

A National Museum of Disability Rights and History: It's Time

James W. Conroy, Ph.D. & Judith A. Gran, J.D.

Pennhurst Memorial & Preservation Alliance

www.preservepennhurst.org

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It's Time for a National Museum of Disability

Without a home, many crucial chapters in American history could be lost.

**By Elianna Gerut, Sarah Levin, Daniel Rabinovitz,
Gabe Rosen and Ben Schwartz**

*The authors are 12th graders
at Gann Academy in Waltham, Massachusetts*

Human History and Disabilities

- Cultural variations – from infanticide to “Holy Innocents”
 - “Let there be a law that no deformed child shall live!” – Aristotle, 350 B.C.
- Late 1800s Social Darwinism led to Eugenics (Greek for “Good Birth)
- The rise of institutions worldwide
- Intended to segregate and prevent reproduction
- Eugenics was accepted worldwide
- Gave rise to the Nazi Holocaust
 - Began with children with disabilities

FEEBLE-MINDED PERSONS

ARE NOT

"Just Simple"

"Merely unfortunate"

"Perfectly harmless"



THEY ARE

Dangerously weak

Irresponsible

An Active Menace

Only constant care and supervision
protects them and the community

In the U.S: Another Jim Crow Era

“A regime of state-mandated segregation and degradation soon emerged that in its virulence and bigotry rivaled, and indeed paralleled, the worst excesses of Jim Crow.”

“Massive custodial institutions were built to warehouse the retarded for life; the aim was to halt reproduction of the retarded and nearly extinguish their race.”

--Justice Thurgood Marshall (*Cleburne*, 1985)

Skewed Values in America

- 1968: The average cost per person at Pennhurst was \$5.90 per day
- The average cost of keeping a leopard at the Philadelphia zoo was \$7.15 per day
- In the richest nation on Earth.....





20th Century Triumphs

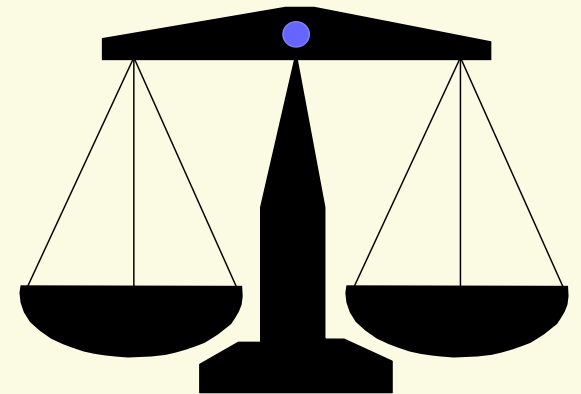
- Disability rights movement in 1960s
- Learning from the other great civil rights movements
- Berkeley University demonstrations
- 1972 First Center for Independent Living
- Ed Roberts – great inspiration
 - His chair is in the Smithsonian
 - And someday will be on public display

Developmental Disabilities: Change Begins With Horrors of Institutions

- Pennhurst TV expose 1968, Bill Baldini
- PARC – shocked, horrified, activated
- Young attorney hired to advise
- No basis in law to sue PA about Pennhurst
- But the segregated education system, Yes
- 1972 Right to Education – prevent the need
- Then, 1974, suit about Pennhurst

1977 Federal Court Victory

- In the midst of America's efforts to create “good” institutions
- A U.S. Federal Court declared Pennhurst to be **“Unconstitutional by its very nature”**
- Because it was specifically and consciously designed to segregate
- And because the people
 - had lost skills (they
 - had been harmed)

