Proactively Redeploying System Resources:

Enabling Choice and Sustainability in Long Term Services and Supports

Connecticut General Assembly

I/DD Caucus

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Definitions

Intellectual/Developmental Disabilities: chronic mental and/or physical impairments which must be evident prior to the age of 22. They are likely to be lifelong and result in substantial limitations in three or more of the major life areas: self-care, receptive and expressive language, learning, mobility, self-determination, capacity for independent living and economic self-sufficiency.

State-Operated Institutions: development centers, training centers, state schools and designated IDD units in state psychiatric hospitals providing 16 or more individuals with IDD with residential services.

Institutional Closure: the state IDD agency has implemented or is implementing a legislatively sanctioned phase-out of the facility.

Source: Braddock et al, The State of the States in Intellectual and Developmental Disabilities, 2015; pp.26-2 and
U.S. Federal Register, Public Law 106-402 (Developmental Disabilities Assistance and Bill of Rights Act of 2000).

National Closure Trends

- In 1967, the residential population of individuals with IDD served in public and private institutions and nursing facilities peaked at 194,650 individuals in 165 state IDD facilities.

- From 1991 to 2013, the residential population declined from 171,897 to 73,609 (**-57%**). Most of this reduction occurred in public institutional settings; from 84,818 to 24,675 individuals served (**-71%**).

- From 1968 to 1990, **46** state-operated IDD institutions had been closed or were in the process of closure. From 1991 to 2013, the cumulative number of state-operated IDD institutions closed or in the process of closure increased by **130** to **176**.

- By 1991, NH and DC closed their last state-operated IDD institutions. By 2013, 14 jurisdictions no longer operated state-run IDD institutional facilities: AL, AK, DC, HI, IN, ME, MI, MN, NH, NM, OR, RI, VT and WV. In 2014, CO joined this group of states. In 2016, OK joined this group.

Source: Braddock et al, The State of the States in Intellectual and Developmental Disabilities, 2015; pp. 26-31.

Trend Accelerators

1. Geraldo Rivera's expose of Willowbrook State School in 1972.
2. Research:
   - showed that adaptive behavior in individuals with IDD that choose to move from an institutional setting to a community setting almost always improves.
   - showed that parents who were often initially opposed to deinstitutionalization were almost always satisfied with the results of a move to a community setting after its occurrence.
3. The *Olmstead v. L.C.* decision in 1999; U.S. Supreme Court ruling that stated that individuals had the right to live in the community if professionals determined it appropriate, be offered the opportunity to move from an institution to the community if they made an informed decision to do so.

Source: Lakin, K. Charlie and Stancliffe, Roger J., Residential Supports for Persons with Intellectual and Developmental Disabilities; Mental Retardation and Developmental Disabilities Research Reviews 13:151-159; 2007

http://www.nasddds.org/uploads/files/DefiningMeasuringHCBSResources/Lakin_and_Stancliffe_-_Res_Supp_IDD.pdf

http://www.nasddds.org/uploads/documents/EBP_Brief_1_Mar_14_2011.pdf

More Trend Accelerators

4. Average Costs of Public Institutional Settings (ICF/ID 16+)
   1990: **$144,905** annually in U.S.
   2013: **$255,692** annually in U.S.
   $413,180 annually in Connecticut

   vs.

   Average Costs of Private Institutional Settings (ICF/ID 16+)
   2013: **$98,951** annually in U.S.

   vs.

   Average Costs of Community Settings
   2013: **$26,708** annually for Supported Living
   $39,249 annually in Connecticut

5. Center for Medicaid Services Settings Final Rule Statement in 2014

6. Reallocation of Resources for Desired System Change

Source: Braddock et al, The State of the States in Intellectual and Developmental Disabilities, 2015; pp. 33, 34, 48.

https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-01-10-2.html

Two Methods: Only One Creates Benefit

Attrition vs. Proactivity:

Attrition: maintains lack of choice, rigidity of routine, and comparative isolation; emphasis on “care” (control); average costs rise as do questions of morality, access, efficiency and equity.

Proactivity: facilitates choice, individualization; comprehensive collaborative planning featuring a vision, timelines, roles, responsibilities and commitments; initial investment is necessary to lower average costs at the end of implementation; enables enhanced resource and service coordination.

A decision to do nothing is a decision to pursue attrition.

