



# **“WE ARE PEOPLE FIRST”: The History and Dynamics of the Self-Advocacy Movement**

Shirley Paceley and Amy Walker

May 26, 2010

Vera Institute of Justice Conference  
San Jose, California

# What is Self-Advocacy?

- “Refers to the civil rights movement for people with developmental...and other disabilities”
- “People with disabilities taking control of their own lives”
- “People with disabilities speaking up for themselves”
- “Having the right to make life decisions without undue influence or control by others”
  - *Quotes from Wikipedia*

# Why Self-Advocacy?

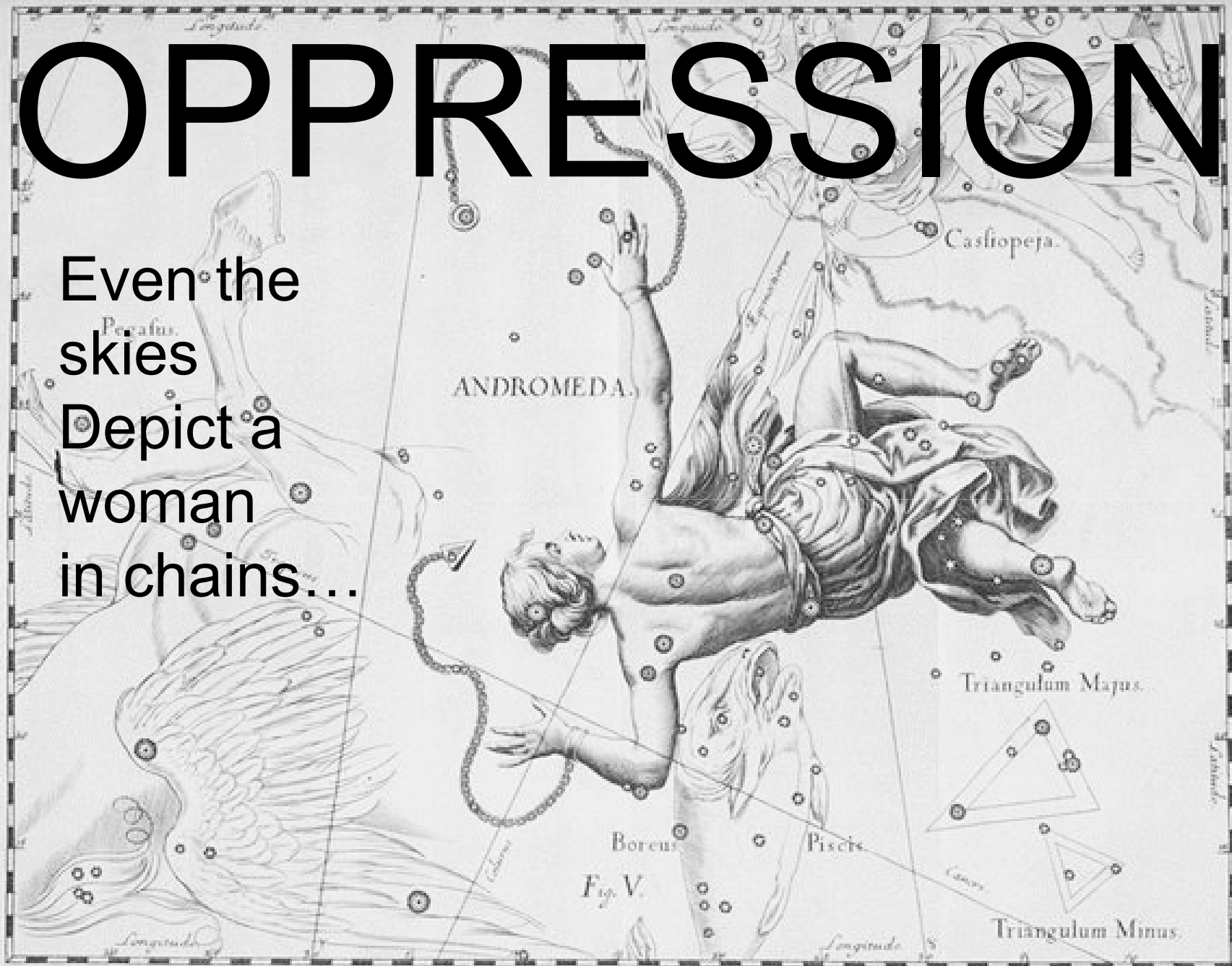
- People with all types of disabilities spoke up for their rights and started the self-advocacy movement to counter the effects and daily practices of OPPRESSION and people using LABELS to “pigeonhole” them.



# OPPRESSION

Even the  
skies

Depict a  
woman  
in chains...





