

The Role of Stakeholder Groups – The Deinstitutionalization Experience in the United States

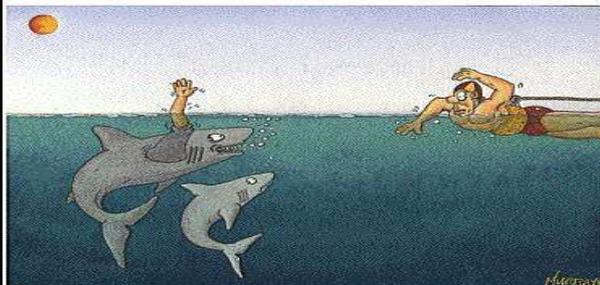
- Moving from facility and program-based services to individual designed and controlled services.



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Things are not always as they seem.



"SEE SON...THIS IS WHY I SAVE THESE BITS."

What have we learned?

- The facilities that have closed were mostly publicly operated facilities
- Some privately operated facilities has closed, both voluntarily and involuntarily.

**Closure
must not be
the goal!**
**Closure is
about
buildings.**

No central authority for institutions

- **Federal Role**
 - Financing, through ICF/MR Program-part of a state's Medicaid plan
 - Standards-through regulations
 - Oversight of state single survey agency
 - Oversight through CRIPA-Justice Department
 - DD Act – philosophy but no \$
 - New Freedom Initiative 2000
 - Goal was to make deinstitutionalization easier
 - Slowest rate of deinstitutionalization in decades
- **State Role**
 - Licensure or certification
 - Match Federal \$
 - Direct Operation of institutions and funding of private institutions

Children and deinstitutionalization

- **Individuals with Disabilities Education Act**
 - Once children with significant disabilities could attend school, institutional numbers dropped significantly

Facilities Closed due to...

- **Litigation** – Willowbrook, Pennhurst, Partlow (after more than 3 decades)
Fairview and dozens of other
 - Becoming Riskier – more than 50% of Federal District Court (trial) Judges have been appointed by Presidents Bush I, Regan and Bush II)
 - Conservative ideology suspicious of individual rights and supportive of states' rights
 - Multiple negative precedents eliminating many of the legal theories previously available
- **Advocacy** – State level advocacy convinced legislatures and/or governors that it was the right thing to do
- **Professional leadership**-within the state disability agency
- **Political leadership**
 - Frequently as a cost saving or anti-union initiative

Some states have closed all institutions

- Alaska
- DC
- Hawaii
- Maine
- New Hampshire
- New Mexico
- Rhode Island
- Vermont
- West Virginia and
- Minnesota
 - Population ~5 Million

Populations continue to decline

- Population peaked in 1967 – beginning of deinstitutionalization movement
- ~40,000 people remain in large state facilities, down from ~130,000 in 1980
- Most people with Intellectual Disability live with family
- 75% of people in facilities over 16 are in privately operated facilities
 - Next wave of deinstitutionalization will be these facilities and large group homes
 - Will be more difficult due to politics

Huge Inter-state variability in % of people with Intellectual Disabilities in Institutions

- Due to state control, leadership and philosophy
 - 47 States most people in residential care of < 6 beds
- Due to weak Federal role

Gone-RIP

- Alabama
 - Glenn Ireland
 - Albert P. Brewer Developmental Center (2004)
 - Lurleen Wallace Developmental Center (2004)
 - J.S. Tarwater Developmental Center (2004)
- Alaska
 - Harborview
- Arizona
 - Phoenix
 - Tucson
- California
 - Camarillo
 - DeWitt
 - Modesto
 - Napa
 - Stockton

RIP, cont.

- Colorado
 - Pueblo
- Connecticut
 - Mansfield
 - New Haven
 - Waterbury
- District of Columbia
 - Forest Haven
- Florida
 - Orlando
 - Tallahassee
- Georgia
 - Brook Run
 - River's Crossing
- Hawaii
 - Waimano

RIP, cont.

