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?

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Are great leaders born or made?

- Yes.
  - All are born.
  - Most are made.
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
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”
Great Leaders
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
Other great leaders.....

- Rebecca Brightwell
- Carrie Coffield
- Julisa Cully
- Rhonda Eppelsheimer
- Christina Espinosa
- Jacy Farkas
- Wilbert Francis
- Brian Freedman
- Karen Health
- Susan Hetherington
- Bruce Keisling
- Brooke Lovelace
- Floyd Masga
- Darren McIntyre
- Kathy Miller
- Joel Nudi
- Sunny Onyeabor
- Elizabeth Perkins
- Ilka Riddle
- Susan Russell
- Erika Ryst
- Michelle Schladant
- Leo Schlosnagle
- Laura Stough
- Jesse Suter
- JoAnn Yuen
Past, Present and Future

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

- 20th 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
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
Things are not as they were, at least in the U.S.
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
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

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

NATIONAL DISABILITY RIGHTS NETWORK
Protection & Advocacy for Individuals with Disabilities
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
Every year fewer people live in institutions

Average Daily Populations of State Institutions for Persons with ID 1880-2008
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

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
The Tale of Four Ideals

1970's
Normalization

1980's
Inclusion

1990's
Self-Determination

2000's
Supports

Slides adapted, with permission from Val Bradley, HSRI
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.
Ideal 1 + 2 -- Attack Segregation

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

Normalization + Inclusion + Self-Determination
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..
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.
What’s next?
Formidable Factors Limiting Change

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

Walt Kelly, Pogo, Earth Day, 1970
Change is about people and behavior... not about bylaws, structure, regulations or policies.
Fear Of Losing

Job, Friends
Focus, Power
Connection, Reputation
Competence, History
Passion, Respect
Culture, Prestige
Input, Control
If I had an hour to save the world, I’d spend 55 minutes defining the problem.

- Albert Einstein
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.
Active Treatment, Unicorns, The need for institutionalization, QMRP’s and other mythical creatures and concepts.
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.
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 $......
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.
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 of 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.
It’s A Living Museum ...

Customized Employment

Group Homes  Day Habilitation

Apartments  Public Institutions

Family Support  Token Economies

ICFs-MR  Supported Living

Supported Work  IEP, ISP, IHP, IWRP, IFSP, IPP

We cannot afford this any longer.
To finish deinstitutionalization and implement second order development of community inclusion, we can learn from our mistakes, and the mistakes of others.
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!

Weighty Legacy
Services & Structures

Rising Demand

Workforce Shortages

Fragmentation

Quality Problems

Antiquated Technologies

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

Albert Einstein
We, as a field, beginning with those with intellectual and developmental disabilities and their families, and including professionals, advocates and policymakers need to have some serious and difficult conversations and develop solutions to many of the challenges facing us.
We need to begin some very difficult conversations to be certain of where and how we want to go before people who do not care much make the decisions for us.

And I need to find more diverse clip art…
Conversation #1
What are families responsible for when their family member with a disability is an adult?

- The old assumption of people moving out of their parent’s home in their twenties, with public support, may no longer be operable
  - What is the new paradigm?
  - What are the new assumptions?
- The ABLE Act
Conversation #2
Inside baseball

☐ Are we willing to tolerate those who continue to advocate for (and are frequently successful) segregated, isolating and expensive services?
Conversation #3
How much is enough?

☐ Some of the early designs of self-determination, person centered, individually controlled supports went to people with well informed families.

☐ Can we afford it?
  ■ What about those who have nothing?

☐ Are we willing to review what is now paid for and change the nature of supports for some people so that those with little or nothing can have something?
Conversation #4

There is no excuse not to know.

- Information dissemination and knowledge management crucial to future success
- Research dissemination in useable formats a shambles
- Much research is the CAT scan framework
- Can we have conversations about reallocation of research dollars and dissemination of research findings to influence policy and practice?
  - In formats useful to mere mortals?
Conversation #5
Can we get serious about technology?

☐ We have barely scratched the surface.
☐ The issues about “big brother,” privacy and control must be addressed.
☐ Given labor force demographics and systems model challenges, the upside of technology is significant.
Conversation #6
How to take leading edge practices to scale?

- Many organizations doing innovative things
- Most are small
- And juxtaposed to innovative practices are old school and very old school practices
Conversation 7

Why Do We Tolerate Lousy Quality?

- It is everywhere.
- It hurts everyone.
- It uses precious resources.
- It is not about $. 


Quality of Community Supports is Spotty- Were All Supports and Services Available Today Were As Good As the Best That Are Available with Current Technology and Resources...

- The quality of life for people with intellectual and developmental disabilities would improve more than all the progress in the past 50 years.

- Everyone here is part of the solution to this issue.
Conversation #8
How do we fully integrate the medical community into our agencies, programs and practices?

- Serious health disparities for people with intellectual and developmental disabilities.
- Some islands of excellence.
- Blaming “the medical model” was an easy out, but enough already.
Conversation #9

We must all learn to make better use of all resources available

- It is easy to rely primarily on Medicaid Waivers
- Resources in health, housing, income support, job training, education, higher education, rehabilitation, community development, etc. must be come part of our programmatic armamentarium.
Conversation #10
No Excuses-invest in staff

- We are a labor intensive, service field with weak investment in ongoing development of people who work in the field
- Make it a priority
- Leadership development a must
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

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

Yogi Berra

The future ain't what it used to be.
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