**DOG**



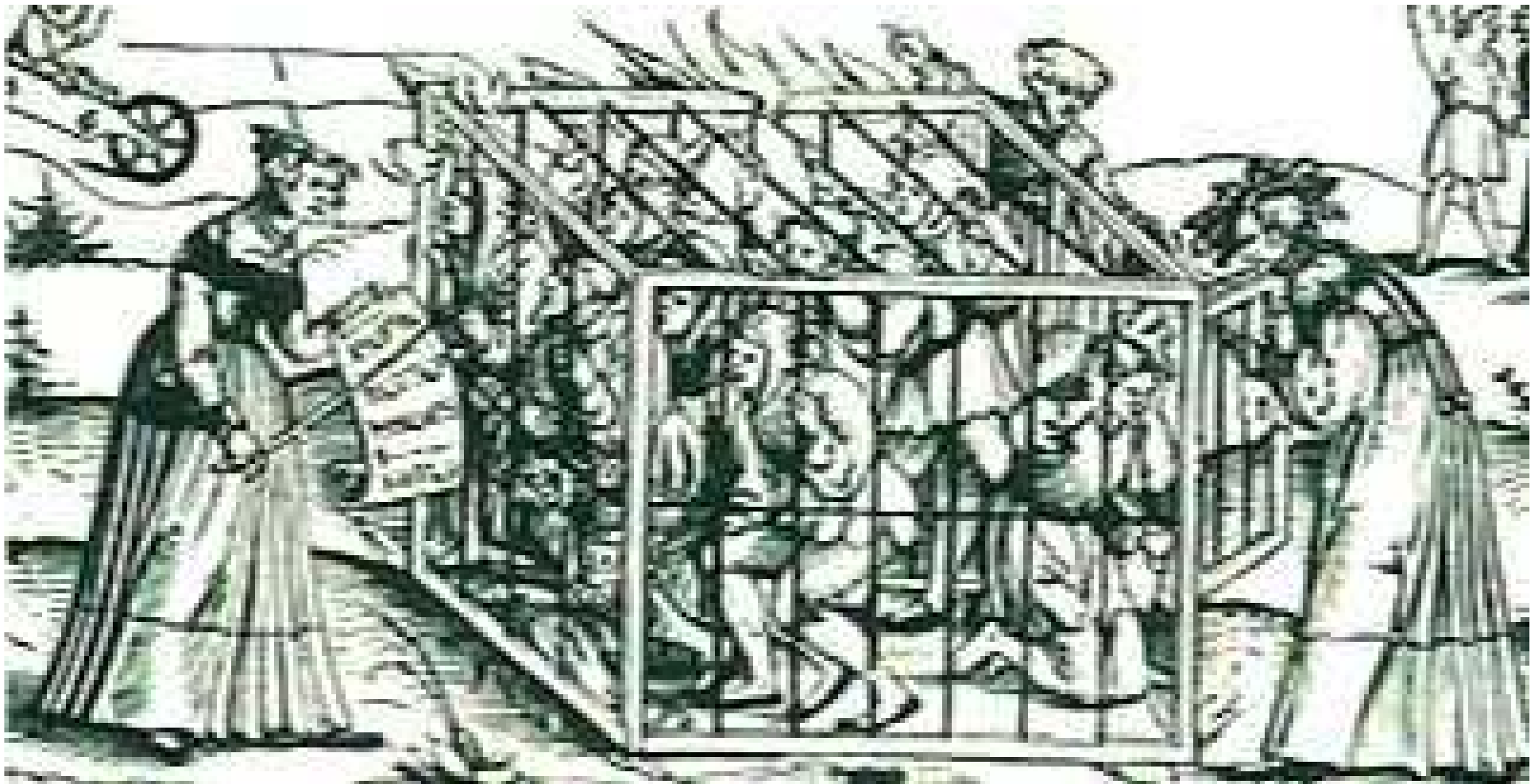
**FOX**



**FIELD**



# “Idiot Cages”: 476-1500 A.D.



# Witch Hunts



# Exorcism/Corporal Punishment



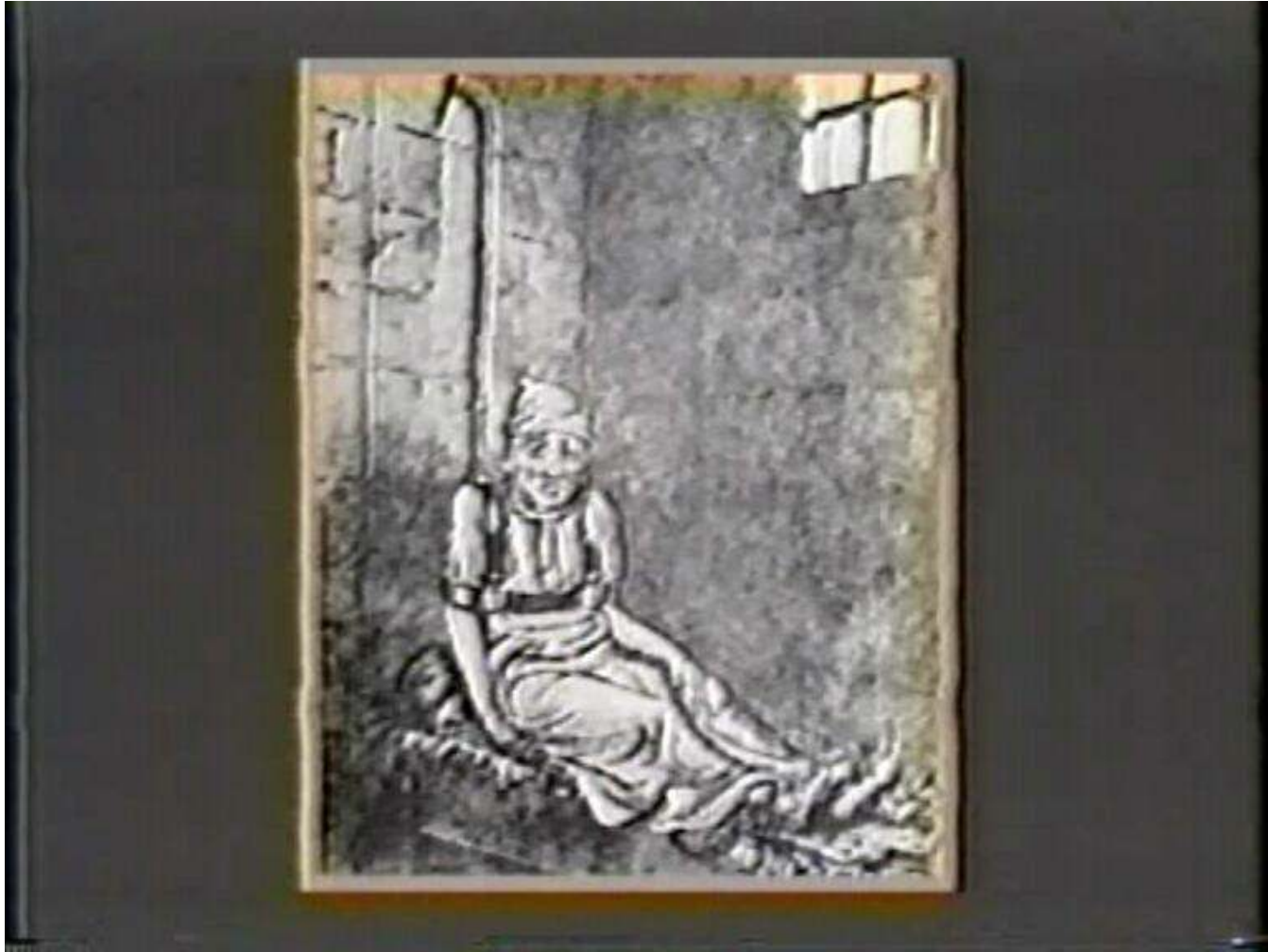
# Corporal Punishment/Restraint



