

Where have we been?  
Where are we going?  
Why are we going there?  
How are we going to get there?  
What will we do once we're there?



Steven M. Eidelman  
H. Rodney Sharp Professor of Human Services Policy and Leadership

UCEDD Leadership Institute  
June, 2012  
Newark, DE

With Thanks to Valerie Bradley (A National Leadership consortium partner) at HSRI  
and John Paul, Partner, Association Works

Are great leaders born or made?

- Yes.
- ☐ All are born.
- ☐ Most are made.



2

## Leadership

- ☐ \*Leadership is an observable set of skills and abilities that are useful whether you are in the executive suite, on the front lines, or in between
- ☐ \*Any skill can be strengthened, honed, enhanced, given the motivation practice and feedback, role modeling and coaching.
- ☐ The instrument of leadership is the self.
- ☐ Leadership is not an affair of the head. Leadership is an affair of the heart.\*\*

☐ \*Paraphrased from Kouzes and Posner p. 386  
☐ \*Kouzes and Posner, P. 399

3

## Warren Bennis (from 2007)

- ❑ "psychologists still tend to see leadership as an individual phenomenon. But, in fact, the only person who practices leadership alone in a room is the psychotic."
- ❑ "leaders do not exist in a vacuum"

4

## Great Leaders

5

## Great Leaders

- ❑ Martin Luther King, Jr.
- ❑ Colin Powell
- ❑ Benazir Bhutto
- ❑ Winston Churchill
- ❑ Barack Obama
- ❑ Michelle Obama
- ❑ Bill Clinton
- ❑ Hillary Clinton
- ❑ Bill Gates
- ❑ Mother Theresa
- ❑ Bono
- ❑ Biblical Figures

6

### Other great leaders.....

- |   |  |
|---|--|
| <input type="checkbox"/> Martin Blain       | <input type="checkbox"/> Marie-Christin Potvin |
| <input type="checkbox"/> Lisa Cauble        | <input type="checkbox"/> Stacey Ramirez        |
| <input type="checkbox"/> Gina Cook          | <input type="checkbox"/> Ann Riley             |
| <input type="checkbox"/> Susan Fox          | <input type="checkbox"/> Kelly Roberts         |
| <input type="checkbox"/> Lori Garnes        | <input type="checkbox"/> Amy Sharp             |
| <input type="checkbox"/> Tierney Giannotti  | <input type="checkbox"/> Ann Marie White       |
| <input type="checkbox"/> Shelly Grinde      | <input type="checkbox"/> Marian Williams       |
| <input type="checkbox"/> Margaretha Izzo    | <input type="checkbox"/> Dalun Zhang           |
| <input type="checkbox"/> Colleen McLaughlin | <input type="checkbox"/> Naomi Brickel         |

7

### Past, Present and Future

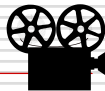
- ☐ The more things change. . .
- ☐ Recent milestones
- ☐ The power of ideas
- ☐ Self-Determination:  
the outlines
- ☐ Pesky constraints
- ☐ What can we do?



This slide from the Late Gary Smith

8

### Looking Back

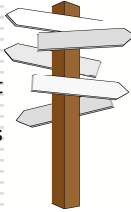


- ☐ 20<sup>th</sup> Century begins with optimism
- ☐ Moral treatment and notions of asylum
- ☐ White House Conference on Child Health  
in 1930 asserting society's responsibility
- ☐ Great Depression and the eugenics  
movement
- ☐ Institutional overcrowding after WWII
- ☐ 1960s – Kennedy Administration -  
beginning of reform era

9

## Major Milestones

- ☐ Engagement of the courts in state systems
- ☐ Engagement of federal policy makers in needs of people with disabilities
- ☐ Engagement of families and people with disabilities as advocates
- ☐ Closure and phase down of institutions
- ☐ Movement to individual supports
- ☐ Emphasis on outcomes
- ☐ Exploration of self-determination
- ☐ The supports paradigm



10

Things are not as they were, at least in the U.S.

### CHRISTMAS IN PURGATORY



A Photographic Essay on Mental Retardation

BURTON BLATT

FRED KAPLAN

## Or are they?

**"Killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all."**

**Professor Peter Albert David Singer, 2003  
The Ira w. DeCamp Professor of Bioethics  
Center for Human Values, Princeton University**

## And then there is....



Eight states are sending autistic, mentally retarded, and emotionally troubled kids to a facility that punishes them with painful electric shocks. How many times do you have to zap a child before it's torture?

— By [Jennifer Gonnerman](#)

<http://motherjones.com/politics/2007/08/school-shock>



After a decade of trying, disability advocates in the US, led by Nancy Weiss, have finally gotten the U.S. Department of Justice to investigate. 31 national disability organizations signed onto a letter in September, 2009 to the Department of Justice about practices at the Judge Rotenberg Center and DOJ has agreed to investigate.