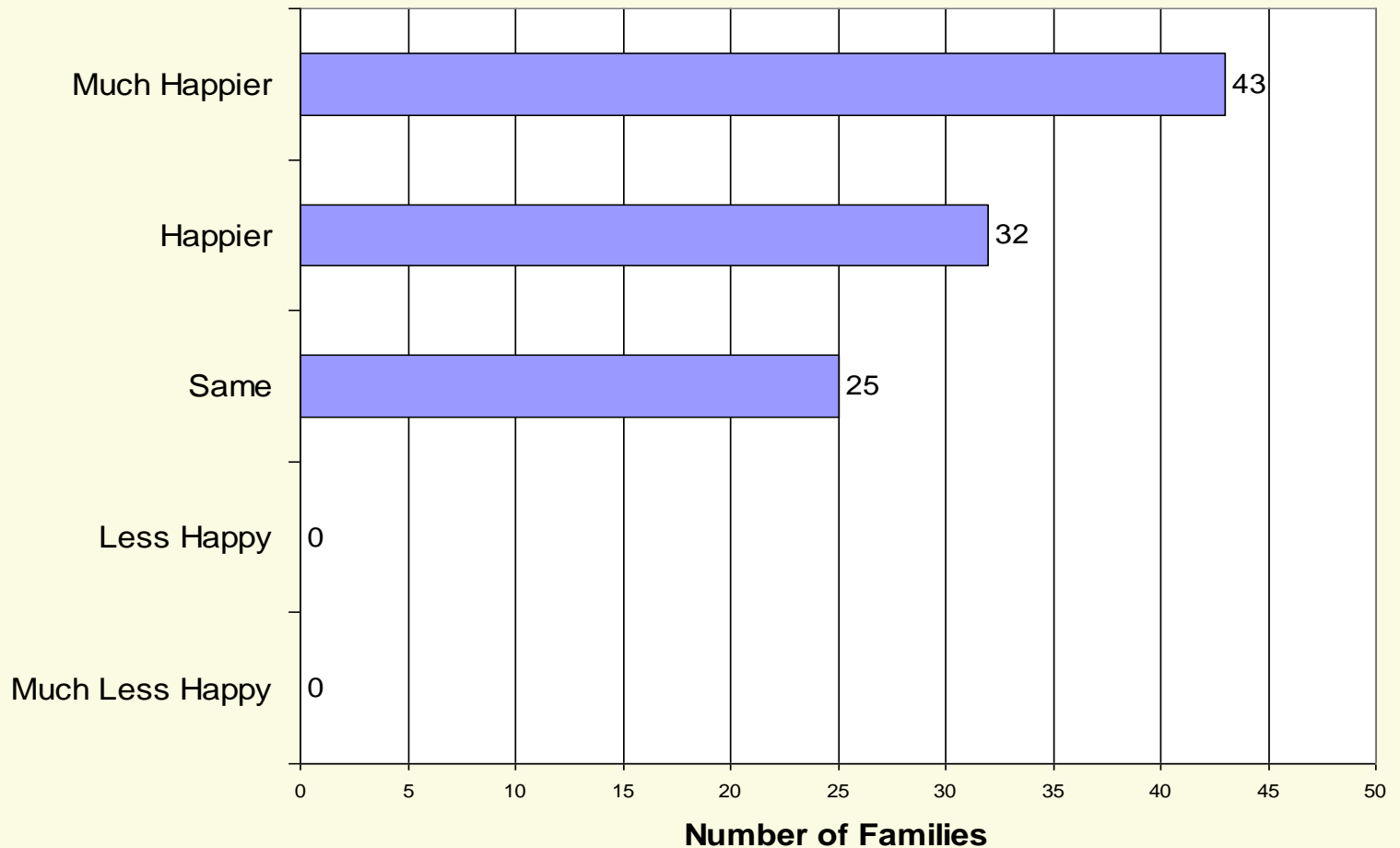


The Pennhurst Longitudinal Study

- Began in 1979
- Largest such study yet done
- Tracked 1,154 people
- Visited every person every year
- Surveyed every family every year
- Measured qualities of life, satisfaction, costs
- Created ways to track & measure quality