# Corporal Punishment/Restraint



# Asylums and Poorhouses



# The Chains of Institutionalization



# Institutions and “Free Labor”: 1800-1950



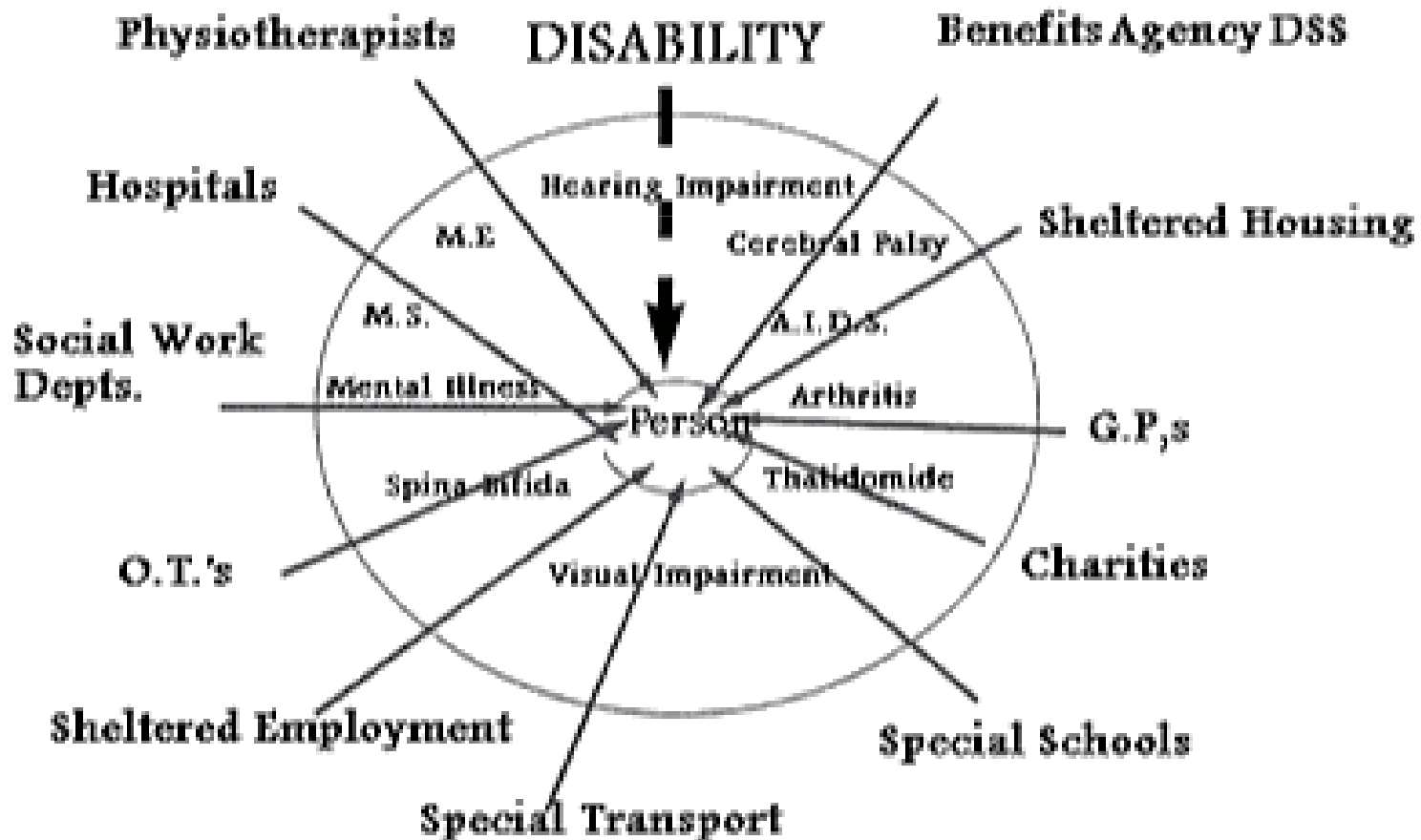
# Eugenics and the “Final Solution”: 1800-1950



Killing stations	Period of operation	Numbers killed
Grafeneck	Jan.–Dec. 1940	9,839
Brandenburg	Feb.–Sept. 1940	9,772
Bernburg	Jan.–Sept. 1941	8,601
Hadamar	Jan.–Aug. 1941	10,072
Hartheim	May 1940–1941	18,269
Sonnenstein	June 1940–Aug. 1941	13,720