Despite repeated requests, Human Rights Watch and Amnesty International express no interest in ending this practice.

## And also....

### School is Not Supposed to Hurt:

Investigative Report on Abusive Restraint and Seclusion in Schools



### The ID/DD System - Where Civil Rights and Science Intersect

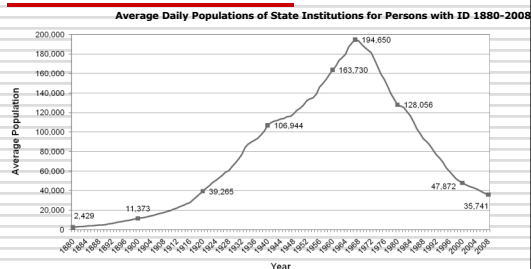
- Changes in the field in the past 50 years have been driven first by rights:
  - Programmatic
    - Early Intervention
    - Special Education
    - Deinstitutionalization and Community Living
    - Employment and economic self sufficiency
  - Law
    - Section 504 of the Rehabilitation Act
    - P.L. 88-164 created the predecessors to the UCEDDS/LEND
    - The Developmental Disabilities Act
    - The Americans with Disabilities Act
    - The Olmstead Supreme Court ruling
- In many cases the science is still catching up
- Many environmental and attitudinal barriers remain
- Practice, in most places, is very far behind

## Achievements ....

- ❑ Community-centered systems that offer more diverse and flexible services and supports, in many places
- ❑ Steady progress toward embracing the principles of person-centered supports, in many places though the embrace is stronger than the practice
- ❑ Massive infusion of dollars into the community, in most places
- ❑ **Heightened expectations:** People and families now expect that public systems will provide them the help they need to live and participate in the community
- **This is a double edged sword**

16

## Every year fewer people live in institutions



UNIVERSITY OF MINNESOTA  
Driven to Discover

## Despite Progress...

- ~ 35,000 people remain in large state institutions
  - They are trapped there due to the political clout of employee unions, rural legislators and families who have guardianship over them
- ~ 90,000 people are still in ICF/MR's though the number continues to decline
  - 20,000 of the 90,000 in large private ICF/MR's
  - Michigan and Oregon are ICF/MR Free Zones
- ~ 50,000 people in large private non-ICFMR facilities
- ~25,000 people are in nursing homes

## The System Has Grown Rapidly

- In 2005, over 344,000 individuals with DD were living in small, community-based settings

- 700% increase since 1982

Lakin, K. C. Challenges of the environment for services and supports. presentation. July 7, 2006. Newark, DE

19

## It all began with a rejection of the Medical Model of Care in the 1970's

- It expressed itself in the move from institutional care to community care.
- Some things that were thrown out, especially the thoughtful participation of physicians, dentists and nurses and must be brought back, albeit differently, into our thinking and practice

20

## The Tale of Four Ideals



Slides adapted, with permission from Val Bradley, HSRI

21

## Ideal 1 -- Illuminates Institutions



Large institutions are exposed as places that strip individuals of their humanity and connection with society; community system is the vision

22

---

---

---

---

---

---

---

## Ideal 1 + 2 -- Attack Segregation



"Home-like" and "job-like" programs are criticized because they enforce segregation and do not lead to community membership

23

---

---

---

---

---

---

---

## Ideals 1 + 2 + 3 -- Shift in Power



For people to have lives that they choose and to be supported in ways that facilitate their preferences, people must have control over the distribution of resources.

24

---

---

---

---

---

---

---



## Ideals 1 + 2 + 3 + 4- The Supports Paradigm



For people to have lives that they choose and to be supported in ways that facilitate their preferences, we need to understand the what and how of supports..

25

---

---

---

---

---

---

---

## Ideals 1 + 2 + 3 + 4+?



During your careers there will be another powerful idea (s) that will help to enhance and sharpen our vision --  
**Your job is to make sure that we are ready to receive it. To help evaluate it. To train people in it.**

26

---

---

---

---

---

---

---

What's next?

27

---

---

---

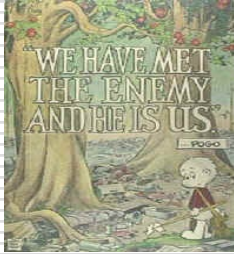
---

---

---

---

## Formidable Factors Limiting Change



Walt Kelly, Pogo, Earth Day, 1970

- The very practices and systems that need to change are the ones developed, as innovative, by the current generation of leaders.

28

Change is about people  
and behavior...

not about bylaws, structure,  
regulations or policies.



