevention, treatment and rehabilitation will be substituted for a desultory interest in confining patients in an institution to wither away." But what we failed to do was provide adequate resources and funding for the families utilizing HBCS and the CMHCs.

Method: Outcomes of CHA

A review of the research shows that by 1980, the patient population of psychiatric hospitals had declined by 75%. By 2009, that same population had decreased by 98%. One would think these numbers meant success, but there was collateral damage. Unfortunately, the outcome showed a failure of ability to provide support and treatment on individuals in home and community based settings. Only 650 community health centers were built. That was less than half of what was needed. They served 1.9 million patients.

Through the years, there were several more Acts including Lanterman-Petris-Short Act (1967), The Mental Health Systems Act(1980), The Omnibus Reconciliation Act(1981), and The Olmstead Act (1999). All of these acts were an extension of the original CHA and had one goal, as described by The Supreme Court in The Olmstead Trial: First, "Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life." Second, "confinement in an institution severely diminishes the everyday life

activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Autism

So where does autism come into place here? "Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects how an individual processes information and interprets the world. Core features of autism are persistent deficits in social interaction and communication, as well as restricted, repetitive or stereotyped patterns of behavior, interests or activities. Each individual with ASD displays a unique combination of characteristics, ranging from mild to severe, requiring individually determined educational and treatment programming. The first signs of autism appear in early childhood and can be detected by an experienced professional as early as 18 to 24 months of age. Early and accurate identification and intervention can change the trajectory for many children on the autism spectrum." (Iowa.gov.)

"One in 54 8-year-old children have been identified with autism, according to an analysis of 2016 data published today in CDC's Morbidity and Mortality Weekly Report (MMWR) Surveillance Summary." An estimated 40% of individuals with autism are non-verbal. Other comorbidities to autism include anxiety, depression, ADHD, an 8 times higher likelihood for gastrointestinal disorders, a higher rate of schizophrenia, and an estimated life expectancy of 36 years, due to elopement/drowning and higher rates of injury.

With this information, surely one can see why a home setting is not the best choice for every individual with autism. In addition, individuals with autism thrive in a routine setting. They may also require skilled nursing care, help with meals, showering, toileting, dressing, as well as specially designed locked doors and windows to prevent elopement and injury that a home setting cannot provide—or at least is not funded to provide, under HCBS at the current time. In an appropriately funded ICF, an individual can be kept safe and have all accommodations met, but what about community?

Caregiver Burnout

This brings me to the next topic of caregiver burnout. A parent of a child with autism experiences excessive amounts of daily stress. In addition, many children with autism have sleep disturbances, which make it difficult for them to fall or stay asleep. This combination leads to overworked and exhausted parents who cannot go beyond the regular duties of parenthood, let alone take their child out into the community to develop social skills. Several studies support this, showing that mothers of children with autism have cortisol levels similar to those of combat veterans. "The research looked at 395 parents of children ages 5 to 20 in Australia. Of the parents, 226 had a child on the spectrum while 139 had a child with a rare disease like Duchenne muscular dystrophy and 30 had typically developing children. All of the parents completed an online questionnaire about their children's behavior, traumatic stressors in their lifetimes and a checklist commonly used to assess symptoms of PTSD. None of the parents of typically developing children met the clinical threshold for PTSD. Among parents of

those with rare diseases, just over 12 percent met the criteria for a provisional diagnosis.”(Ali Schnabel, Deakin University in Australia)

Beyond the peer comradery that ICFs provide, refreshed workers/caregivers can spend time taking children on outings to social and community events. This can be impossible for some with high behaviors in a family setting because they often do not have the resources to provide protection of the child in public. Emergency scenarios would include elopement or self-injurious activity.