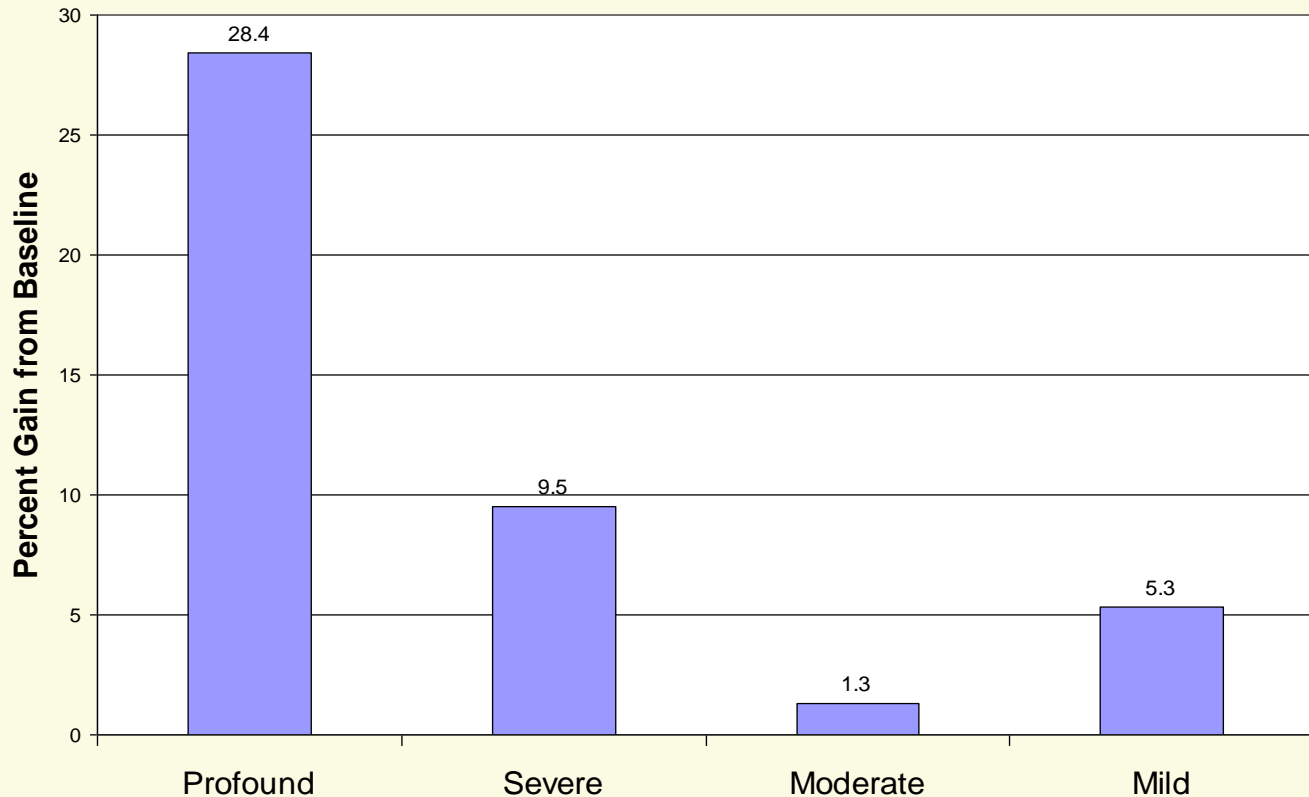
One Example of Outcomes

Has Your Relative's General Happiness Changed Since Moving?"