29

## Fear Of Losing

<b>Job</b>		<b>Friends</b>
<b>Focus</b>	<b>Power</b>	
	<b>Reputation</b>	<b>History</b>
<b>Connection</b>		<b>Respect</b>
<b>Competence</b>	<b>Culture</b>	<b>Prestige</b>
<b>Passion</b>	<b>Input</b>	<b>Control</b>

30

---

If I had an hour to save the world, I'd spend 55 minutes defining the problem.

- Albert Einstein

---

31

---

---

---

---

---

---

---

### Why is it?

---

- We live in the age of
- But some still promote congregate care setting and even institutions as service models .....villages, gated communities, etc.



32

---

---

---

---

---

---

---



---

Active Treatment, Unicorns, The need for institutionalization, QMRP's and other mythical creatures and concepts.

33

---

---

---

---

---

---

---

## Medicaid Institutional Context

- Because of Medicaid, people have needed to demonstrate the need for Institutionalization and Active Treatment to live in the community.
  - There is no such thing as the need for institutionalization.
  - No one has ever actually seen active treatment.
    - Apparently, it occurs on three days each year in select locations

34

We have learned that All people benefit from pursuit of their dreams

- **Fixing-improving institutions cannot be an option.**
- **Why try to do a good job doing the wrong thing?**
- **But if your state needs help and you are on soft \$.....**

35

## What have we learned?

- People with disability do better outside of institutions than inside of them.
- This holds true for all levels of disability.
- **Community Supports can be developed in a cost-effective manner.**

36

Saying to families that people are going to live independently



The goal is interdependence, self governance and control of the major variables in your life.

---

---

---

---

---

---

---

No one in this room lives independently

- ☞ We are all interdependent
- ☞ Interdependence builds social capital
- ☞ Social capital strengthens communities
- ☞ Talking about independent living scares families
  - It scares me

---

---

---

---

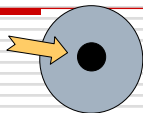
---

---

---

## What To Do???

We can't stay  
on this spot



We need to rethink what we do – affirm our values but resolutely search for “value”

---

---

---

---

---

---

---

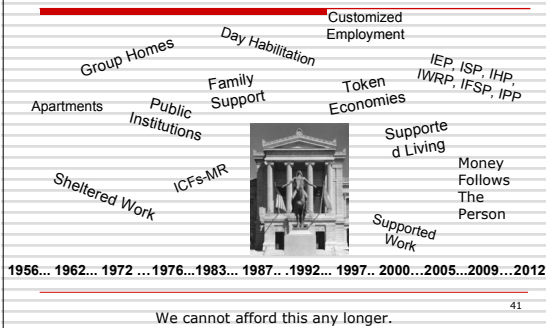
## How?



- ❑ Accept that community-based supports and services are not a place.
- ❑ The movement to deinstitutionalization people 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.

40

## It's A Living Museum ...



41

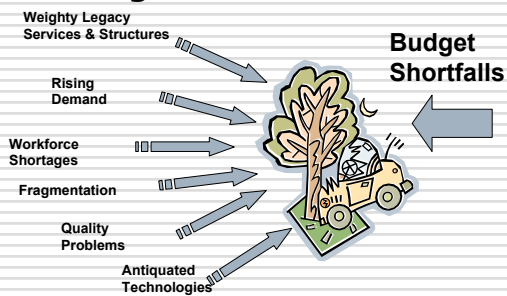
To finish deinstitutionalization and implement second order development of community inclusion, we can learn from our mistakes, and the mistakes of others.

42

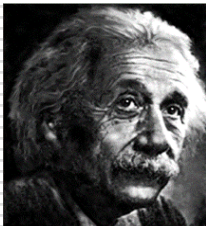
## Mistakes to be corrected....

- ☐ Sheltered workshops
- ☐ Group homes where people are placed
- ☐ Segregated education
- ☐ Re-named institutions
- ☐ Programs that separate people from the communities in which they live
- ☐ Rejection of medical professionals
- ☐ Others?

## Heading for a crash!



44



*The significant problems we face can not be solved at the same level of thinking we were at when we created them.*

Albert Einstein

45

So given all our constraints, what now?

The trouble with our times is that the future is not what it used to be.

Ambroise Paul  
Toussaint Jules  
Valery 1871-1945



The future ain't what it used to be.

Yogi  
Berra

"Well, there it goes again. ... And we just sit here without opposable thumbs."

46



**Steven M. Eidelman**  
**312 Alison Hall West**  
**Newark, DE 19711**  
**302-831-8536**  
**sme@udel.edu**

The National Leadership  
Consortium on Developmental  
Disabilities



47