

**Challenges and Opportunities for Collaboration in
Healthcare for Persons with I/DD:
Our Collective Obligation and Opportunity to
Achieve Social Justice for People Who Are
Medically Underserved**

**DDNA/AADMD
Reno, Nevada: May 16, 2010
by
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I am a professor. I brought charts.



The context for
Talking about
health equity and
health disparities
and the rights of
people with
Intellectual and
Developmental
Disabilities is
framed in the
context of Human
and Civil Rights



"Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

Eleanor Roosevelt March 27, 1958 "IN YOUR HANDS: A Guide for Community Action for the Tenth Anniversary of the Universal Declaration of Human Rights"

In the tradition of Eleanor Roosevelt, another strong woman from another famous political family was in the lead focusing our modern perspective on people with intellectual and developmental disabilities.



Rosemary (right) with Eunice and Jack two years before she was placed in an institution.



The Framework of the Kennedy-

Era

- Maternal and Child Health
 - "Crippled Children's Services – 1930's"
 - Prevention
 - Training
 - Research
- In part projecting the needs of a large generation of adults with intellectual and developmental disabilities was outside the framework
- Subsequent actions around education, rights, deinstitutionalization did not include training for adult clinical practitioners

CHRISTMAS IN PURGATORY

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



A Photographic Essay on Mental Retardation

BURTON BLATT

FRED KAPLAN

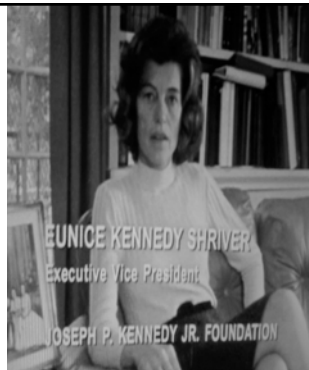
Things are not as they were....From Christmas in Purgatory Published in 1966



Things are not as they were...



Robert E. Cooke, MD
Pediatrician in Chief
Johns Hopkins Hospital, 1956-1963



Who Should Survive? – Publicized the issues concerning hospitals and infants born with repairable defects

Or are they?

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

**Peter Albert David Singer, Ph.D.
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



And, of course.....

ABUSE OF POWER
Part 1 of 2

Since 2000, **75** workers have been fired from state institutions for the disabled for extreme abuse or neglect

Of those, **13** have been charged with crimes

Only **2** have served jail time

Source: State abuse records, arrest warrants and court filings

<http://www.texastribune.org/stories/2010/jan/20/abuse-power/>

Torture Not Treatment:
Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center

Urgent Appeal to the United Nations Special Rapporteur on Torture

Mental Disability Rights International

MDRI has asked the United Nations Special Rapporteur on Torture to investigate JRC as well.

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
- Nor have the environmental and attitudinal barriers

Multiple Constructs of Disability

- Disability is socially constructed.
 - Medical Model – Disability inherent in the person, and is directly related to an individual's physical or mental limitations.
 - Also called functional-limitation model.
 - The contemporary disability movement was a rejection of the medical model of disability.
 - Social Model – Focus on disability as related to environment, social issues and attitudinal barriers
 - Civil rights approach to disability

Multiple Constructs of Disability

- Expert/Professional Model
 - Related to medical model
 - Inequality between treatment professionals and the person with a disability
- Rights-based model
 - Socio-political construct
 - Disability rights movement – Self Advocated Becoming Empowered or People First in the US

Multiple Constructs of Disability

- Tragedy/Charity model of disability
 - People with disability seen as victims
 - Used a lot in fundraising...e.g. see Jerry Lewis
- Religious/Moral Model of Disability
 - Punishment
 - More prevalent in less developed countries
- Economic Model of Disability
 - Inability or limited ability to generate income

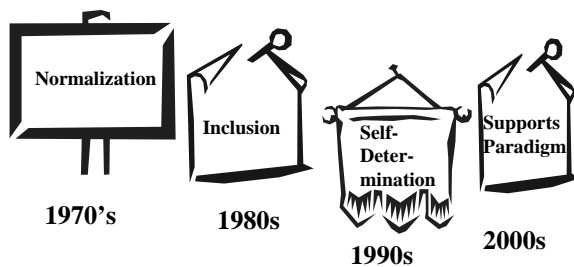
Multiple Constructs of Disability

- Customer/Empowering Model of Disability
 - Opposite of Expert Model.
 - Professionals work for the person.
- Rehabilitation Model
 - Related to Medical Model
 - Rehabilitation professionals work to “fix” person

Multiple Constructs of Disability

- Models are by necessity hybrids
- Most people at different points in their lives need aspects of many models

The Tale of Four Ideals



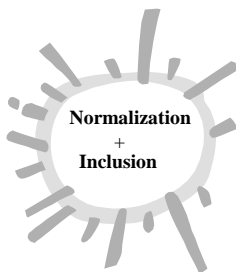
Adapted with permission from Val Bradley (1999), President, Human Services Research Institute, Boston USA

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.

