

# ADVOCACY AND DISENFRANCHISED POPULATIONS

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# Advocacy

- “When I was a boy on the Mississippi River there was a proposition in a township there to discontinue public schools because they were too expensive. An old farmer spoke up and said if they stopped building the schools they would not save anything, because every time a school was closed a jail had to be built.” ( Mark Twain)

# Advocacy

The practice through which all people can make their voices heard, express their concerns and priorities, press for recognition of their rights, and insist on the importance of their voice in public policy.

# The Disability Law Center

- The only statewide disability organization that provides self-advocacy assistance, legal services, disability rights education and public policy advocacy on behalf of more than 400,000 Utahns with disabilities
- Broad statutory powers to safeguard human and civil rights
- 4 long range goals – *People with disabilities will...*
  - ▣ *be free from abuse and neglect*
  - ▣ *receive appropriate services*
  - ▣ *be free from discrimination*
  - ▣ *have equal employment opportunities*
- Services are provided at no charge

# About Disability

- A naturally occurring part of the human experience
- At least 54 million people in the U.S.
- At least 400,000 Utahns
- 15% to 20% of any state population
- Unemployment for working-age (16-64) around 70%
- 1 in 5 people will experience a serious psychiatric illness
- At least 40,000 Utahns have a brain injury
- If you live to the age of 70, you have an 82% chance of experiencing disability for yourself

# What is a Disability?

- No universally accepted definition
- What constitutes a disability depends on
  - ▣ Who you ask
  - ▣ What services a person can or may receive
  - ▣ Medical diagnoses (or the lack, thereof)
    - These things become a sociopolitical passport to services and legal status

# What is a Disability?

- Disability “criteria” for early childhood services is different from Vocational Rehabilitation
- Disability is a social construct created to identify people who may be entitled to specific services or legal protections

# ADA Definition

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- Having physical or mental impairment that substantially limits one or more major life activities
- Having a record of such an impairment
- Being thought of as having a disability

# Race and Disability

- People of color and those in lower socioeconomic groups tend to be disproportionately impacted by disability and its related issues
- Native Americans have higher rates of disability than other ethnic groups (STDs, mental illness, substance abuse and violent death) (UDOH, 2009)
- African-Americans experience disability at a more severe level than other groups (ACRES, 2003)
- Prevalence of disability increases with age at a faster rate for African-Americans, Native Americans and Hispanics than for any other ethnic groups (ACRES, 2003)

# Common Challenges in Working with Disenfranchised Populations

## □ **Establishing rapport and trust**

- Must work to identify mutual purpose
- Don't assume the person needs or wants your help
- Usually have a history of abuse and/or neglect
- Usually takes repeated interactions primarily focused on relationship building
- Can help to piggyback efforts with those who are known and trusted in the community

## □ **Communication**

- Particular challenge for individuals with limited English, people with cognitive and psychiatric disabilities
- Approach everyone as an individual
- Develop easy-to-read materials, be concrete and avoid jargon
- Ask what works for them (preferred mode of communication and learning)

# Other Challenges and Strategies

## □ **Defining boundaries**

- Be clear about your role and expectations
- Make written agreements when necessary
- May be particular challenge for individuals with psychiatric and cognitive disabilities
- Enlist allies for support

## □ **Attitude**

- Paternalism is the biggest barrier to independence and success
- Authenticity is the key
- Apologize when necessary
- Remember that you are in service to the individual
- Remember what separates you from your client – very little

# More Challenges and Strategies

- Co-occurring disorders
  - ▣ 59% of people with a history of drug abuse or dependence also had experienced a mental disorder (SAMHSA, 2006).
  - ▣ Mental health problems often predate substance abuse problems by 4-6 years (SAMHSA, 2006).
- Language and cultural barriers
- Lack of access to basic healthcare and social services
  - ▣ Once eligible, difficulty navigating the service system
- Previous experience with “helping agencies” and government organizations
- Others?

# Common Issues Faced by Disenfranchised Groups

## □ **Discrimination**

- Housing, employment, financial, etc.
- Can be difficult to identify root cause (i.e., disability, race, culture, language, poverty)

## □ **Poverty**

- People with disabilities in developing countries are over-represented among the poorest people
- Poverty and disability – multidirectional cause relationship

## □ **Violence**

- Violent death (intentional and unintentional) rates for Utah's Native Americans is higher than for all other Utahns (UDOH, 2009)

# Violence and Ethnicity

<b>Race</b>	<b>All Violent Crimes</b>	<b>Rape</b>	<b>Robbery</b>	<b>Aggravated assault</b>	<b>Simple assault</b>
<u>White</u>	38%	25%	47%	54%	37%
<u>Black</u>	51%	48%	65%	61%	41%
<u>Native</u>	42%	47%	55%	59%	43%
<u>Asian</u>	40%	16%	55%	51%	31%
<u>Hispanic</u>	44%	28%	48%	55%	39%
All	43%	31%	57%	55%	38%