- Illinois
 - Adler
 - Bowen
 - Dixon
 - Galesburg
 - Kiley
 - Lincoln Developmental Center (2002)
 - Meyer
- Indiana
 - Central State
 - Muscatatuck Developmental Center (2005)
 - New Castle
 - Northern Indiana
- Kansas
 - Norton
 - Winfield
- Kentucky
 - Frankfort
 - Outwood

RIP, cont.

- **Maine**
 - Pineland
- **Maryland**
 - Victor Cullen
 - Great Oaks
 - Henryton
 - Highland Health
- **Massachusetts**
 - Belchertown
 - John T. Berry

RIP, cont.

- **Michigan**
 - Alpine
 - Coldwater
 - Fort Custor
 - Hillcrest
 - Macomb-Oakland
 - Muskegon
 - Newberry
 - Northville
 - Oakdale
 - Plymouth
- **Minnesota**
 - Fairbault
 - Moose Lake
 - Owatonna
 - Rochester

RIP, cont.

- **Missouri**
 - Albany
 - Hannibal
 - Joplin
 - Kansas City
 - Kirskville
 - Poplar Bluff
 - Rolla
 - Sikeston
 - Springfield
- **New Hampshire**
 - Laconia
- **New Jersey**
 - Edison
 - Johnstone
 - North Princeton

RIP, cont.

- **New Mexico**
 - Fort Stanton
 - Los Lunas
 - Villa Solano
- **North Dakota**
 - San Haven

RIP, cont.

- **New York**
 - J.N. Adam
 - Bronx
 - Craig
 - Gouverneur
 - Letchworth
 - Long Island
 - Manhattan
 - Newark
- Rome
- Sampson
- Staten Island
- Syracuse
- Valatie
- Westchester
- Wilton

RIP, cont.

- **Ohio**
 - Broadview
 - Cleveland
 - Orient
 - Springview Developmental Center (2005)
 - Apple Creek Developmental Center (Feb. 2006)
- **Oklahoma**
 - Hissom
- **Oregon**
 - Columbia Park
 - Eastern Oregon
 - Fairview

RIP, cont.

- Pennsylvania
 - Cresson
 - Clark Summit
 - Embreville
 - Holidaysburg
 - Laurelton
 - Marcy Center
 - Mayview
 - Pennhurst
 - Philadelphia
 - Somerset
 - Western

RIP, cont.

- Rhode Island
 - Dix Building
 - Ladd Center
- South Dakota
 - Custer
- Texas
 - Fort Worth
 - Travis
- South Carolina
 - Clyde Street
 - Live Oak

RIP, cont.

- Vermont
 - Brandon
- Washington
 - Interlake
- West Virginia
 - Colin Anderson
 - Greenbrier
 - Spencer
 - Weston

How many feel this?



Closure is the vehicle.

The goal is to let every person pursue the American dream.
It is about freedom and the opportunity to experience the community.

All people benefit from pursuit of the American Dream

- You cannot pursue the American dream when in a large facility, out in the country, with each minute of your day planned and no public transportation

Closure is the vehicle, not the goal.

- Resistance to closure is growing stronger.
- The organized resistance does not play by the same rules as those promoting community inclusion.
- We are selling, albeit poorly, freedom, opportunity and the promise of a better life.
- They are selling fear, lies and someone else's agenda.

Closure is the vehicle, not the goal.

- The challenge is both political and programmatic
- The decision to close an institution is political
 - It is about resistance to change
 - It is about fears
 - It is about jobs
 - It is about the economic impact on local communities
 - It has nothing to do about what is best for people with intellectual disability

Closure is the vehicle, not the goal.

- The opponents of deinstitutionalization have been:
 - Some families of people in institutions
 - AFSCME (a public employees union)
 - Other Unions - SEIU – another major union, has signed the Community Imperative
 - Employees of facilities
 - Elected officials-facilities=jobs
 - Local business-facilities buy goods and services

We need to market the agenda of community inclusion

- It is honest and proud.

We need to market the agenda of community inclusion

- It is counterintuitive.

We need to market the agenda of community inclusion

- Must be sold on benefit, not price.
 - We have started talking about outcomes, not costs
 - Have begun to focus on how people live and deemphasize how much it costs to support them
 - Once you get into the argument of price, then people with significant disabilities who may cost more to support, loose.
 - It is about the cohort cost, not the individual cost.