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.

The Supports Intensity Scale (SIS) was developed. SIS measures support requirements in 57 life activities and 28 behavioral and medical areas. The assessment is done through an interview with the consumer, and those who know the person well.

SIS measures support needs in the areas of home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy. The Scale ranks each activity according to *frequency* (none, at least once a month), *amount* (none, less than 30 minutes), and *type* of support (monitoring, verbal gesturing).

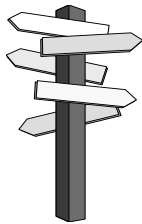
Ideals 1 + 2 + 3 + 4+?



Someday in the future there will be another powerful idea (s) that will help to enhance and sharpen our vision -- Our job is to make sure that we are ready to receive and act on it.

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 Arc and HSRI, 2003

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.**

The Arc and HSRI, 2003



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 and families now expect that public systems will provide them the help they need to live and participate in the community**

The Arc and HSRI, 2003

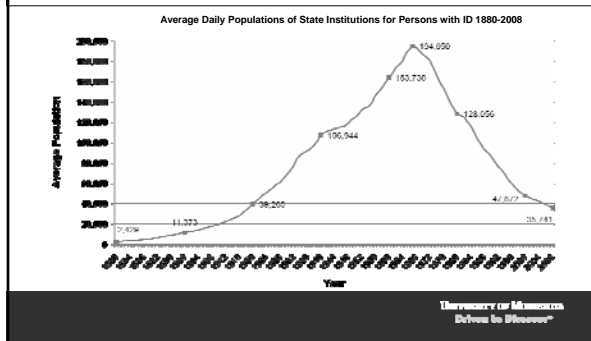
Stages of Evolution of Institutional Models in the US

(Wolf Wolfensberger, *The Origins and Nature of Our Institutional Models*, Syracuse U., Human Policy Press)

- Making Deviant Individuals Un-Deviant
- Protecting Deviant Individuals from Non-Deviant People
- Protecting Non-Deviant Individuals from Deviant People
- Momentum Without Rationales

Credit: K. Charlie Lakin, U. MN.

Average Daily Populations of State Institutions for Persons with ID/DD 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
- ~ 50,000 people in large private non-ICFMR facilities
- ~25,000 people are in nursing homes

In the U.S., some states (total state population ~22,100,000) have closed all institutions for people with intellectual and developmental disabilities.

- Alaska
- DC
- Hawaii
- Indiana
- Maine
- New Hampshire
- New Mexico
- Rhode Island
- Vermont
- West Virginia
- Minnesota?

What have we learned?

- In 38 large scale studies in western nations, people with all levels of intellectual disability were shown to do better in the community in 35 of them!
- **Bricks and mortar-buildings have nothing to do with helping people with intellectual disabilities to thrive, grow and live their lives.**
- **Buildings are obstacles them!**

Why is it?

- We live in the age of



- But some still promote institutions as a service model



The Community Imperative

- **A REFUTATION OF ALL ARGUMENTS IN SUPPORT OF INSTITUTIONALIZING ANYBODY BECAUSE OF MENTAL RETARDATION (1979)**
- **In the domain of Human Rights:**
 - All people have fundamental moral and constitutional rights.
 - These rights must not be abrogated merely because a person has a mental or physical disability.
 - Among these fundamental rights is the right to community living.
- **In the domain of Educational Programming and Human Services:** All people, as human beings, are inherently valuable.
 - All people can grow and develop.
 - All people are entitled to conditions which foster their development.
 - Such conditions are optimally provided in community settings.
- **Therefore:** In fulfillment of fundamental human rights and in securing optimum developmental opportunities, *all* people, regardless of the severity of their disabilities, are entitled to community living.
 - Signed by 195 organizations
 - Signed by 649 individuals



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

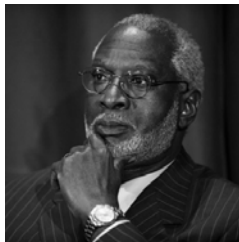
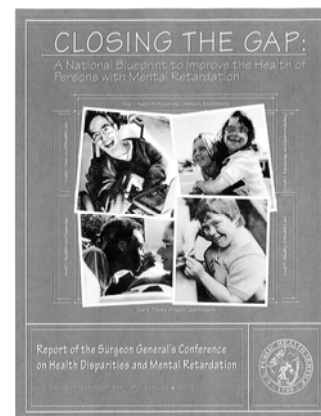
Are Health Disparities the DMZ?



