# Brief History and Future of Intellectual Disability Services in America

Scott Spreat 23 March 2017

*"Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18."*[1]

The intellectual and developmental disability sector has seen tremendous positive change since its inception in the U.S. in the mid-1800s. With the changes in technology and more innovative products and services, the sector will continue to evolve and to become more and more integrated within mainstream America.

## The Institutional Model Period

The institutional model came to the United States from Germany. Samuel Gridley Howe opened the Massachusetts School for Idiot and Feeble-Minded Youth in 1848. At that time, the institutional model was largely a self-sufficient agrarian model, in which persons who had what we would now call intellectual disability were removed from the stresses and tribulations of urban life. Persons living at the institutions would work the fields, growing crops that would support the people living at the institution. Designed as a humane, protective model, Howe’s was perhaps too successful for the good of the people living there. Reviewers of the program concluded that persons living in Howe’s program were so successful that they should live there permanently. Howe opposed this notion, arguing that individuals with mental disabilities had rights to participate in the community and should not be segregated. Note that Howe was also an abolitionist with opposition to other forms of segregation.

While conceived of as a kindly, educative type of setting, the state institution as a general model declined over time. The decline appears to have been at least a partial function of funding and social values. In 1912, Henry Goddard published his review of the Kallikak family of the Southern Pines region of New Jersey. He was able to trace back the Kallikak family to about the Revolutionary War era, and he concluded (inaccurately), based on the Kallikak family genealogy, that mental defects and criminality were somehow linked. The eugenics movement was associated with the gross devaluation of individuals with cognitive challenges, with the continued segregation of growing numbers of individuals in state developmental centers. Around this time, families who had children with any form of mental defect were encouraged by their physicians to place them in an institution and get along with their lives. Physicians argued that trying to keep the child within the family would not benefit the child and would potentially endanger the welfare of the family unit.

The institutional model continued through the early first half of the previous century, with increasing numbers of individuals being placed in institutions and minimal funding provided for their support. Institutions became overcrowded. Pennhurst Center in PA was designed to hold 700 individuals. At its peak census, 3500 individuals lived there. Crowding, lack of service, and peonage characterized the institutional model in the first half of the 1900s. Note that these shortcomings were worsened by the Great Depression and the costs associated with fighting two world wars.

## The Kennedy Era & the Introduction of Community-based Care

In 1960, John Kennedy was elected President. His sister, Rosemary, as a result of a botched frontal lobotomy, functioned as an individual with intellectual disability. She needed assistance in most areas of daily living. The Kennedy family placed Rosemary in St. Coletta's in Wisconsin. The Kennedy family had sufficient funds to pay the tuition to St. Coletta's until Rosemary died about 12 years ago; however, John Kennedy recognized that the typical American lacked similar financial resources. Private schools like St. Coletta's were not an option for the typical American family. Kennedy was familiar with the limitations of public institutions, having toured Massachusetts institutions when he was a Senator.

Kennedy created the President’s Commission on Mental Retardation. Bringing together a panel of clinical experts and advocates, he tasked them to recommend to him how to best serve/support individuals with what we now call intellectual disability. The commission reviewed literature, held hearings to gather the input from others, and toured other countries to learn about alternatives to the United States institutional model. They returned from the Scandinavian countries particularly impressed because these countries did not rely on the institutional model. They encouraged and supported families to keep their children at home and they rejected the notion that people should be segregated on the basis of intellectual ability. The commission came back to Kennedy with over 90 recommendations, which can be distilled to three:

1. There are 200,000 individuals currently living in institutions in the United States. The panel would like these institutions closed. To do this quickly would result in deaths. Thus, in the interim, conditions in the state centers must be improved.
2. A system of community-based supports must be developed and put into place so that individuals with what we now call intellectual disability can be part of our society.
3. When that system of supports is developed, the state institutions should be closed and people transferred to community based settings

At this point in time, state institutions were entirely funded by the states. Quality of care varied at least partly as a function of the wealth of the state and the amount of money that the state devoted to the institutions. In all cases, the quality of the state centers fell below the quality offered by the various private programs that charged families a tuition for their services. Kennedy and his successors engineered a way to supplement the state funding of state institutions with Medicaid dollars. This was the start of the Intermediate Care Facilities/Mental Retardation (ICF/MR) program, and under this program, states received an approximate match of state dollars in return for meeting some basic quality standards. Participation in the ICF/MR program, which was specifically targeted at large institutional programs, grew and quality of care did indeed improve. People were still segregated from the community, but the quality of care was enhanced. Arguably, the improved quality of care may have slowed the deinstitutionalization process.

Community supports became increasingly available. The Community Mental Health Center model initiated under the Kennedy administration made various forms of mental health services both available and affordable to the typical American. In Philadelphia, a group of parents sued the Pennsylvania Department of Education over the right to education for children with handicaps. The resulting consent decree (PARC Consent Decree) resulted in Pennsylvania guaranteeing a free and appropriate education for all children. This consent decree was followed by federal law (Education for all Handicapped Children) making a similar guarantee across the entire country.