Technology

We have made incredible advances in technology since the inception of deinstitutionalization. Previously, facilities did not have the usage of live-feed cameras, on staff nursing, full-home security systems, transportation, training on holds and other safety precautions, or the mere advancements in communication that we now have for autistic individuals, such as Picture Exchange Systems or Assistive Technology Devices. These new advancements are the difference between thriving lives in an ICF, versus the previous dysfunctional existences that we saw in facilities in the 1950’s.

Conclusion: Intermediate Care Facilities

The definition of an intermediate care facility, per CHAPTER 82 INTERMEDIATE CARE FACILITIES FOR PERSONS WITH AN INTELLECTUAL DISABILITY [Prior to 7/1/83, Social Services[770] Ch 82] [Prior to 2/11/87, Human Services[498]] 441—82.1(249A) is as follows; “Intermediate care facility for persons with an intellectual disability (ICF/ID)” means an institution that is primarily for the diagnosis, treatment, or rehabilitation of persons with an intellectual disability or persons with related conditions and that provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination and integration of health or related services to help each person function at the greatest ability and is an approved Medicaid vendor. “Intermediate care facility for persons with an intellectual disability level of care” means that the individual has a diagnosis of intellectual disability made in accordance with the criteria provided in the current version of the Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association; or has a related condition as defined in 42 CFR 435.1009; and needs assistance in at least three of the following major life areas: mobility, musculoskeletal skills, activities of daily living, domestic skills, toileting, eating skills, vision, hearing or speech or both, gross/fine motor skills, sensory-taste, smell, tactile, academic skills, vocational skills, social/community skills, behavior, and health care.”

There are currently 41 ICFs in the state of Iowa for ages 5-18. ICFs are not to be confused with group homes, because for individuals with intellectual disability or severe autism, a group home is not a suitable setting for safety, nor would they be accepted. Astoundingly, ICFs will not admit an individual with intellectual disability or high behaviors—the very reason these facilities exist. Waitlists can be anywhere from 2-15 years for a spot. These are numbers that I have personally attained, from calling 20 facilities myself, to inquire about the waitlist.

Iowa has a population of 3.155 million as of 2019. 23% of Iowans are under the age of 18.

That's approximately 725,650 children. If 1 in 54 of those children have autism, that's 13,437.963. If we use the stat of the 40% of non-verbal individuals, we can even lower that to 30% for some wiggle room, we have an estimation that 4,031.3889 individuals with autism who may be in need on an Intermediate Care Facility at some point in their life. We currently have 41 facilities that hold anywhere from 4-20 individuals at any given time. 41 facilities x 20 spots = 820 beds. For 4,031 individuals. 4,031 families in crisis. 4,031 human beings who deserve to be supported both financially and in more ways than a typical home setting could ever provide. Now is the time to consider better funding for ICFs, because even under the best of circumstances, a home-based setting is not safe or equitable autistic children and their families. HCBS is not always the best choice.

Resources

<https://www.cdc.gov/media/releases/2020/p0326-autism-prevalence-rises.html>

<https://www.healthline.com/health/autism/autism-rates-by-state#2>

<https://educateiowa.gov/pk-12/special-education/programs-and-services/autism-spectrum-disorder-asd>

<https://dhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs/waivers>

<https://www.autismspeaks.org/autism-statistics-asd>

<https://www.disabilitycoop.com/2020/03/10/autism-parents-may-be-at-risk-for-ptsd/27951/>

<https://www.thebalance.com/deinstitutionalization-3306067>

<https://www.legis.iowa.gov/docs/publications/FCTA/798799.pdf>

<https://iowacompass.org/work/get-a-list-of-providers/>

<http://search.iowacompass.org/MatchList.aspx?k;;0;;N;0;0;Group%20Homes%20for%20Children%20and%20Youth%20with%20Disabilities>

<http://search.iowacompass.org/MatchList.aspx?k;;0;;N;0;0;Intermediate%20Care%20Facilities%20for%20Individuals%20With%20Developmental%20Disabilities>

<https://www.legis.iowa.gov/docs/ACO/chapter/441.82.pdf>