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The “divorce” from the Medical Model has allowed for great progress, and has caused great harm.

- If a “remarriage” is possible what are the terms?
 - Can there be a reconciliation?
- How can people with disabilities live full and inclusive lives without optimizing their health status?
 - They can't
- How can there be an almost total absence of formal training programs to teach clinicians to care for adults?



Reports don't have arms and legs. Like many others, this report will just sit on shelves unless we turn it into action. It is important to listen to those affected to learn what needs to be done, but to listen and not respond with determined action will only heighten the injustice this community has too long endured.

David Satcher, M.D., Ph.D.
Surgeon General
January 2002

Credit: Rick Rader, MD

What Are Health Disparities

Differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States

NIH Working Group, 1999
<http://healthdisparities.nih.gov/whatare.html>

Types of Disparities

- **Race/ethnicity**
- **Geographic location (rural vs. urban)**
- **Age**
- **Gender**
- **Disability Status**
- **Sexual Orientation**

Disparity

- A dearth of reliable evidence (especially population based) about the comparative health status and needs of people with ID, but powerful evidence of unmet needs.
 - The Health Status and Needs of Persons with Intellectual Disabilities (Horwitz et al 2000)
 - SG Report - Closing the Gap (DHHS 2002)
 - Special Olympics International Health Screening Data (2000-09)
 - Surgeon General's Call to Action to Improve the Health and Wellness of People with Disabilities (US DHHS 2005)
 - A Cascade of Disparities (Krahn et al 2006)

Credit: S. Corbin, DDS, MPH

Health Needs: People with ID

- Poorer health and increased risk for preventable health conditions compared to general population.
- More likely to receive inappropriate, inadequate, delayed or no healthcare.
 - In part, for adults, related to poverty
- Reasons include:
 - Higher rates of adverse health conditions
 - Reliance on support providers for care
 - Support providers themselves with poor health literacy
 - Disparities in access to all types of care, including preventive care and health education
 - Insufficient training of healthcare providers – especially for adults
 - Inadequate policies and funding mechanisms

Credit: Modified from S. Corbin, DDS, MPH

Disparity Indicators – SO Athletes

Indicator	Percentage
Untreated Tooth Decay	45.7%
Missing Teeth	29.5%
Failed Hearing Tests	25.2%
Low Bone Density	13.4%
Eye Diseases	11.3%
Gait Abnormalities	41.6%
Bone Deformities (feet)	15.1%
Overweight/Obesity (US)	64%

From a presentation by S. Corbin, DDS, MPH, Vice-President, Special Olympics

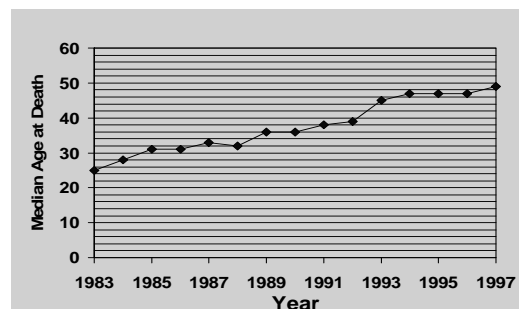
Disadvantage

- People with ID “fly under the radar”
- Many people with ID can't advocate well for themselves, especially with providers
 - Many support staff themselves have poor health status
- People with ID don't have access to appropriate health promotion
- Adults with ID disproportionately live in poverty
- Funding mechanisms inadequate
- Monitoring and surveillance systems “spotty”
- Not “medically underserved” according to DHHS

Adapted from a presentation by S. Corbin, DDS, Vice-President, Special Olympics

People with Intellectual and Developmental Disabilities are Living Longer

Median Age at Death Among Persons with DS



From a presentation by Sonja A. Rasmussen MD, MS, CDC

Evolving Perspectives on Services for Persons with Developmental Disabilities

Earlier Years

- Individuals should stay in institutional or other settings until they have mastered the skills taught in those settings and are ready to move another step toward independent living ("continuum of care" model)
- Individuals can best be prepared for a community living setting through task analysis and teaching of the skills needed in those setting.

Today

- There are no prerequisite skills for living in any particular kind of place. "Success" in community living or any particular setting is more dependent on the appropriateness of accommodations to an individual's limitations than to the skills the individual possesses.
- The best place to teach/learn the skills needed for living in a particular setting takes place in the specific setting in which one will live. The more severely impaired the individual is the more true this appears to be.