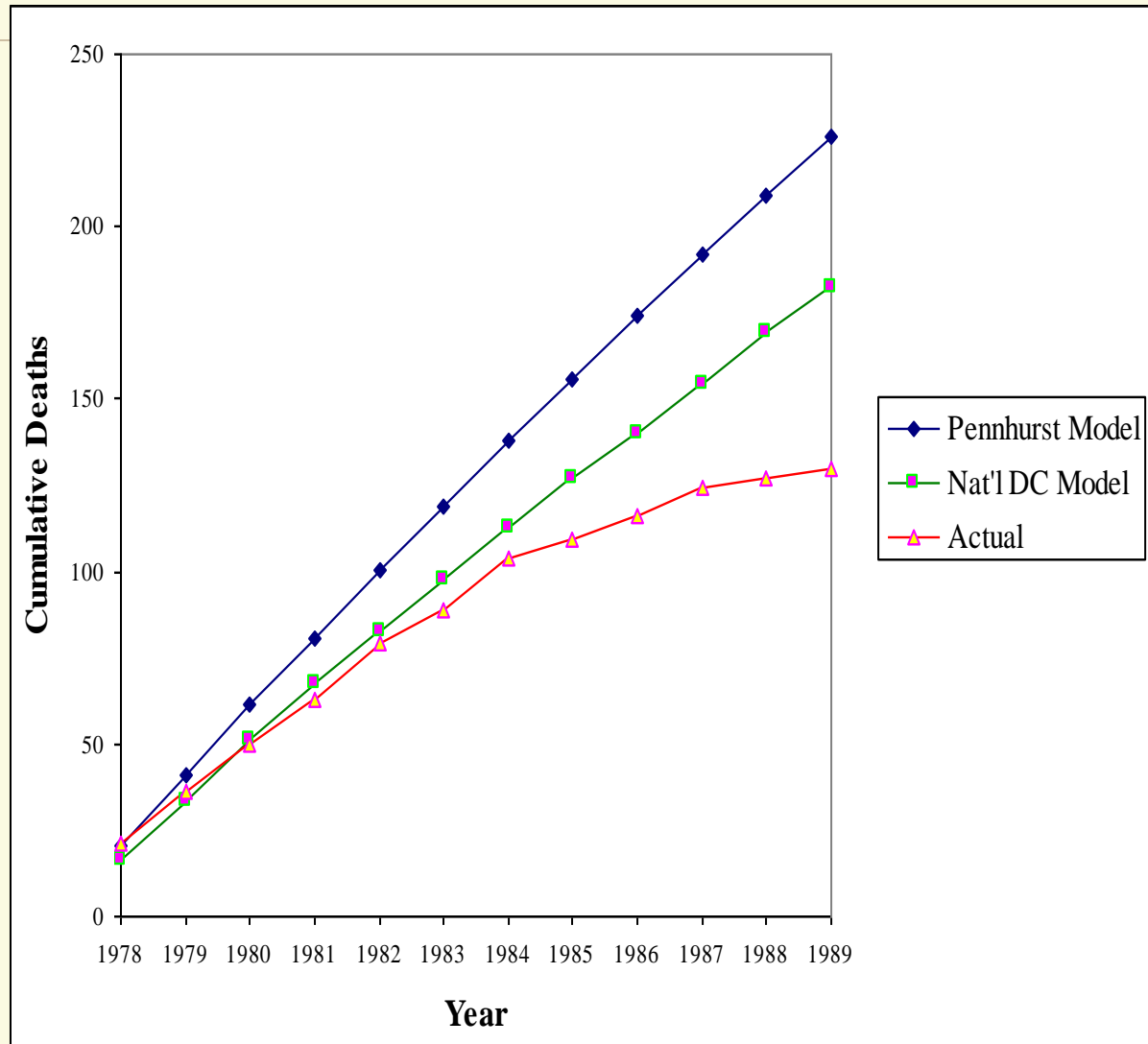


What Kind of People Made the Largest Proportional Gains?

