



WEST VIRGINIA INTEGRATED BEHAVIORAL HEALTH CONFERENCE

Alone in a Crowd: The experience of vulnerable people in our culture

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People, Partnerships & Possibilities

- People – recognizing, acknowledging, accepting diversity at all levels
- Partnerships – forging alliances across professions, beliefs and cultures
- Possibilities – seeing things in new ways, asking how, believing in a better future rather than a continuation of what is seen today.



Children and Adults with Intellectual and Developmental Disabilities

- Vulnerability to trauma
- Vulnerability to criminal abuse/neglect
- Vulnerability to negative beliefs
- Vulnerability to negative attitudes
- Vulnerability to myths & stereotypes
- Vulnerability to failures to provide equal support, consideration, services.



How many People with Disabilities are there?

People with Disabilities represent approximately 20% of the population, with 10% having severe disabilities (DOL)

- There are current increases in certain types of disability due to:
 - Violence/Intentional Injury - Accidents
 - Longer life spans - War veterans
 - -Idiopathic causes -Improved medical care
(600% increase in autism over last 10 years, for example)



Who are People with Disabilities?

- **People born with disabilities**
- **People who acquired disabilities as children**
- **People who acquired disabilities as adults (TABs)**
- **People who acquired disabilities as a result of domestic violence**
- **People who acquired disabilities as a result of criminal behavior by others**
- **People who acquired a disability by other means**



Data on Prevalence of Abuse

Children with Disabilities are:

- 3.4 times more likely to be abused than others (Sullivan, 2001)
- 1.7 times more likely to be abused than others (Westat, 1991)
- 4-10 times more likely to be abused than others (Garbarino, 1989)

Adults with Disabilities are:

- Equally as likely to be abuse victims as the generic population (women/physical disabilities) (Nosek, 1999) BUT
- The extent of the abuse is said to be much worse for women with disabilities. (difficult to compare pain)
- Have equal vulnerability as children with disabilities (Baladerian,, 2001 [anecdotal]) (Why would it be different, since vulnerability transcends age categories)



Data on Prevalence of Abuse

- Powers et. al. (2002) study found that of women with physical and cognitive disabilities:
 - 67% experienced physical abuse in their lifetime
 - 53% experienced sexual abuse in their lifetime
 - These are approximately twice the rates in the non-disabled population
- Nosek, Young & Rintala (1995) study found of women with physical disabilities:
 - 62% experienced some form of abuse in their lifetime



Data on Prevalence of Abuse

- For those with developmental disabilities increased rates of abuse among both men and women ranging from 31-83%
- For women with intellectual & other developmental disabilities rates from 40-90%



Data on Prevalence of Abuse

SUBSTANTIATED CASES ANNUALLY:

- 5 million vulnerable adults (NAS, Petersilia, 2001)
- 2 million elders
- 1 million children (generic)

Thus, vulnerable adults become crime victims more than children and elders combined.



Adults abused as children:

- Have ongoing sequelae that impact physical, psychological and social functioning
- More than 80% of those presenting for General Practice internal medicine concerns experienced childhood maltreatment.
- Study showed that the long term impact of childhood maltreatment is almost completely unrecognized in the health care community. (Vincent Felitti, M.D./Kaiser)
- Are more likely than others to become repeated abuse victims – polyvictimization is the new term.
- Are less likely to have resources to report and recover.



Attitudes – Beliefs - Stereotypes

- Barriers to effective service delivery may occur when providers are unaware they are operating under the influence of unfounded but widely accepted myths, negative attitudes, stereotypes or cultural mindsets.
- We may not notice micro-traumas inflicted by others or ourselves.



Barriers to Effective Support

- Devaluing, dehumanizing and distancing.
- Limited or lack of personal contact with individuals with similar backgrounds.
- Belief that individuals with mental illness, intellectual disability or communication differences cannot be effectively or reliably interviewed.



Myths and Stereotypes

- Deviancy & Evil
- Contagion
- Spread
- Innocence
- Wildness
- Shame



Myths and Stereotypes

- Cannot distinguish the truth from a lie
- Cannot understand the consequences for lying
- Don't have a sufficient or correct vocabulary to describe the abuse.
- Alternative methods of communication cannot be used.
- Do not experience physical or psychological pain



Person First Language

How to properly and respectfully describe an individual with a disability, when talking with or about them, or documenting your contact.

Using Person First Language is a sign of respect.

Use Person First Language in all written and spoken communications.



Person First Language-Hints

- Avoid making the individual's disability the main focus.
- Say, the individual “has” a disability, not “is” a disability
- Say, the child “acquired a brain injury” not “is brain injured”
- For example you would say you “have” the flu, not “are” the flu.
- Small distinctions that make a huge difference.



LANGUAGE PC...OR RESPECT?



LANGUAGE

PC...OR RESPECT?