# The “Medical Model” of Disability: 1950-1980 and Today

## MEDICAL MODEL



CHRISTMAS IN PURGATORY

# Christmas in Purgatory

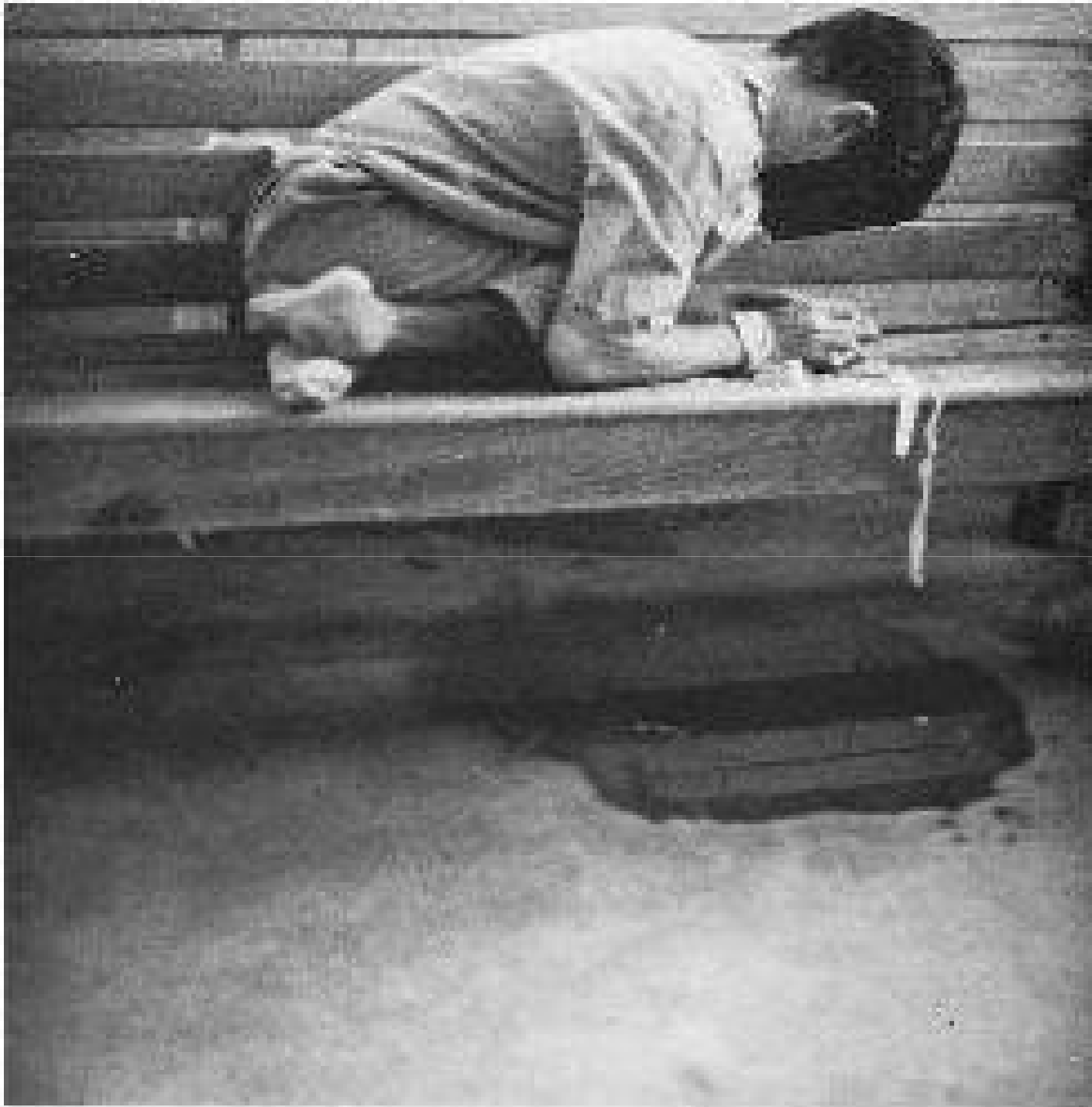
*Excerpts from a photographic  
essay by Burton Blatt  
and Fred Kaplan ©1974*



“In one dormitory, that had over 100 infants and was connected to 9 other dormitories that totaled 1000 infants...”



*“There is a hell on earth, and in America there is a special inferno. We were visitors there during Christmas, 1965.”*



**“We saw children with hands tied and legs bound. After discussions with attendants and supervisors in the four institutions, we were convinced that one of the major reasons for the heavy use of solitary confinement and physical restraints was the extraordinary shortage of staff ...”**



