NTAR Leadership Center

National Technical Assistance and Research Center to Promote Leadership for Increasing the Employment and Economic Independence of Adults with Disabilities

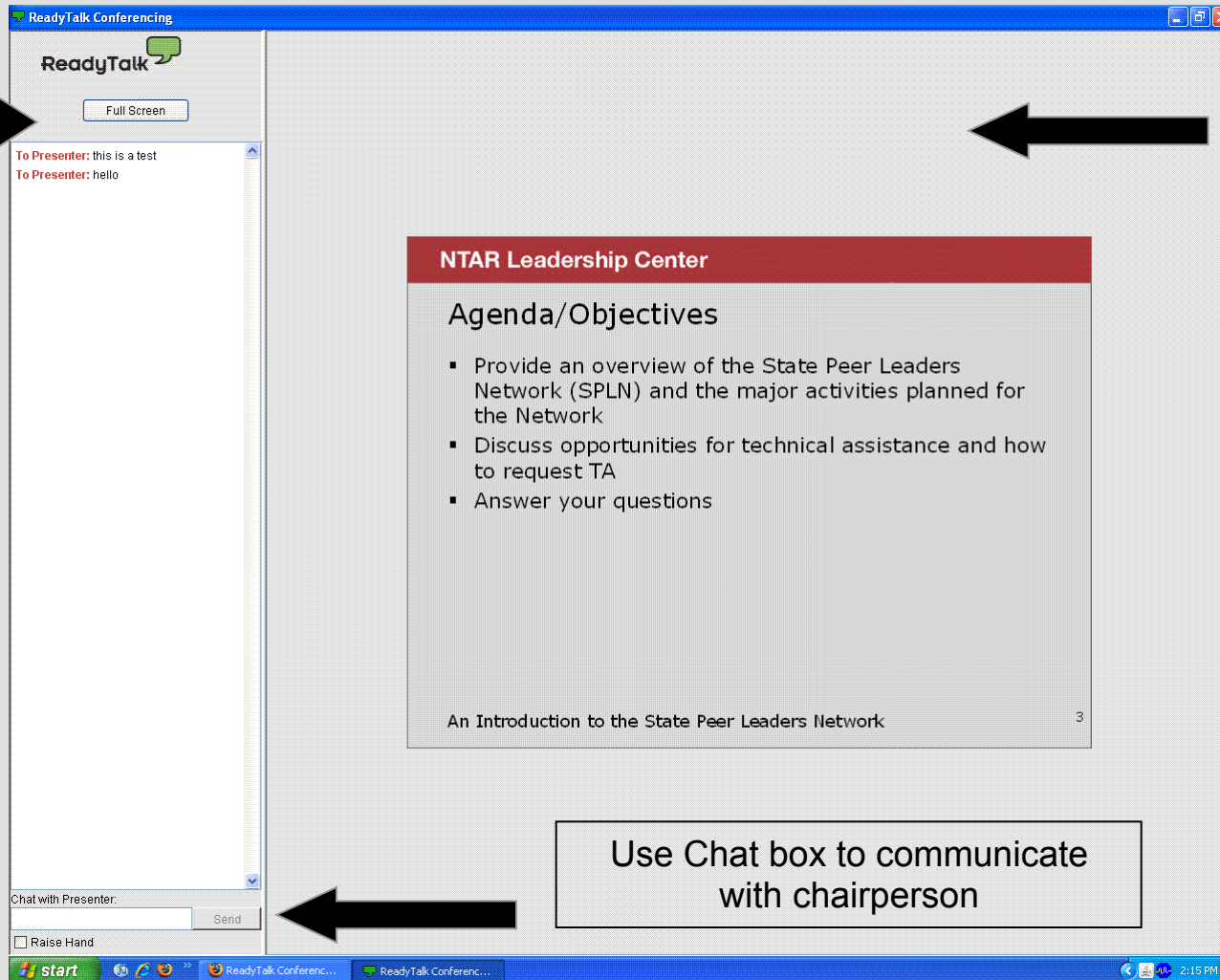# Employment of People with Disabilities: Why Are We Losing Ground?

