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FROM YOUR FACILITY TO MY HOUSE: THE CHANGING FACE OF RESIDENTIAL SERVICES

- I. History
 - A. Community – Institute – Community
 - B. Samuel Gridley Howe/Gheel Connection
 - C. “Worthiness” and custodial connection
 - D. Institutional growth – 1867-1967
 - E. JFK/Civil Rights/Deinstitutionalization
 - F. Great Society – 1965 – Medicaid/Medicare
 1. Medicaid created as an insurance program for the poor
 - G. Title XIX – ICF/MR – First federal participation in residential services – not originally intended for people with disabilities
 - H. ICF/MR splits focus – one on improving institutions; the other on funding community services
 - I. ICF/MR splits again >16 and <16 different roles, same issues
 - J. 1967 – Institution census peaks at 250,000, begins dropping
 - K. Advent of HCBS Waiver – 1981 – Katie Beckett – focus started at home, not on provider community
 - L. Continued community growth – ENCOR Model takes hold – becomes part of national trend called “continuum”
 - M. Community providers proliferate – some agencies developed by parents, others by ARCs, some for profit, zoning issues
 - N. Continuum blossoms – where one lives determines the support one receives
 - O. 1985-1995 – Continuum challenges begin – advent of supported living/size issues
 - P. Key tenet emerges – separation of housing and services
 - Q. Some states begin supported living before waiver/some marry supported living and the waiver – very different issues emerge

- R. Some early generation residential providers begin conversion/agency transformation to supported living
 - S. Mid 90's – advent of Self-Determination – probably most significant development since ICF/MR and the HCBS Waiver – for the first time shifts control of money to the customer
 - T. 2000 on – retrenchment of Medicaid, advances in technology pose new issues, dilemmas, challenges and opportunities.
- II. Now What?
- A. Continued growth of Supported living and Self-Determination
 - B. Providers real estate has limited implementation of strategic march to self-determination
 - C. Federal grant through CMS begins New Freedom Initiative, Independence Plus and other waiver innovations, puts them ahead of most states and providers
 - D.
 1. Pending “perfect storm”: younger parents wanting a totally different service system than exists
 2. Existing parents of continuum generation are happy with current services; many of which are not best practices
 3. Increasing need and diminishing resources
 4. Emergence of new “boutique” models, microboards, microenterprises, parent/family-run services, “ala carte” contracting with providers for specific supports.
 5. People with disabilities outliving their parents. Previous continuum model based on “disability bubble” yields many individuals who are healthy, poor, segregated and lonely with poor social skills.
 6. The ultimate answer probably lies in changing the system one person at a time. We need more “do-search” than research. People with disabilities will be pilots and we will be navigators.