**Connecticut Movers, 1985-1991:
Percentage Gain in Adaptive Behavior**



Pennhurst Mortality



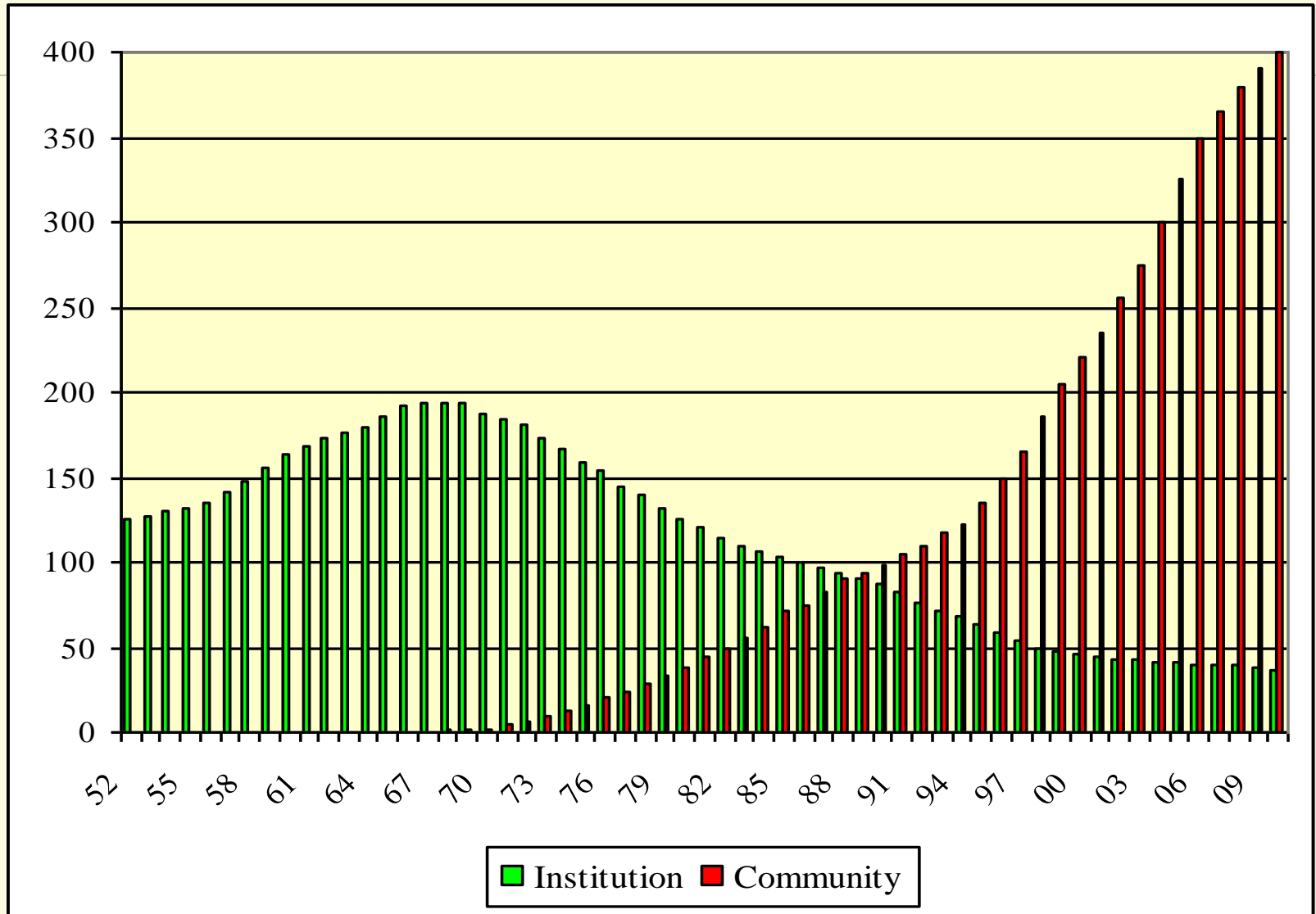
40 Years of Scientific Research

- “Better off” in community – conclusive
- Studies in 25 states
- More than 10 other countries
- 13 states now have no people in public institutions
- ADA
- United Nations Convention on the Rights of Persons with Disabilities – Article 19
- Few people know how much of this began here

Pennhurst as a Microcosm

- **Original Source of a Right to Education**
 - 1971 PARC v. PA settlement
- **Focal Point re: a Right to Treatment**
 - 1982 Romeo v. Youngberg, Supreme Court
- **Battleground for a Right to Community**
 - 1977 Halderman v. Pennhurst, Supreme Court
- All three forward the disability rights movement vastly
- Helped lead to the ADA in the U.S. in 1990
- And the CRPD in the U.N. in 2006

Institutional Decline, Community Rise



Vanishing History

- The institutions are largely closed
 - (NOT COMPLETELY!)
- The buildings are gone or repurposed
- Needed: methods to make it impossible for future generations to forget

Example: Pennhurst Upper (Women's) Campus



Going, going



Gone!