December 10, 2008

Audio Dial-In Information

866.740.1260

Access Code: 9324100

NTAR Leadership Center

Webinar Classroom Layout

Presentation Slide Area

Select Full Screen to maximize presentation; minimizes chat feature

Use Chat box to communicate with chairperson

Employment of People with Disabilities, December 10, 2008

2

Access to Class Materials

- A direct link to the class materials, including web and audio content, will be posted on the NTAR Leadership Center website by 5:00 p.m. Eastern Time, Wednesday, December 10, 2008

www.ntarcenter.org

How to Submit Questions

Click **Raise Hand** to ask a question; the chairperson will call on participants in the order that questions were received

Use Chat box to send your question(s) to the chairperson

Employment of People with Disabilities, December 10, 2008

Faculty

- **Steven M. Eidelman**, H. Rodney Sharp Professor of Human Services Policy and Leadership, University of Delaware

Moderator:

- **Nancy Weiss**, Co-Director, National Leadership Consortium on Developmental Disabilities, University of Delaware

The NTAR Leadership Center

- Established in September 2007 through a grant from the U.S. Department of Labor's Office of Disability Employment Policy (ODEP)

- A collaboration of partners with expertise in workforce and economic development, disability employment, financial education and asset building, and leadership development

- Created for the purpose of building capacity and leadership at the federal, state, and local levels to enable change across workforce development and disability-specific systems that will increase employment for adults with disabilities

Guiding Principles

- **Increasing partnerships and collaboration** among and across generic and disability-specific systems
- **Increasing the use of self-direction** in services, and integration of funding across and among systems
- **Increasing economic self-sufficiency** through leveraging work incentives, financial education, or other strategies that promote profitable employment and asset building
- **Increasing the use of universal design** in employment services and as a framework for employment policy
- **Increasing the use of customized and other forms of flexible work options** for individuals with disabilities and others with barriers to employment

Employment of People with Disabilities, December 10, 2008

Agenda/Objectives

- Agenda
  - Overview of contemporary disability history
  - Identification of some leading issues
  - Change management basics
  - Questions and answers

- Objectives
  - To provide overall background for participants
  - To acquaint participants with issues in the field
  - To develop a framework for systems change
  - To answer questions raised by participants

I live from one tentative conclusion
to the next, thinking each one is final
The only thing I know for sure is that
I am confused.

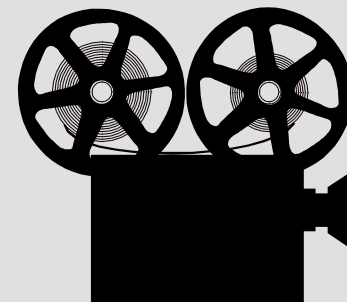Hugh Prather
Notes to Myself

Overview of Presentation

- The more things change. . .
- Recent milestones
- The power of ideas
- Some future possibilities
- Pesky constraints
- What can we do?

With thanks to Valerie Bradley (a National Leadership consortium partner) President, HSRI and John Paul, Principal, Association Works

Employment of People with Disabilities, December 10, 2008

10

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
- 1970-present – Rapid increase in medical and rehabilitation technology increases survival of people with acquired disabilities

Major Milestones

- Engagement of the courts in state systems
- Engagement of federal policymakers 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
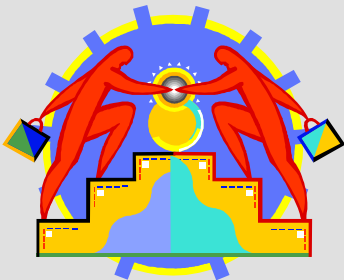- Emphasis on outcomes
- Exploration of self-determination

What Have We Learned?

- People with all types of 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.

- Work as a desired outcome has lagged behind community and independent living.

Achievements...

- Community-centered systems that offer more diverse and flexible services and supports

- Steady progress toward embracing the principles of person-centered supports

- Massive infusion of dollars into the community

- **Heightened expectations:** People with disabilities and families now expect that public systems will provide them the help they need to live, work, and participate in the community

The Tale of Three Ideals

Normalization

1970s

Inclusion

1980s

Self-Determination

1990s

Employment of People with Disabilities, December 10, 2008

15

Ideal 1: Illuminates Institutions

Normalization

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

Ideals 1 + 2: Attack Segregation

Normalization

+

Inclusion

"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

Normalization

+

Inclusion

+

Self-Determination

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.

