The Power of Language
Understanding and respecting disability begins with language –

Comments from Eulogy:
“He never seemed like he had a disability to me”
“He was the least disabled person I know”

- Person First Terminology
- “Lebensunwertes Leben”
- Eugenics
- 1942 AJP
- Larry James McAfee
- 2004 Wounded Warriors
- And making headlines today…

Woman Pleads Guilty After Urging People Not to Help Choking Son

- She tried to stop people from helping her son who has an intellectual disability and was choking at a restaurant.
- 68 year old Rolaine Foigelman pleaded guilty to endangering the welfare of an incompetent person, which prosecutors say is the highest charge she could have been convicted of in trial.
- Foigelman admitted to shouting “let him die” when he was choking on food at Boulevard Family Restaurant back in June.
- Other customers helped, but Foigelman attempted to stop them
Realities for Children with Disabilities

- Privacy and sense of own body
  - ADL support

- Expectations for life and achievement

- Obedience and passivity

- History of attention for maladaptive behavior
  - Otherwise ignored

Realities for Children with Disabilities

- Social isolation

- Difficulty being accepted by peers

- Understanding and perception of the criminal justice system
  - “Take him away he is being bad”

- Technology Influence

- Disproportionately criminally victimized

Disproportionate Victimizations

People with developmental disabilities are disproportionately at high risk for violent victimization, abuse, and neglect (USDOJ, 2012; Petersilia et al., 2001)

- **USDOJ Data 2009**
  - 47,000 rapes
  - 79,000 robberies
  - 114,000 aggravated assaults
  - 476,000 simple assaults

- **USDOJ Data 2011**
  - 58,000 rapes
  - 143,000 robberies
  - 199,000 aggravated assaults
  - 521,000 simple assaults
Average Annual Rates: 2011

- Violent victimization for persons with disabilities was more than **twice** the rate among persons without disabilities
- Serious violent victimization for persons with disabilities was more than **three times** than that for persons without disabilities
- Rate of violence for males with disabilities was 42 per 1,000 compared to 22 per 1,000 for males without disabilities.
  - Almost double the rate
- Rate of violence for females with disabilities, was 53 per 1,000 compared to 17 per 1,000 for females without disabilities.
  - Over triple the rate

Average Annual Rates: 2009 - 2011

- Persons with intellectual disabilities had the **highest rate** of violent victimization from 2009 to 2011.
- Among persons with intellectual disabilities, the average annual rate of serious violent victimization **doubled** from 2009 to 2011.
- The average annual rate of serious violent victimization against persons with self-care disabilities **more than tripled** from 2009 to 2011.
- The average annual rate of serious violent victimization against persons with multiple disability types was **double** compared to persons with one disability type.

Disproportionate Victimizations

- Victimization rates for persons with disabilities is highest:
  - Sexual assault (up to 10 times as high)
  - Robbery (up to 12 times as high)
  - (Sobsey, et al., 1995; Sobsey, 1994)
- Some offenders specifically seek victims with disabilities because they are perceived (Lang & Frenzel, 1988):
  - To be vulnerable
  - Unable to seek help
  - Cannot or will not report the crime
- Risk of victimization is likely increased if the offender believes the victim will not be able to successfully or credibly tell anyone about the crime (Bryen, Carey, & Frantz, 2003)
Disproportionate Victimization

- 49% of people with developmental disabilities who are victims of sexual abuse will experience 10 or more abusive incidents (Valenti-Hein & Schwartz, 1995).
- 88 to 98% of sexual abusers are known by the victims with disabilities (Sobsey & Mansell, 1994)
- About a quarter of all victims of violent crime with disabilities were injured (USDOJ, 2009)

Reporting, Prosecutions and Convictions

- Underreporting
  - Only 3% of sexual abuse cases involving people with developmental disabilities are ever reported (Valenti-Hein & Schwartz, 1995.)
  - Over 70% of crimes against individuals with severe mental retardation are unreported (Wilson & Brewer, 1992).
- A recent study in Boston suggested that only 5% of serious crime against people with disabilities were prosecuted compared to 70% general population (Boston Globe, 2001).

Convictions?