- Use “People First” language. Maria, the woman who is blind asked for large print brochures. NOT: the blind lady wants a hamburger. Cue: say “Person Who has” before naming the disability.
- Best: avoid any use of the term mental retardation. Preference is for slow learner or learning. Person with special needs is OK. Challenged is not. “Intellectual Disability has now replaced it.
- Don’ t say handicapped, cripples, lame, deaf and dumb, wacked, loosely wrapped...not even joking around.
- Use powerful images: uses a wheelchair NOT wheelchair bound or “the wheelchair guy” or “the wheelchair” without the person.



“Consumer”

- **CONSUMER:** When this word is used regarding a shopper or consumer of a service, this is not their entire identity. Nor should it be for an individual with a disability. Better to say, individual who has a disability, or people with disabilities. Consumer implies the person is not a whole person who both gives and receives, but only one who receives. No one is like that. Everyone gives and receives. It is pejorative, it demeans, and denies the “whole person” as well as individual nature of each person.



Common Beliefs About People with Intellectual and/or Developmental Disabilities

- Have multiple disabilities
- Are asexual
- Are unable to
 - Understand and learn
 - Feel
 - Feel pain
- Cannot distinguish truth from fantasy
- Are unable to reliably, effectively communicate



Common Reactions to Persons With Disabilities

- Dread
- Embarrassment
- Shame
- Pity
- Disbelieve, disregard and discount
- Dehumanize



Significance of Beliefs

- Can make them more of a target for victimization
- Can make us less effective in handling crimes against them
- What may look like threatening conduct may be behaviors associated with a disability
- Importance of distinguishing a disability from suspicious conduct



INDIVIDUALS with disabilities are treated differently at all stages of the public services & abuse response continuum



Why Is This Important?

- Individuals with cognitive impairments are identical to and different from “the norm”.
- Both the similarities and differences get overlooked when one’s lack of familiarity & lack of academic preparation allow myths and stereotypes to invade or even dominate one’s thinking, attitudes & behavior. Thus,



Why is this important?

- Skilled & trained professionals improve the experience of abuse victims with disabilities,
- Professionals expand their skills, knowledge, and cultural understanding of members of this population
- And can recognize or avoid “Wrong Thinking”



Translation of Attitudes, Ignorance to Action: Uh-Oh. Let's learn together

- Unbeknownst to the teacher, a 13 year old autistic & non-verbal boy had been raped by his dad during a weekend visit. During school the boy was rubbing (over clothing) his penis. The teacher told him not to touch his penis as “that’s dirty.” The boy went home and poured shower cleanser on his penis. The doctor did nothing saying that he could not feel pain because of the autism, although he was crying and screaming.



Translation of Attitudes, Ignorance to Action: Uh-Oh. Let's learn together

- A young woman with Down Syndrome had been raped. She had several sx of PTSD including new behaviors of lying, re-enacting, crying. A Behaviorist “cured” her with a point system. Reward and punishment. Later the sx. Re-emerged. With supportive therapy she drew the name and image of the perpetrator and revealed many other abuses. This led to a strengthening of her family ties and psychological well-being.



Translation of Attitudes, Ignorance to Action: Uh-Oh. Let's learn together

- Dubnoff Center: Day School & Residential Program for 13-18 yoa, with Dev. Disab. + Out of Home Placement + Hx. Of Abuse + Beh. Sx.
- Allow or “treat” Survival skills? (at home the boy had to scavenge for his food)
- Where to draw the line with behavioral sx?
- Respect, support, family sabotage



Translation of Attitudes, Ignorance to Action: Uh-Oh. Let's learn together

- Boy with mild intellectual disability is thought to be gay. P.E Teacher assesses. Team Plan: Vasectomy (age 14). Boy is not gay.
- Boy (13) w/ mild intellectual disability pats toddler on her rear end. Mother c/o rape. Boy is sent 200 miles away for 2 years to institution to teach sex education and remove from community as a danger.



How can you know that you don't know?

- Self-awareness
- Take classes, attend conferences for people with disabilities
- Ask others about their thoughts, beliefs, attitudes and the source of these.
- Great example: Why do people wonder about the veracity of abuse allegations *automatically* when the victim has a disability?



Negative attitudes toward people with disabilities...

- ...is said to be the biggest disability.



Current best ACTIONS to counteract

- Adopt “Nothing About Us Without Us” as a working tool
- Increase awareness of internal thinking that uses disability-related disparaging comments



Mottos that teach

- Presume competence
- Just because I can't talk does not mean I have nothing to say
- The right to communicate is a basic human right, without which no other rights are available.



Trauma and People with Disabilities: What to do? How to Help?