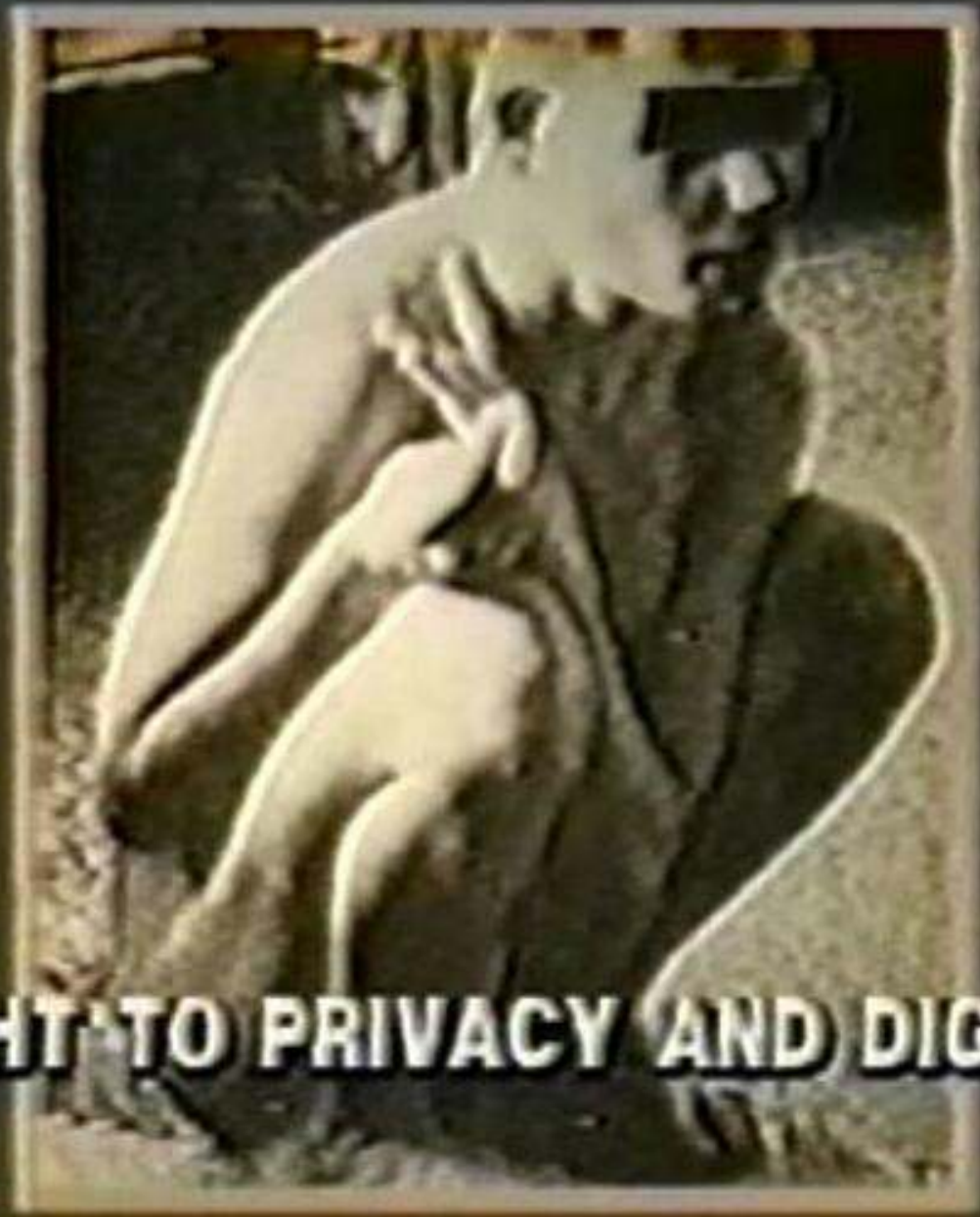
**"In some of the children's dormitories, we observed "nursery programs." What surprised us most was their scarcity and primitiveness of those in operation. Therefore, we were not unprepared to see several children with severe head lacerations. We were told these were *head bangers*."**



**"The living quarters for older men and women, were, for the most part, gloomy and sterile. There were the rows and rows of benches on which sat countless human beings, in silent rooms, waiting for dinner call or bedtime. We saw resident after resident in "institutional garb." Sometimes, the women wore shrouds inside out."**

# *We All Have...*

*A brief presentation on our human rights*




**A RIGHT TO PRIVACY AND DIGNITY**



**A RIGHT TO WEAR PERSONAL CLOTHING**



**A RIGHT TO KEEP PERSONAL POSSESSIONS**



**A RIGHT TO HAVE VISITORS AND  
TO USE THE TELEPHONE**



**A RIGHT TO BE FREE OF PHYSICAL  
RESTRAINT**



**A RIGHT, TO BE FREE OF EXCESSIVE  
MEDICATION**

A black and white photograph of a patient lying in a hospital bed, surrounded by medical equipment. The patient is looking towards the camera. The text is overlaid on the lower half of the image.

**A RIGHT NOT TO HAVE INTRUSIVE  
PROCEDURES USED WITHOUT INFORMED  
CONSENT**

# The Legacy of Institutions

**Sun-Times**

Special  
Report

**Abuse,  
neglect  
& death**

**Why it's so rampant**  
Breakdown



*Four Critical Questions:*

**IS IT OPTIMAL?**

**IS IT APPROPRIATE?**

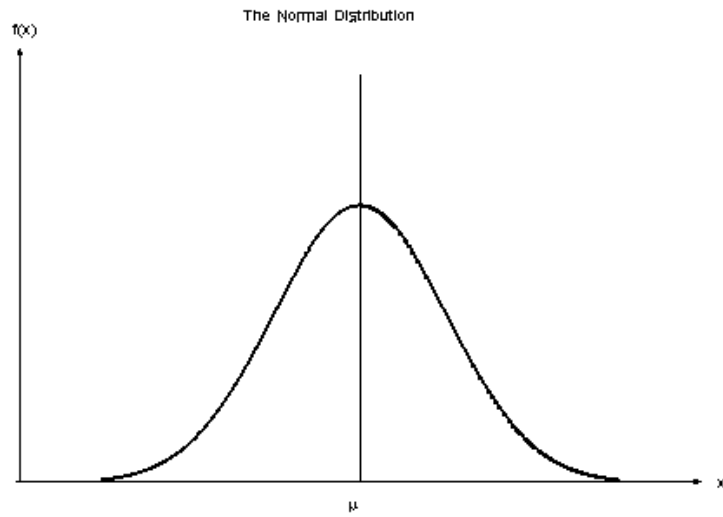
**IS IT LEGAL?**

**IS IT HARMFUL?**



*“Those who deny freedom to others, deserve it not for themselves.”*

*Abraham Lincoln, April 6<sup>th</sup>, 1859*



“An institution is not just a place...  
**...it is the way people think.**”