Ideals 1 + 2 + 3 + ?

Normalization
+
Inclusion
+
Self-Determination

During your careers there will be another powerful idea(s) that will help to enhance and sharpen our vision – The job of leaders is to make sure that you are ready to receive it and adapt to it.

Employment of People with Disabilities, December 10, 2008

What Comes Next?

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

"Brown is the new black."

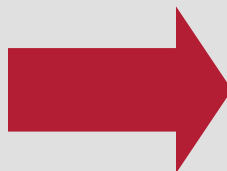*Employment of People with Disabilities, December 10, 2008*

In our world…

Sheltered workshops, day activity centers, enclaves, pre-employment programs, and segregated schools are the new institutions.

Why Is It?

- We live in the age of

- But some still promote sheltered workshops, "pre-vocational training," and sub-minimum wage as service models…?
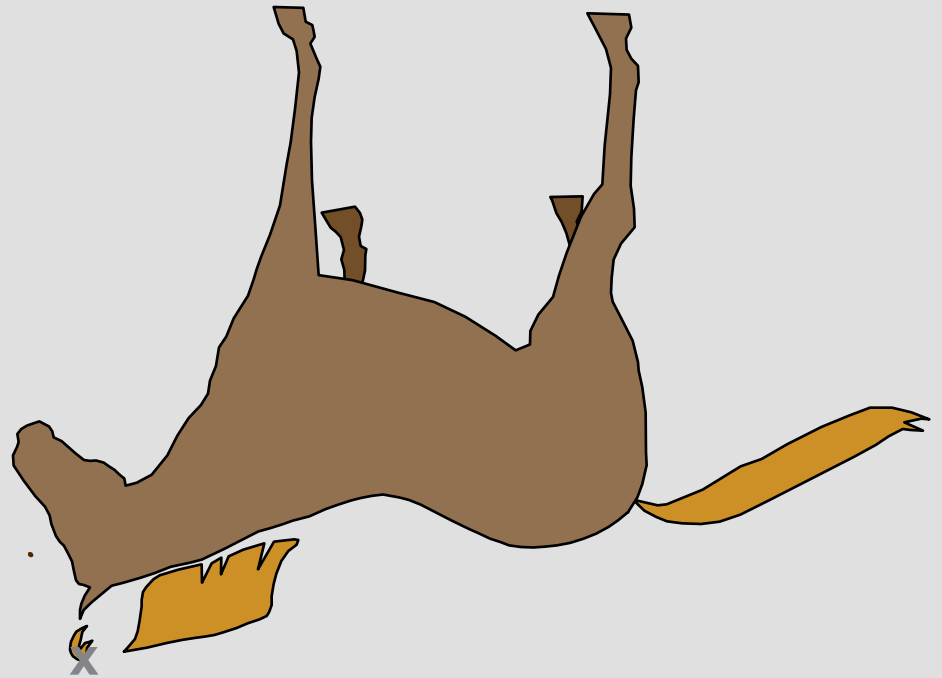
Formidable Factors Limiting Change

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

- Leaders needs to change their heart, minds, and practices.
  - If that fails, at least change funding policies

Employment of People with Disabilities, December 10, 2008

Horse Story

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

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 horses parents; the problem is often breeding

Are We Losing Ground?

- The quality of the national data sets in not such that we can draw that conclusion.
  - Quality of data insufficient to draw policy conclusions (Silverstein, et. al. 2005)
  - It is not due to the ADA
  - It is not due solely to changing demographics
  - It is not due to the economics of the workforce

- **Supply-side efforts have not produced large-scale results.**

- **Unemployment data do not include people with significant disabilities.**
  - **Most people with significant disabilities are unemployed**