We need to market the agenda of community inclusion

- It is pro-family, pro-community, pro-individual freedom.
- Institutions are:
 - anti-family
 - anti-community
 - big-government and
 - anti-freedom.

We have begun to talk about it differently

- Not deinstitutionalization, but developing community capacity for all people
- Inequity of resources between those in institutions and those at home with families
 - Same people, different support
 - Incentives in the wrong place

We need to do a better job...

- | | |
|--------------------------------------|------------------------------------------|
| ■ Growing community based leadership | ■ Acknowledging the problems we have |
| ■ Developing infrastructure | ■ Working with the health care community |
| ■ Fighting apathy | ■ Fixing what's broken |
| ■ Educating the public(s) | ■ Speaking with one voice |
| ■ Fighting dis-information | |

It is not automatic

- We must build infrastructure.
- We need to change the existing system of services and supports.
- As long as institutions exist, state governments turn to them first...
 - to fix buildings
 - fill beds in response to pressure for residential services
 - give staff salary increases
 - to replace funds lost due to decertification.

The Community Imperative

The Time Has Come

The last decade has seen remarkable changes in how services and supports are delivered.

- Institutions continue to decline in population, and those who remain are aging rapidly.
 - No one wants them.
 - They are expensive.
 - They are not good for people.
 - They are especially bad for people with significant disabilities.

But the language and rhetoric far exceed the reality for most people.

- As Americans, we have an edifice complex.
- When we see people who are different, we think “program”.
- When we think “program” our default position is building.
 - In part, an artifact of our roots in education.

So how do we deliver on
The Promise of Community-Based,
Long Term
Supports and Services
for **All**?

Heard from the fashion students walking the corridors in Allison Hall...

“**Brown** is the new black.”

In our world.....

Workshops are the new institutions.

For people with disabilities...

- Services and supports are not the goal.
 - They are the vehicle to a meaningful life.



- The vehicle needs a tune up.

It's A Living Museum ...



Thanks to Gary Smith from HSRI for this slide

Services and supports for people with disabilities are highly fragmented.

- Happened because of how policy is made in Washington and State Capitals.
- Risky to change all at once.
- How we integrate supports can be improved.
- Many people are committed to a particular line or model.

Silos are good for storing corn



They are not so good for people with disabilities.

There are two issues with Silos...

Silo Type 1

Silos that represent the different areas of community life that are readily crossed by people without disabilities – and where some people with disabilities need support.

Silo Type 2

Silos that are disability specific programs, by category, with varying eligibility and services.

What do we want from the silos?

- Is the goal to make the silos bigger?
- Is the goal to make it easier to move from silo to silo?
- Or is the goal to find something better than silos?

Why Silos?

Silos were built for specific purposes by families, professionals and advocates and, in many ways are functional.

Why Silos? *continued*

- They allow a focus for identification, legislative advocacy, rules and regulations and an affinity group for discussions and debates about common issues.
- The question is...*have they outlived their usefulness?*

Medicaid, CMS and People in institutions

- Medicaid is the overwhelming financing vehicle for people receiving services and supports.
- CMS policy and regulations are based on outmoded concepts.
 - Recognizes providers and not families.
 - Doesn't like things that are non standardized.
- Medicaid will change and people with disabilities, families, advocates and professionals must be part of shaping how it changes.
- The individual entitlement must be maintained.
- Medicaid's institutional bias has been partially eliminated.

To finish deinstitutionalization and implement second order development of community inclusion, we can learn from our mistakes, and the mistakes of others.

Dead Horse Story

Common advice from knowledgeable horse trainers includes the adage, "When the horse dies. . .dismount."



Thanks to Val Bradley from HSRI for the Horse Story Slides

Seems simple enough.

However, we don't always follow that advice. Instead, we choose from an array of other alternatives:

- Buying a stronger whip
- Switching riders
- Moving the horse to a new location
- Changing the fee schedule for riding a dead horse
- Appointing a committee to study the horse
- Creating dead horse riding standards

Or, Maybe . . .