Another Example: The Landmark Water Tower



New Horizons Building Pennhurst Center and Water Tower Spring City, Pa.

The Dome - Cut and Dropped



The End of the Landmark

May 2017



The People are Older Now...

- Their lives and stories must be preserved
- PMPA supported the “Lives Remembered” project of Dr. Mary Schreiner
- It’s Time
- We envision many faces, voices, and stories in short formats with touch screens

Ways to Remember with Dignity

- PMPA began in 2008
- Remember the great triumphs – never go back
- Place an Historic Marker
 - Largest attendance in PA marker history
- Created the Pennhurst Traveling Exhibit
- And several documentaries
- Displayed in U.S. Capitol and all over the country – and other countries
- Speaking internationally
- Two books

Historic Marker 2010



Communicating the Message: Documentaries, Videos, Social Media

- A Call of Conscience
 - 12 Minute video produced by the Pennhurst Memorial and Preservation Alliance in 2010
- i go home
 - Public TV documentary on Pennhurst & DI
- Going Home
 - Follow up by WTIF Harrisburg
- Pennhurst - a new independent film
 - About to be released for educational purposes

Traveling Exhibit

- All over PA
- Capitol, PA
- Schools
- Service agencies
- Colleges
- Other countries
 - Korea 11/26/2015
- U.S. Senate
 - 6/29/2016



Tom Gilhool, Janet Albert-Herman, and Senator Bob Casey in the Rotunda



Commemorating Human Rights in the Capital

- Three Great Achievements
- None of them happened quickly
- Two more are stalled
- This won't be easy

United States Holocaust Memorial and Museum

Begun 1987, Opened 1993



National Museum of the American Indian

Begun 1989, Opened 2004



National Museum of African American History and Culture

Begun 1915, Opened 2016



Our Prototype



Museum *of*
disABILITY History

— A PROJECT OF PEOPLE INC. —

Buffalo, NY 14226

□ www.museumofdisability.org

Past and Future Of the Nation's Only Physical Museum on Disability

- The Museum was located in Buffalo New York.
- Chartered in 2010.
- It was the only “Bricks and Mortar” Museum dedicated to preserving disability history.
- The Museum was a project of a leading non-profit human service agency.
- Had to close during pandemic.
- Will be transferred to a permanent home in a University to be named.



Museum of disABILITY History

Accomplishments & Methods

- *The Museum of disABILITY History has been dedicated to advancing the understanding, acceptance and independence of people with disabilities.*
- Traveling Exhibits
- Disability History Curriculum
- Disability Awareness & Etiquette Programs
- Disabilities Film Festival
- Person First Forum
- Publications
- Cemetery Restoration
- Lives Left Behind - Stories Preserved

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Draft Strategic Plan Outline

- Write a draft Bill for Congress
- Involvement of major advocacy organizations
- PMPA passes the baton
- Create an Ad Hoc Steering Committee including all disability advocacy interests
- Committee includes great national leaders and self-advocates
- Ensures that the process will be led by non-politicians
- Generate wide support and endorsement
- Introduce Bipartisan bill to establish a Commission
- Work together to get that bill passed
- When passed, 2 years of Commission work
- During the 2 years, create a Smithsonian Traveling Exhibition on Disability History and Rights

Winston Churchill on Americans

- “You can always count on Americans to do the right thing....
- After they've tried everything else.”

It's Time

- Discussion
- Questions
- Comments
- Ideas