Source: National Crime Victims Survey, 2000

# Violence and Disability

- 60% of people with disabilities will be seriously physically abused in their lifetimes
- 83% of women with disabilities are sexually abused
- 53% of men with disabilities are sexually abused
- People with developmental disabilities are 4 to 10 times more likely to be abused than the general population and experience an average of 10 or more abusive episodes per perpetrator
- Youth with disabilities are bullied more often and severely than non-disabled youth

# Strategies

- Understanding basic rights issues
- Disability etiquette
- People first language
- Additional resources

# Understanding Basic Rights Issues

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- Disability is a natural part of the human experience
- People with disabilities are full and equal citizens under the law
- The right to inclusion is a birth right – a human right

# Equality, Equity and Fairness

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- Right to equal access to the opportunities afforded to all members of the society
- Right to be free from abuse, neglect ,exploitation, discrimination and isolation and to be treated with respect and dignity

# Meaningful Choice

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- The right to make choices with respect to daily routines and major life events, regardless of age, type and level of disability

# Advocacy scenario

- You have a 28 year-old client who is diagnosed with schizophrenia, a seizure disorder that is well controlled with medications and hypertension. She lives in a small group home with two other people.
- One day, she tells you that she wants to smoke, but you tell her that she cannot because of her hypertension and a “no smoking rule” at the group home.

# Advocacy Scenario

- Your client has met with her doctor who explained the risks associated with smoking. She understands that this could make her hypertension much worse, but she wants to do it anyway.
- Your client has a limited guardian in the areas of financial and medical decisions. The guardian does not want the ward to smoke and is considering using their power as the financial guardian to withhold the ward's daily spending money so she cannot buy cigarettes.
- The Residential Program Coordinator supports the guardian, which is beginning to have a negative impact on the Coordinator's relationship with the client.

# What do you do ?

- What rights does the client have?
- What about the rights of the provider?
- What rights do the other clients have?
- What about the rights of the guardian?
- What about the client's best interest?

# Supports and Participation

- Shaped by the unique needs and preferences of each individual
- Assure opportunities for integration in all aspects of life
- Must be age appropriate and premised on the fact that individuals continue to learn, grow and develop throughout their lives

# Independence

## □ Services

- based on equal access , peer support and self – determination
- maximize leadership, independence ,productivity and integration
- reflect the diverse cultural, ethnic and racial composition of society

# Disability Etiquette (General)

- ❑ Ask before you help
- ❑ Be sensitive to personal touch
- ❑ Speak directly to the person
- ❑ Show respect for personal privacy
- ❑ Don't' make assumptions about abilities
- ❑ Use people first language
- ❑ Disability equipment is part of personal space
- ❑ Don't touch a service animal
  - ❑ Don't ask permission to pet a service animal

# Etiquette for People who are Deaf or Hard of Hearing

- People who are Deaf communicate with sign language and consider themselves to be members of a cultural and linguistic minority group
- They don't typically identify with the broader disability community
- They refer to themselves as Deaf with a capital "D" and may be offended by the term "hearing impaired"

# Etiquette for People with Physical/Mobility Impairments

- ❑ Individuals who use wheelchairs are people, not equipment
- ❑ Don't lean over someone in a wheelchair to shake another person's hand
- ❑ Don't push or touch a person's wheelchair – it's an extension of their personal space
- ❑ If you help someone down a curb without waiting for instructions, you may dump them out of their chair

# Etiquette for People with Mental Illness

- People who have psychiatric disabilities have varying personalities and different ways of coping with their disability
- Some may have trouble picking up on social cues; others may be overly sensitive
- Treat each person as an individual
- Ask what will make him/her most comfortable and respect his needs to the maximum extent possible

# Etiquette for Someone with a Traumatic Brain Injury

- A person with a brain injury may have poor impulse control
  - ▣ They may make inappropriate comments and may not understand social cues or “get” indications that they have offended someone
  - ▣ In their frustration to understand, or to get her own ideas across, they may seem pushy
- They may have trouble concentrating or organizing their thoughts, especially in an overstimulating environment

# People First Language

- Puts the person *before* the disability and describes what a person has been diagnosed with - NOT who a person is
- Group designations such as "the blind," "the retarded" or "the handicapped" are inappropriate because they do not reflect the individuality, equality or dignity of people with disabilities

# People First Language

- Words like "normal person" imply that the person with a disability isn't normal, whereas "person without a disability" is descriptive but not negative
- Consider whether or not you would like to be known primarily because of your psoriasis, gynecological history, gingivitis or other condition(s)?
- Do you prefer to be known by the multitude of positive characteristics which make you a unique individual?

# Resources

- Go to [www.disabilitylawcenter.org](http://www.disabilitylawcenter.org)
- Click on “*Advocacy and Disenfranchised Populations*”
  - You will find:
    - Presentation materials
    - Supplementary disability etiquette information
    - Information on people first language