Common Strategies for Successful Outcomes

- Individuals with IDD:
  - robust person-centered planning process;
  - assurance of equal or better supports and services;
  - clarity on process, placement options, timelines.
- Families:
  - participation in person-centered planning, but subordinated to the choices of the individual;
  - assurance of equal or better supports and services;
  - process and planning transparency.
- Direct Support Workers:
  - participate in development of facility and individual plans;
  - access to vocational transitional services and job placement support;
  - commitment to collaborate with unions and other facility staff to minimize employment and service impact.

Common Strategies for Successful Outcomes

- Private Providers:
  - capacity expansion of provider services and staffing driven by individuals with IDD's placement choices and needs;
  - development of new community settings.
- State IDD Agency/Government:
  - present the vision;
  - provide assurance of equal or better supports and services;
  - develop planning and oversight mechanisms to assure diverse stakeholder input and transparency;
  - provide assurance that all settings are aligned with individual need and compliant with federal funding requirements;
  - identify job opportunities in community, department, other state agencies or other settings for impacted employees.
- Communities Local to Closure:
  - establish planning committees to receive input on plan implementation, community residential setting formation, economic development priorities and facility re-use.

What We Can Learn From Others

Examples from other States

	Vermont	Tennessee	Massachusetts	Pennsylvania
Facility	Brandon Training School	Greene Valley Dev. Ctr.	Fernald, Monson Templeton, Glavin	Norristown (civil), Hamburg
Individuals	181 (1990)	95 (2016)	329	202
Closure start	1976	1996	2008	2017
Closure finish	1993	2016	2014	2018-2019
% moved to community	90%+	DK	75%+	80%+*
Catalyst	Brace Decree (1980)	fed. invest.of cond./pract.	Olmstead Plan/Ricci Decision	Benjamin Settlement
Institutional Cost	$71,800 (1990)	$448,333 (2015)	$172,922/$233,902 (2014)	$330,200 (2015)
Post Community Cost	$53,900 (1990)	$156,184 (2015)	$95,000-$150,000 (2014)	$47,000-$145,170 (2015)
Employees Impacted	450	619	906	369 (2015)
Capacity Building	School transition In-home Support young adults/SS IDD + MI IDD w/ crim. record in crisis	quality management new provider support provider perf. surveys ind'l waiver-specific revs. psychotropic meds behavioral respite	commitment to serve all replication of clinical supports parallel quality mgmt. facility re-use efforts specialized respite services	transition efficiency "keep savings in budget" IDD + MI equiv. paymts to communties advocacy
Predominant solution	CTH	ongoing	CTH, CLA	becoming more varied
Employment Solutions	priority for state emp. campus job resources job fairs	campus job resources adult education needs/wants assessment	community res. dev. state job visibility retraining, job dev.	other PADHS jobs other PA state jobs community providers
Facility Re-Use	multi-use	TBD	sold, leased, TBD	State uses, sold, TBD
Proj. Closure Savings	N/A	N/A	$40,000,000	$175,400,000 annually**

It's About Making Choices

- Each person with IDD impacted by a closure made an informed choice of supports and services that were deemed appropriate and changed their residence to another setting of their choosing.
- Each state made a choice to use institutional closure as a tool to improve its support system for citizens with IDD. By enabling people with IDD to make choices, the state improved outcomes for those receiving services, lowered system costs, and increased system capacity and sustainability.

- **The Choice:**

No personal growth, high average costs, waiting lists

OR

Personal growth, budget savings, system sustainability

Reading List

Braddock, D. et al, The State of the States in Intellectual and Developmental Disabilities; 2015, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado/Department of Disability and Human Development, University of Illinois at Chicago; *distributed by The American Association on Intellectual and Developmental Disabilities*

Lakin, K. Charlie and Stancliffe, Roger J., Residential Supports for Persons with Intellectual and Developmental Disabilities; Mental Retardation and Developmental Disabilities Research Reviews 13:151-159; 2007 http://www.nasddds.org/uploads/files/DefiningMeasuringHCBSResources/Lakin_and_Stancliffe_-_Res_Supp_IDD.pdf

Conroy, James W., Lemanowicz, James A., Feinstein, Celia S., and Bernotsky, Joan M., 1990 Results of the CARC v. Thorne Longitudinal Study; The Connecticut Applied Research Project Report Number 10; 1991 https://static1.squarespace.com/static/53dfdc3be4b0a86a2dbf76ae/t/5671ccbdcbced6829d5f191b/1450298557957/1990+Results+of+the+CARC+Vs+Thorne+Longitudinal+Study.pdf