Credit, K. Charlie Lakin, U. MN.

So what does this mean?



Two World Views to Think Through

Choice

Is the primary consideration so that...

Choices that exemplify community integration or segregation are ALL equally acceptable

A Society for All

Is the primary consideration so that...

Policy favors options that promote community integration and discourages, even eliminates, options that segregate people from the community mainstream.

Which is it in this room?

Credit: John Agosta, HSRI

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.

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

"Brown is the new black."

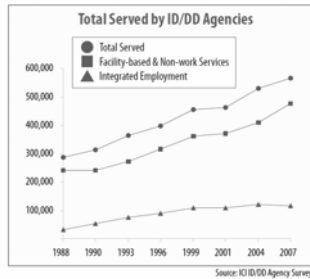
In our world.....
Sheltered workshops and segregated schools are the new



The Riot, Issue 14, October, 2007

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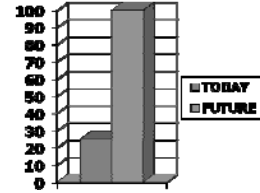
Work, for most people, is segregated



From NASDDDS.ORG

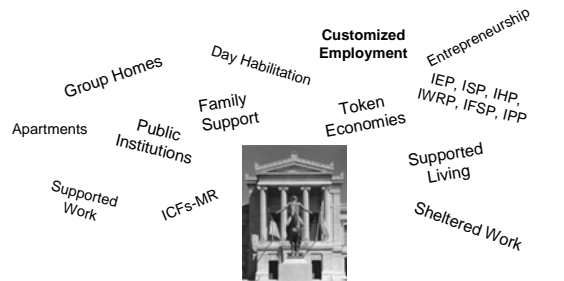
If All Supports and Services Available Today Were As Good As the Best That Are Available with Current Technology and Resources...

- 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.



This is a Human Rights Issue and Health Disparities play a large role.

It's A Living Museum Out There...



1956... 1962... 1972 ... 1976...1983... 1987... 1992... 1997.. 2000... 2007...2010

Source, HSRI and The Arc, 2003

Death By a Thousand Cuts

- Creeping normalcy: the way a major negative change, which happens slowly in many unnoticed increments, is not perceived as objectionable
 - The intention was community inclusion, participation, self-determination
 - The reality is, all too often, segregation, isolation poor health status, and days filled with meaningless activity

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

Challenges and Major Issues

- Autism –Reports of increasing numbers of children and adults with Autism demanding services
 - Not looking for the same things as previous generation of parents of people with ID/DD
 - Whether this is an “epidemic” or diagnostic issue(s) remains unclear and highly disputed on multiple sides of the issue
 - Parallel track or integrated into the ID/DD system?

Challenges and Major Issues

- Aging – of people with id/dd and of their parents
 - Over 800,000 people with id/dd in US living with parent over 65 years of age
 - First generation of elderly people with significant disabilities in the history of the world

Challenges and Major Issues

- Health Disparities
 - When we threw out the “medical model” we forgot that good health takes work.
 - No focused federal responsibility for or financial support of training of medical personnel to work with adults
 - most people with intellectual disability are adults
 - Reimbursement models frequently do not account for intensity of time
 - Many paid caregivers lack knowledge of health care and health system
 - Significant gaps in care & health disparities for people living in communities in the US

Self Advocacy

- Movement is growing
- Lacks infrastructure
- Different than the parents movement
- Self-advocates need to be incorporated into leadership, governance and planning
- A rights approach-people demanding respect and a voice

Supporting Families

- The movement was begun primarily by families after WWII
- That generation is fading away
- Families of younger children have different priorities and perspectives
- When the family voice is strong in all people with intellectual and developmental disabilities are better off

So given all our constraints, what now?

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

Ambrose 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."

Some solutions.

1. Everyone must work with elected officials to solve whatever problems we all face. "Get involved in politics as if your life depends on it...because it does."

Justin Dart

Some solutions.

2. A five (or three or ten) year plan to get rid of the old, segregated ideas and programs...the ones that separate people from their communities.

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Some Solutions

3. Stop building, repairing or improving institutions, sheltered workshops and segregated schools.

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Some Solutions

4) Ramp up training of clinicians and other support models to improve both primary and specialty care for people with intellectual and developmental disabilities

Sign the Community Imperative

- Both DDNA and AADMD
 - http://thechp.syr.edu/community_imperative.htm

The National Leadership
Consortium | on Developmental
Disabilities

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