- Reorganizing the stables
- Developing a training course for riding a dead horse
- Complaining about the state of horses these days
- Starting a pilot project to demonstrate new ways to ride a dead horse
- Getting an advocate for the horse
- Blaming the horse's parents. The problem is often breeding

To implement second order deinstitutionalization, the provider community **must** reposition itself to assure it is truly responsive to individual needs, as determined by the individual.

How?



- Accept that community-based supports and services are not a place.
- The movement to deinstitutionalization has mostly been about state owned real estate. Private institutions are next.
- Changing to individualized budgeting and person centered planning is going to happen, so embrace it.

Opportunities for providers in the future.

- Become obsessed with meeting customer needs
- Conversion of programs that are facility based to those that include people in the life of the community
- Growth due to innovation
- Merger/collaboration to build infrastructure
- Be the organization people come to when they have the opportunity and portability of support funds.

Challenges

- Workforce
- Benefits and indirect costs
- Public perception of not-for-profit community as unreliable, dishonest and untrustworthy
- Increased accountability and government oversight without increased support
- Same store sales
- Increased demand without increased support
- Financial support for change and innovation-transition financing

Some possibilities

- Market innovation.
- Train and support lower level staff to adapt, make decisions, take action.
- Clean up the mess that a few have left for the many.
- Be flexible, responsive.



The Challenge Lies in Changing What We, Not Others, Have Developed

- It was easier when we could blame the “bad” institutions.
- Much of what is wrong now is what “we” created.
- As we wanted to do good things for people, how could this be?

The Challenge *continued*

- Providers of services are doing what we asked them to do.
- We are now telling them they must change!
- Debate and discussion are good, but not changing is ***not*** acceptable.

People Who Earn Their Livelihoods in Systems Will See Major Changes

- They must be nurtured and supported as we move forward
- They are not the enemy
- Providers are not the enemy
- The state is not the enemy
- ***Complacency is the enemy***

We have promised two generations of families and people with intellectual disability so much

- Inclusion
- Self-Determination
- Services and supports when needed
- Acceptance in their community
- Chance at the American Dream
- A job, a decent place to live, friends

Yet...

- Are we prepared to deliver?
- Do we have the courage of our convictions?
- Do we have what it takes?
- Can it be done?
- Can it be done in every state?

There Are Problems with the Quality of Services and Supports

- Many people are not getting what they want or need.
- Community services are a necessary but not sufficient part of a good life.
- The voice of families, consumers and concerned citizens must be strong.
- Government and “cookbook” programs cannot do it alone.
- Federal policy for supports and services still has a bias toward congregate settings.
- Mainstream institutions still discriminate.
- Over 2/3 million adults live with parents over 65.

Advocacy is moving from access and quantity to quality and outcomes.



- Services and Supports Are the Means to an End, Not the End Itself.
- There is a difference between a high quality of services and supports and a high quality of life.

Future Advocacy Challenges

- Develop both process and outcome standards and/or measurements for advocacy.
- Develop sustainable financing vehicles for individual advocacy.
- Dealing with Big-Money Interests at systems and political levels.

Challenges *continued*

- Move advocacy from quantity and access to quality and outcomes.
- Manage Advocacy and Self-Advocacy so that they work together when need be, separately when called for.
- Balance individual rights and responsibilities.
- Differentiate between wants and needs.

Challenges *continued*

- The tidal wave of baby-boom retirements and the impact on state and Federal revenues.
- Working in coalitions while maintaining specific interests and identity, as well as the needs of constituents.
- Involvement of grassroots in systematic advocacy, not just specific issues.

How can each state meet these challenges and deliver on the promise of Community-Based, Long Term Supports and Services for **All**?

Three solutions.

- 1 Not another dollar to agencies. Freeze it where it is now and move all the new money immediately to person controlled supports, and phase in the transition of existing funds to the people.

Three solutions.

2 Everyone must work with legislators to solve whatever problems we all face.

Three solutions.

- A five year plan to get rid of the old, segregated ideas and programs...the ones that separate people from their communities.

It can be done

- We know how to do it
- Some are doing it well
- It will be hard work
- Most important work is hard.



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