# The Myth of Freedom

## Normalization and De-Institutionalization

# Amy Speaks Out



# LABELS



Starring our friend, Mr. Yuck™!

burden

daughter

poor

**victim**

mentally  
retarded

insane/crazy

teacher

**slow**

friend

college  
student

advocate

statewide  
committee  
member

**author**

**stupid**

mother



## Rights of the Incompetent

# INCOMPETENT



\*A legal term

\*Also a label





*"Words are, of course, the most powerful drug used by mankind."*

- Rudyard Kipling

# HISTORY

*“It’s not something you find in  
a book, but within all of our  
lives...”*

*--Amy Walker*

# Self-Advocacy: A Timeless Idea

- People have been practicing self-advocacy—fighting for their rights and speaking up for what they want and need—since the beginning of time, but only in the late 20<sup>th</sup> century did they begin to organize and rally within official groups.



# The Self-Advocacy Movement Begins

- In the late 1960's in Sweden, Dr. Bengt Nirje helped people with disabilities organize a club. The club had no leaders; members would plan a trip into the broader community, go on it, and then discuss their experiences.



# The Self-Advocacy Movement Begins

- “This is akin to any decent revolt. Some of the...adults themselves want to play a new role in society, to create a new image of themselves in their own eyes, in the eyes of their parents and in the eyes of the general public.” –*Dr. Bengt Nirje*

# The Self-Advocacy Movement Progresses

- 1973—People First formed in Salem, OR
- 1991—Self-Advocates Becoming Empowered (SABE) formed in Nashville, TN
- 1995—Self-advocacy groups form all over Present the USA

*What does the future hold???*

# DYNAMICS



*“...the wheel keeps on turning  
and turning and turning, and  
Nothing’s disturbing the way it goes around..”*  
--Edie Brickell and the New Bohemians, “The Wheel”

# The Dynamics of Self-Advocacy

- We are PEOPLE FIRST!
- NOTHING ABOUT US WITHOUT US!!!
- We speak up for ourselves and others.
- We are NOT our labels.
- We have human rights.
- Our dreams matter far more than our disabilities.



# The Dynamics of Self-Advocacy

- We have the right to make decisions.
- We know ourselves. We know what we need and what is “best” for us.
- We are capable, strong and wonderful.
- We have different gifts and talents.



# The Dynamics of Self-Advocacy

- We sometimes face barriers that SOCIETY puts in our way. Help us break them!
- Sometimes we have to “give and take” when we work with other advocates and advocate groups.
- However, OUR voices COUNT and MATTER!

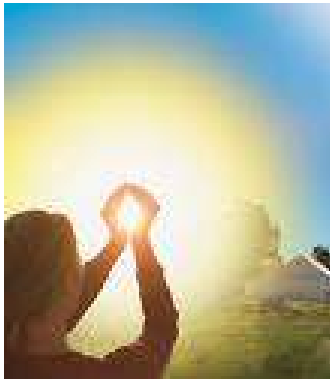


*...the greater the resistance,  
the higher the kite flies...*

*--Oreida Horn Anderson*

# Thoughts on Self-Advocacy

*“Self-advocacy is fundamentally about true equality, respect, and power, and about recognizing and changing the current imbalances in all of those things. Real self-advocacy will always upset the status quo in some way.”*



—A.M. Baggs, 2005



# PARTNERSHIP

*“Do not work on me. Work with me.”*

--A Credo for Support

# Partnering with Women with Disabilities

- Invite them to take part in your project by serving on boards, committees, and subcommittees.



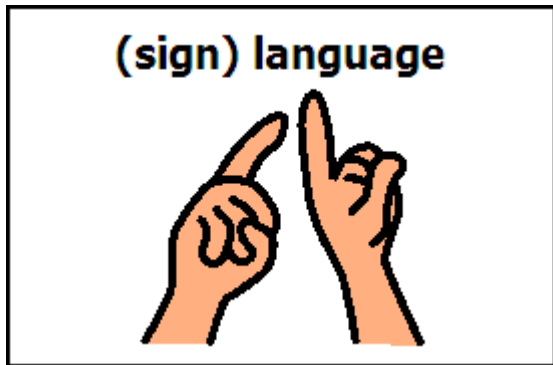
# Partnering with Women with Disabilities

- At your project meetings, use plain language. Don't use lots of jargon, acronyms, and technical terms.