Employment of People with Disabilities, December 10, 2008
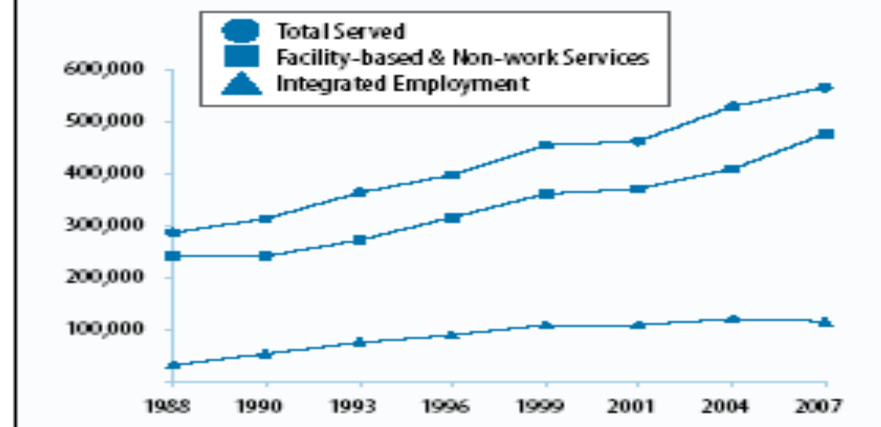
Are We Losing Ground?

- **It is not the cost of accommodations that is at issue**
  - **Most accommodations (2005 data) less than $600**

- **It is not the recession**
  - **Even in booming 1990s, numbers were poor**

While over the past 20 years the number of individuals with developmental disabilities supported in facility based and non-work programs increased steadily, the number of individuals supported in integrated employment has remained essentially flat since 1999 (see figure on right). The system of day and employment services for people with intellectual disabilities still favors facility-based service options.
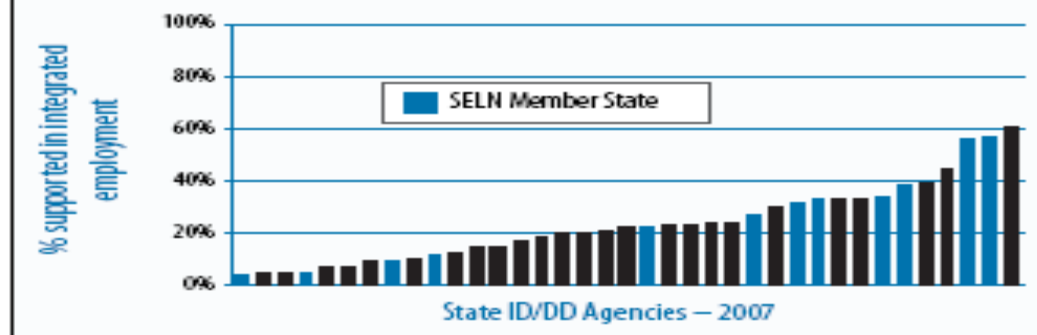
Integrated employment includes both individual employment and group supported employment and facility-based settings include both facility-based work services and facility-based non-work services.

Total Served by ID/DD Agencies

- ● Total Served
- ■ Facility-based & Non-work Services
- ▲ Integrated Employment

Source: ICI ID/DD Agency Survey

State success in Integrated employment varies widely

% supported in integrated employment

■ SELN Member State

State ID/DD Agencies — 2007

Source: ICI ID/DD Agency Survey

Despite the lack of progress on a national level, states' success in enabling individuals with ID/DD to achieve integrated employment outcomes varies significantly from one part of the country to the next. The figure to the left demonstrates the impact of state policy, strategy and culture on employment opportunities.

Systems changes happen slowly over time and the Network members are committed to tackling the important issues impacting employment outcomes across the country.

SELN helps states enhance their capacity to develop, implement, and support effective integrated employment initiatives designed to improve employment outcomes for individuals with developmental disabilities.

