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

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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.
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
The “Medical Model” of Disability: 1950-1980 and Today
“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 RIGHT NOT TO HAVE INTRUSIVE PROCEDURES USED WITHOUT INFORMED CONSENT
The Legacy of Institutions

Sun-Times

Abuse, neglect & death
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 6th, 1859
The Myth of Freedom

Normalization and De-Institutionalization

“An institution is not just a place... ...it is the way people think.”
Amy Speaks Out
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
INCOMPETENT

*A legal term
*Also a label
“Words are, of course, the most powerful drug used by mankind.”

- Rudyard Kipling
“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 20th 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.
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.

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