**NO**





# People First Language

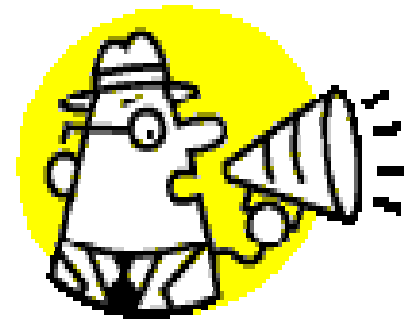
Put people first

Do not focus on disability

Do not portray successful people with disabilities as superhuman

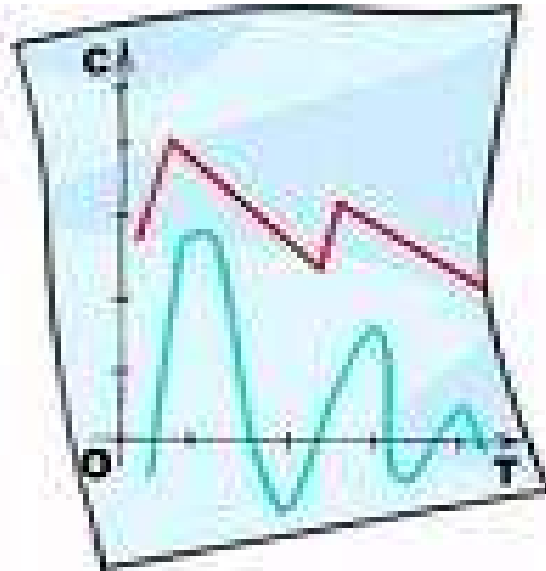
Do not sensationalize a disability

Do not use general labels



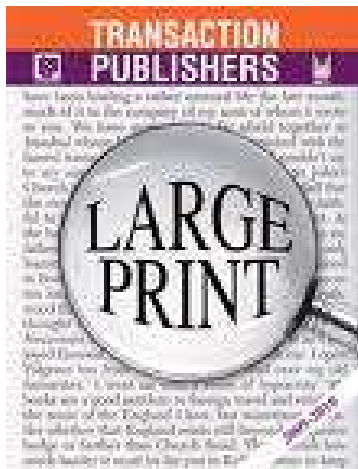
# Partnering with Women with Disabilities

- Invite them to complete critical tasks for your project such as reports, interviews, needs assessments, surveys, and data analysis.



# Partnering with Women with Disabilities

- Make sure that all the materials at your project meetings are in a format that everyone can understand (large print, pictures, Braille, etc.)



# Partnering with Women with Disabilities

- Listen carefully to the ideas, insights and suggestions that women with disabilities have. Thorough discussions always help!



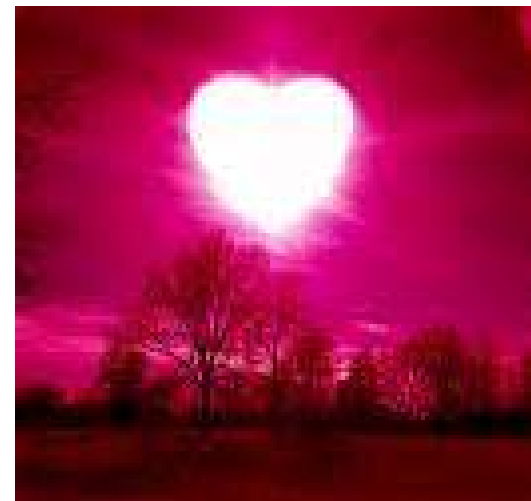
# Partnering with Women with Disabilities

- Provide for accommodations such as sign language interpreters and service animals.



# Partnering with Women with Disabilities

- Most of all, be proud of who you ALL are and of the vital work you're doing to change the service system for people with disabilities who experience violence!





Blue Tower Training Center (BTTC) is a division of Macon Resources, Inc. (MRI) which provides training, consultation, training materials and resources on a national as well as international basis.

## **Shirley Paceley**

P.O. Box 2760

Decatur, IL 62524-2760

[spaceley@maconresources.org](mailto:spaceley@maconresources.org)

## **Amy Walker**

P.O. Box 2760

Decatur, IL 62524-2760

[awalker@maconresources.org](mailto:awalker@maconresources.org)

Learn more about BTTC by logging on to  
<http://www.bluetowertraining.com>