The goal is real jobs for people.
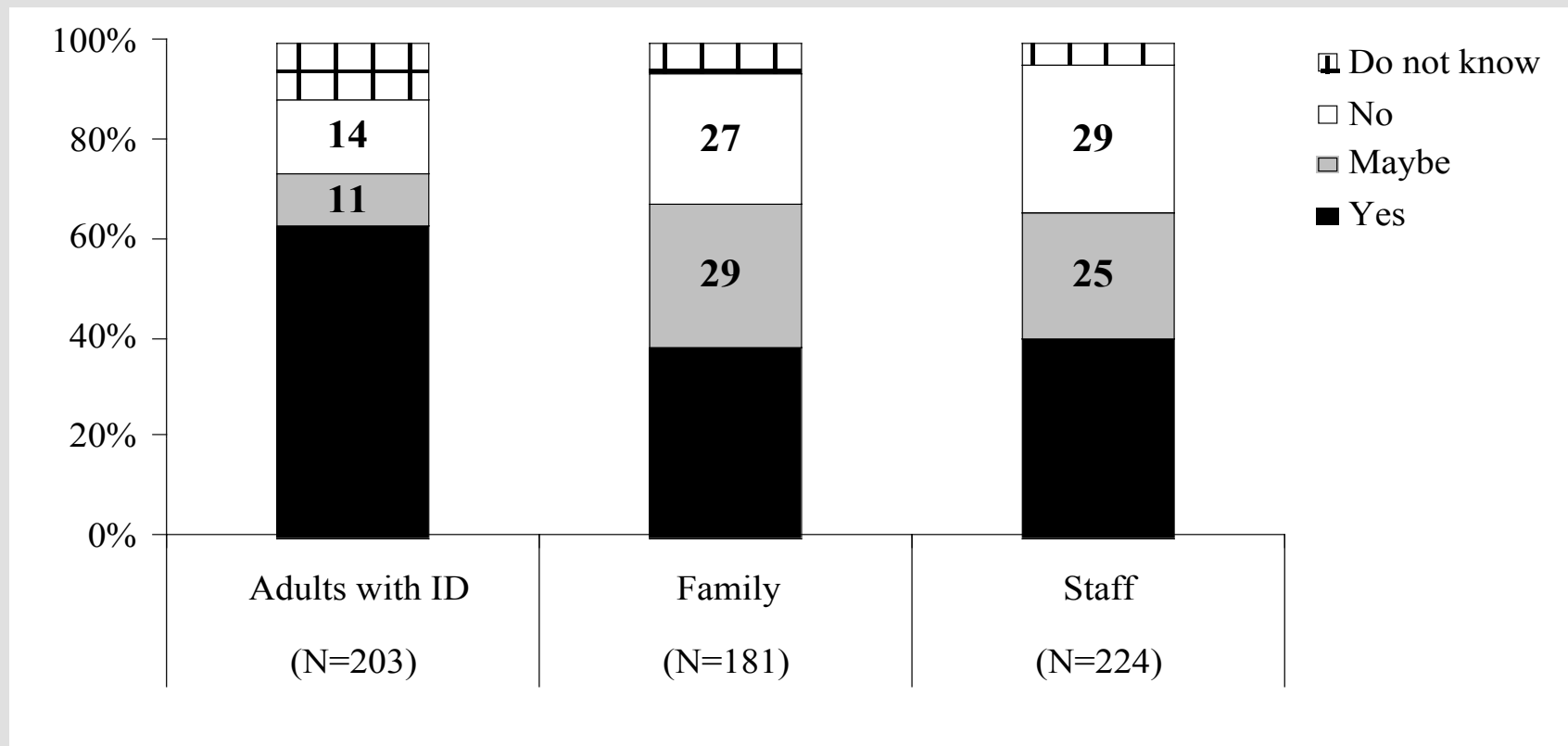
30

www.nasddds.org

Question: What did people with disabilities, families, and staff say about individuals' employment preferences?

- **Answer: The majority of the individuals with disabilities and their caregivers reported that they would prefer employment outside sheltered workshops.**

  – Only 14% of adults with intellectual disabilities and 27% of their family members stated that they did **not** want employment outside the workshop. Staff confirmed this finding: Twenty-nine percent reported that they believed that adults with ID did not want outside employment.

  – Sixty-three percent of adults with ID wanted employment outside sheltered workshops, and 11% thought they might like it. The remaining 12% did not know or had never thought about the option. (See Figure 1.)

Employment of People with Disabilities, December 10, 2008

What People Say

Figure 1

Question: Given that many adults with ID preferred community employment and thought they could succeed, why did they attend sheltered workshops?

- **Answer:** Adults with disabilities and families expressed a number of concerns that influenced the choice of sheltered workshops over community employment. It is noteworthy that most of these mirrored preoccupations that people without disabilities typically have when applying for jobs. Over half of the families considered the following issues important or very important when choosing the type of employment: transportation to and from the workplace (69%), long-term placement (66%), safety (69%), convenience of work hours (59%), retention of disability benefits (57%), work skills requirements (55%), and friendly social environment (55%).