- According to the 2012 National Survey on Abuse of People with Disabilities:
- Less than 1/3 received any therapy
- Of those who received therapy 83% said it helped
- More than 63% of Phys. Abuse victims and 52% of Sexual Assault received no therapy.
- Overall <5% received VOC assistance though 8.6% of Sexual Assault victims received help.



People with Disabilities Benefit from Therapy

- Due to the attitudinal barriers noted earlier, there are relatively few mental health practitioners trained, experienced and eager to provide therapy to people with disabilities.
- Lack of exposure to people with disabilities during their training is a factor. Lack of awareness of the great rewards of this work is a barrier.



How does abuse/violence affect people with disabilities?

- I believe in all the same ways it effects people without disabilities (NT's), with variations for the victim's individual life history and typical adaptations to traumatic life events.
- However, we must acknowledge that no matter how severe the disability, it is more than likely that they have been negatively impacted by the abuse, and can benefit from therapy.



Trauma Recognition & Validation

- The fact that the individual feels s/he has been heard, believed, respected, and her/his psychological trauma validated is very healing
- Since we know that most do not tell of their abuse experiences, it is essential to ask, and have a supportive response when they do tell you.



Trauma and its description: Words

- Trauma
- Wounding
- Hurt
- Pain
- Micro-aggression
- Trauma impact



It is important to communicate!

- When different professional worlds integrate, language must also be integrated to insure communication as well as the meaning, implication of the words within each group's professional world. Identification of the terms used and their implication and use is an important discussion.



Reducing the Risk of Abuse for People with Disabilities

- The principle idea is to
 - Acknowledge that abuse and violence is not likely to be washed off the face of the earth very soon.
 - Create practical, realistic action plans that actually can reduce the risk of abuse and/or the impact of the abuse.



Being aware of our own mindsets that can cause unawareness on our part

- While at DPSS, I nearly challenged someone because of their voice...a quick review of their chart showed: laryngectomy. Yikes
- While visiting a new residence for a client, the director said, “Hi, Johnny, I’m Dr. Fish.” I told “Johnny” to say, “Hi Bobby, I’m Mr. Smith.” I nearly lost my job on that one! R-E-S-P-E-C-T!
- Naming a residence “Signs of Life” ...? Really?



Reducing the risk of abuse: Individual Planning

- Must take into account each individual's skills and abilities
- Create an IRP – An Individual Response Plan
- Use the model described in “Reducing the Risk of Abuse.” This has 3 time periods for planning
 - Before the abuse
 - During the abuse
 - After the abuse



Reducing the risk of abuse: Individual Planning

- Use the model described in “Reducing the Risk of Abuse.” This has 2 (or more) parties:
 - The individual for whom the plan is designed
 - The individual’s IRP Plan Partners. These are persons identified as those to whom abuse can be reported if it happens, who have their plan designed for how to respond when abuse is reported to them.



Reducing the risk of abuse: Individual Planning

- Using this model, several problems can be resolved:
- The Plan Partner is prepared for the event
- They can now react quickly and effectively to
 - Call the police and get help
 - Listen calmly, believe the report of abuse
 - Tell the victim they believe them – an enormously important step; and
 - Tell the victim that they know what to do and do it.



Reducing the risk of abuse: Planning for Agencies & Organizations

- Developing a workplace-wide written abuse response and reduction plan creates a template for all employees, volunteers, etc.
- The plan when implemented creates an “Abuse Awareness Atmosphere” that will deter most predators...not all, however.
- The plan acknowledges individual and corporate responsibility



Reducing the risk of abuse: Planning for Agencies & Organizations

- The plan includes the standard and expanded hiring, reporting and employment practices, to focus on abuse awareness, reporting, and standard actions when abuse is suspected. Equal response for any level employee or Board member or volunteer.
- The risk of abuse is in the awareness of all employees, who know a failure to report will result in suspension or firing.



Risk Reduction

- Adding these practices to your work can create a refined approach to abuse awareness, as well as strengthen community ties, as part of the plan calls for interdisciplinary in-service meetings and trainings.
- Using the term “Risk Reduction” rather than “Prevention” keeps us aware of the risk
- It also improves shared responsibility, so when abuse happens, no one is left hanging out to dry!



Pulling it all together

- Many disciplines with different perspectives, all with one goal: be of the best service possible to our clients and constituents
- All sharing information, ideas, attitudes, resources to improve our skills and knowledge bases.
- All acknowledging that individuals with any type of disability can be abused, and such abuse leads to changes in mood, behavior, learning and social interaction as well as communication.



Pulling it all together

- As we learn from each other, each is strengthened.
- Ongoing collaboration strengthens the safety net for our young people...improving their and our future.
- The key: Communication and Action!



Appreciation to Conference Attendees, Sponsors and Planners

- Thank you for creating this amazing collaboration.
- I expect that the ideas, information, and creativity created at this Conference will reverberate not only in our work but our hearts as we return to our offices and communities.



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