While quality was improved in state institutions, major deficits were still evident. In New York, Geraldo Rivera went on the grounds of Willowbrook State Center with a hidden camera, and documented the horrors of life there for his television audience. In Philadelphia, local hero Bill Baldini conducted a similar investigation at Pennhurst State School and Hospital. Litigation followed both of these investigations, as well as over 30 other lawsuits filed across the country regarding the institutional model.

## Community Services Model

Ultimately, it was litigation that spurred the greatest growth of the community services model. Group homes were being used, but litigation ordering the closure of a number of state institutions prompted the growth of the group home model. In Pennsylvania, Judge Raymond Broderick ordered Pennhurst closed and all 700 residents placed in community settings. The federal government saw this as an opportunity to study and evaluate the impact of an institutional closure, and they awarded a research grant for that purpose to Temple University and the Human Services Research Institute. Local researcher Dr. Jim Conroy was the principal investigator. This study revealed that:

1. Skills increased when people moved to the community. To some extent, this was a function of greater opportunities to participate in domestic type activities.
2. People who moved to group homes experienced greater opportunities to participate in the rhythms of community life. In a sense, they were able to live an "everyday life."
3. People who were capable of answering interview questions reported that they were happier in the community.
4. People were better able to exercise choice.
5. Families reported equal satisfaction with the community programs as they had with the institutional programs. Note that there are legitimate methodological questions as to whether satisfaction surveys actually measure satisfaction, or whether they measure some sort of personality variable.
6. Community programs were cheaper, arguably on the backs of underpaid Direct Support Professionals.
7. Concerns regarding increased mortality do not appear to have a legitimate empirical basis.

As a combined result of litigation, legislation, and social values, group homes became the dominant form of residential support in 1991, with approximately 95,000 individuals living in group homes.

As increasing numbers of individuals were being served/supported in community homes, the recognition grew that the federal government was subsidizing the segregated institutional model via the ICF/MR program, but no similar supports were available to support people living in the community. In a sense, states were given a disincentive to actively explore community options because they paid roughly 50% of the costs of institutional care but 100% of the costs of community care. In 1991, the federal government initiated the Medicaid Waiver program that would extend a variant of the old ICF/MR program to community programs. This infusion of federal money further enhanced the growth of community programs. Currently, about 400,000 individuals with intellectual disability live in various community homes, while about 40,000 live in state developmental centers. Most individuals living in community homes are funded under the waiver program.

Today, community-based homes funded under a variety of federally approved Medicaid waiver plans are the dominant form of residential support for individuals who have intellectual disability. They do promote growth, integration, and consumer satisfaction. They are, however, expensive. Annual costs in excess of $200,000 per person are not uncommon. There are significant and legitimate questions as to whether the system of heavily funded community supports can be sustained. One might suggest that the mere existence of waiting lists in most states is evidence of the unsustainability of the model. For this reason, most administrative entities are activity exploring less expensive options such as adult foster care (sometimes called Life Sharing) and funding family members to take care of their family members at home.

With the shift from the ICF/MR medical model employed in institutional settings to a community-based support model came a shift in focus of interventions. Early interventions were, in a sense, directed towards fixing/repairing the broken person. Goals were team-selected to help an individual with intellectual disability become more like the typical person. This medical model has faded over time, with a growing emphasis on supporting the individual with disabilities to achieve his/her personally selected goals. Accommodation, rather than change, became the byword.

## The Future

Complicating our efforts to answer Kennedy’s question of what we should do with the people who have intellectual disability is the fact that the current term, intellectual disability, describes a broad and diverse group of individuals. Intellectual disability, while being inclusive of only about half a percentage point of the general population, includes individuals capable of attaining a high school degree and individuals who have been unable to develop basic personal care skills. The range included within the category is as wide as the range between mild intellectual disability and genius. The net impact of this diversity is the growing recognition that one size does not fit all. No program or regulation is going to work well across the entire spectrum of intellectual disability. Services, supports, and regulatory protections must be individualized and models must be developed whether in the healthcare or human services sector to better serve those individual needs.

We face a considerable challenge as we move forward. We continue to exist in a curious world in which the sellers of services and supports do not set the prices for those services and supports. Regardless of whether the label is managed care, fee for service, acuity-based funding, or some other term, the sellers of services and supports have lost control of pricing. In Pennsylvania, this loss of control is responsible for the fact that 1/3 of intellectual disability providers are losing money each year[2] (Spreat, in press) and the fact that Direct Support Professionals are paid something less than a living wage (Spreat, Brown-Mchale, & Walker, in press).[3] It seems unlikely that this funding model will change appreciably in the near future.

We are faced with the legitimate question of whether our existing system of supports and services can sustain against increasing demand for service, a stagnant economy, and a funding model that is not controlled by the sellers of services and supports. We must begin to develop innovative models, both technological and programmatic, that will enable us to do more with less. Examples might be wider adoption of smart homes that permit lower staffing levels in some cases, paying families to care for their family member who has a disability, providing in-home supports rather than residential supports, instituting back-office sharing strategies that will reduce costs, and cultivation of alternative funding streams that recognize the healthcare needs of the people being served/supported. It seems clear that efforts to continue doing business as we have been doing business will result in failure.

## References

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