Question: Given that many adults with ID preferred community employment and thought they could succeed, why did they attend sheltered workshops?

- **Answer:** It should be noted that often these concerns were not based on actual personal experiences, since adults with ID had seldom experienced employment outside workshops. In fact, according to the families, 66% of adults with ID in this study had no paid work experience (or respondents did not remember), 20% had only one paid work experience, and only 14% had more than one paid work experience (N = 183).

Indicators of Success of Employment Programs

- Increased % of PWD who are employed
- ↑ number of hours worked per week or month
- Increase in disposable income
- Improvement in employment of health benefits

- Increased satisfaction from work
- Improvement in work schedule flexibility
- Increase in rate of pay, earnings or net income from employment

Silverstein et al 2005

Systems/Organizational Change

- As state leaders, how do we do a better job changing organizational culture in the state:
  - How do we incorporate proven practices to convert old models of employment to full-paying jobs within the community?
  - How do we harness and **hear** the wisdom of people with disabilities?
  - How do we change organizational cultures from those that produce long-term dependence to those that promote long-term independence?

System Configuration

- What role does the increasing concentration/ consolidation of providers play in "deconstructing" the system?

- Where will the political support and will come from in light of weakening advocacy and/or aging advocates in many states?

- How can we maintain passion as overt abuses are fewer and the "bigotry of low expectations" remains?

Next Stages of State-Level Reform: The Challenge for State Leaders

- Increased power to people with disabilities
- Increased devolution and decentralization
- Maturing of self-advocacy
- Deconstruction of prefab services
- Integration of funding from multiple revenue streams
- Elimination of work disincentives
- Reform of quality assurance
- Translation of research to practice

There is no private marketplace

- In what other area could you sell people something they do not want to buy, charge them a lot for it, and be surprised when they don't like it?

It is all about change!

How People React to Change

Top Management: Isolated, underestimate reaction, don't communicate, people should go along, feel betrayed

Middle Management: Pulled in different directions, often lack information, pressured to make changes

Employees: Caught off guard, anger, frustration, afraid to take risks, confused, loss of friends, etc.

What Usually Happens During a Process of Change

Rate of acceptance varies by knowledge of what is happening:

- 10-20% will be in favor
- 60-80% will be on the fence
- 10-20% will be opposed

Change is about people and behavior…

not about structure, regulations, funding streams, or policies

Employment of People with Disabilities, December 10, 2008

Resistance

- Resistance comes in different forms
- Don't take it personally
- Some will never accept
- Resistance is not necessarily bad

Change Fantasies

- It's not disruptive

- Doesn't cost much

- It's quick to implement

- Everyone will see the value

Fear of Losing

Job

Power

Friends

Focus

Reputation

History

Connection

Respect

Competence

Culture

Prestige

Passion

Input

Control

Employment of People with Disabilities, December 10, 2008

Why Change Initiatives Fail

- Misunderstandings
- Power plays
- No "say" in process or outcomes
- Inequality
- Self interest overrides everything
- Fear of the unknown

Why Change Initiatives Fail

- Ego issues

- Completed too fast or too slow

- Poor planning and implementation

- Inappropriate behavior

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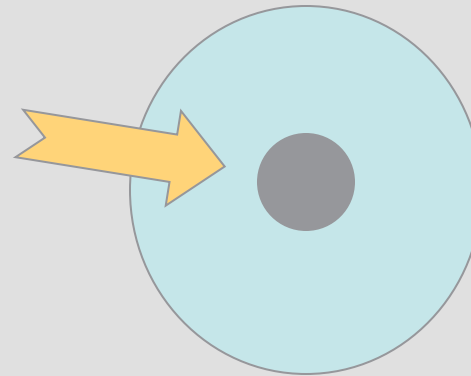
Albert Einstein

And finally...

- Without resistance you can do nothing
    Jean Cocteau

- To profess to have an aim and then to neglect the means of its execution is self-delusion of the most dangerous sort
    John Dewey

- You've got to be a fool to stop the march of time
    Pierre Auguste Renoir

Employment of People with Disabilities, December 10, 2008
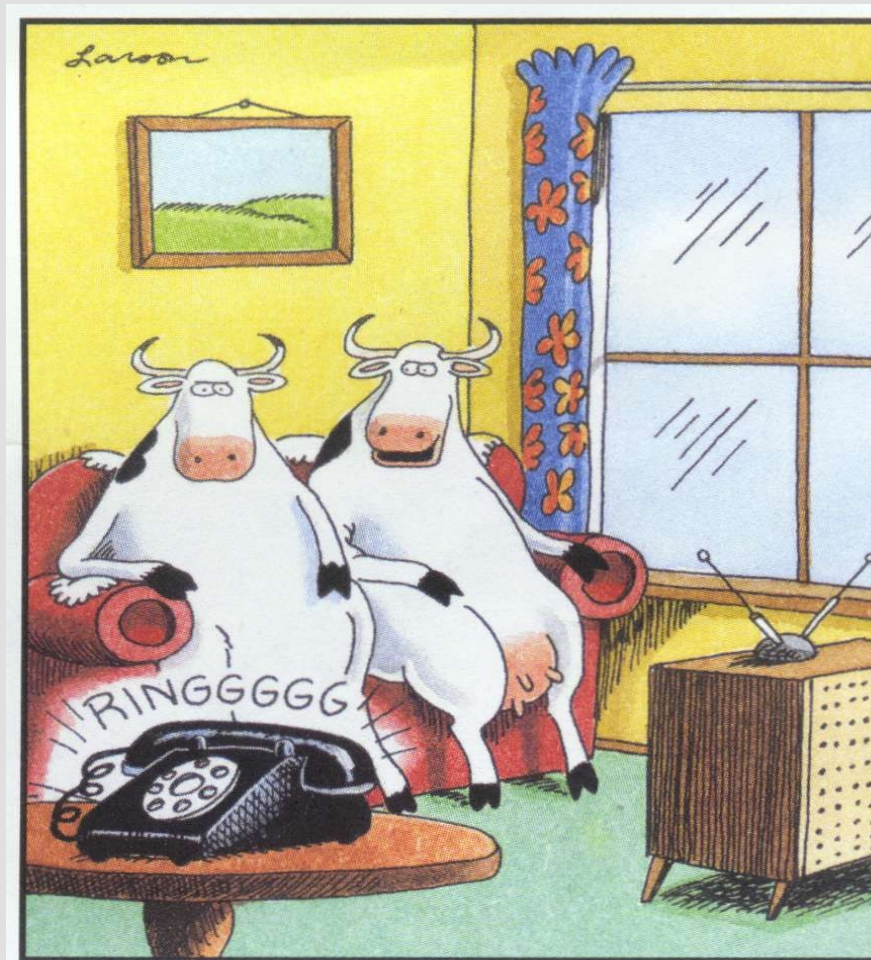
What to Do???

We can't stay on this spot

As state leaders, we need to rethink what we do – affirm our values but resolutely search for "value"

This portion of the presentation is from a series of slides - *Sustainable Futures* - A joint project of The Arc of the United States and HSRI

Employment of People with Disabilities, December 10, 2008

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."

The future ain't what it used to be.

Yogi Berra

Employment of People with Disabilities, December 10, 2008

52

Some Resources

- Disability Employment 101
  - http://www.ed.gov/about/offices/list/osers/products/employmentguide/disabilityemployment101.pdf
- Diversity World
  - http://www.diversityworld.com/Disability/index.htm
- The Job Accommodation Network
  - http://www.jan.wvu.edu/
- The U. S. Chamber of Commerce
  - http://www.uschamber.com/icw/strategies/disabilityemployment.htm
- The U. S. Business Leadership Network
  - http://www.usbln.org/

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

www.nlcd.org

Employment of People with Disabilities, December 10, 2008

54

NTAR Leadership Center Contacts

- Nanette Relave, Center for Workers with Disabilities nrelave@aphsa.org or 202-682-0100, x241

- Damon Terzaghi, Center for Workers with Disabilities dterzaghi@aphsa.org or 202-682-0100, x265

- Kathy Krepcio, John J. Heldrich Center for Workforce Development, Rutgers University krepcio@rci.rutgers.edu or 732-932-4100, x6306

- Maria Heidkamp, John J. Heldrich Center for Workforce Development, Rutgers University heidkamp@rci.rutgers.edu or 732-932-4100, x6313

NTAR Leadership Center Website

www.ntarcenter.org