Susceptibility to Victimizations
Susceptibility to Victimizations: Intellectual Disabilities

- Intellectual Disability
  - Infantilized
  - Lack of understanding of what constitutes abuse
  - Perceptions of:
    - Lack of assertiveness
    - Memory difficulties
    - Restricted vocabulary
  - Fear of retribution
  - Fear of vacancy

Susceptibility to Victimizations: Autism

- Autism
  - Perceived Vulnerability
  - Deficits in Expressive Communication
  - Referential Communication Deficits
    - Referential communication requires a speaker to provide enough specific information to a listener so that the listener knows to what the speaker is referring (i.e., communicating information not already known by the listener)
  - Deficits in Detecting Deception
  - Attribution of “Autism” Behaviors
    - Assuming behaviors are attributable to the child’s autism and not some other cause

Susceptibility to Victimizations: Speech/Language Disorder

- Communication Disorder
  - Assumed intellectual deficit*
    - Bias in the U.S.
  - Communication Difficulties
  - Use of Alternative Communication
    - Limitations
    - Misuse
    - Damage
  - Repeated victimizations
Susceptibility to Victimization: Cerebral Palsy

- Cerebral Palsy
  - Reliance on others for:
    - Bathrooming / Bathing
    - Eating
    - Mobility
  - Possible Difficulties in Communicating
  - Use of alternative communication
  - Repeated victimizations
  - Assumed intellectual deficit*

Case Studies
Autism – Case Study

- 911 Call
  - “I’ve terminated the life of my autistic son”

- Police Respond to Home
  - Father sitting on couch
  - Two bloody knives in kitchen sink
  - Ulysses in bathroom

- Bathroom

- Father – 10 previous arrests for domestic violence

- Neighbor comment

Intellectual Disability – Case Study

- Danieal Kelly died from malnutrition and maggot-infested bedsores that ate her flesh
  - She died alone on a putrid mattress in her mother’s home, the floor covered in feces
  - She was 14 but weighed just 42 pounds

- Mother embarrassed by her daughter and didn’t want to touch her, take her out in public, change her diapers
  - The mother was confronted repeatedly by her own mother, uncle, friends and even two of her sons about Danieal’s deteriorating health

- The Department of Human Services received at least five reports of Danieal being mistreated between 2003 and 2005
  - All described a “helpless child sitting unattended, unkempt and unwashed, in a small stroller in her own urine and feces,” her screams ignored by her mother

- Ambulance responded to 911 call - she had been dead for several hours
  - She was so emaciated she looked like the victim of a concentration camp
  - She had been lying on the filthy mattress for so long that her body outline was imprinted on it

Cerebral Palsy – Case Study

- Casey – 19 yr Quadriplegic Spastic CP and Severe Intellectual Disability

- Annual – doctor reports scratches / lacerated hymen

- Parents report that “she was masturbating when we walked in her room and she quickly removed her hand….and that caused the laceration to her hymen”

- APS investigation – found four finger bruises on each upper thigh

- Confession
Facility Abuse Case Study

- JoAnne, a fourteen-year-old girl, lives in a skilled nursing facility.
- She has profound mental retardation and multiple disabilities, including seizure disorder and cerebral palsy.
- She requires assistance for all her daily living activities.
- When she was discovered to be eight months pregnant, facility staff reported suspected child abuse.
- The perpetrator was never identified.
- Of the remaining ninety-eight residents living in the same facility, over 80% tested positive for a variety of venereal diseases.

Case: 16 year old Developmental Disability

- A recent trial in Korea found four men guilty of repeatedly raping a sixteen-year-old girl with developmental disabilities.
- The grandfather and three uncles of the victim were convicted after years of sexual violence that the police described as gruesome.
- The judge in the case gave all four men suspended sentences, suggesting that this would allow the offenders to continue to care for the victim.

Disability Characteristics

Considerations that Impact Communication
Intellectual Disability

- Individuals with intellectual disabilities fall on a spectrum – Mild to Severe
  - Language capabilities vary
  - Conversational capacities vary
  - Intellectual (IQ) capacities vary

I.Q. and Function

- I.Q.
  - Specific measure of intelligence
  - Should not be used to determine overall function

Case study example

- Bob: IQ – 35
- Henry: IQ – 65
- Which individual is higher functioning?

Characteristics: Intellectual Disability

- Cognitive Considerations:
  - Need concrete information
    - Abstract Concept Issue
    - Poor incidental learning

- Social Considerations:
  - Lack age-appropriate behavior
  - Few friends and social opportunities
Characteristics: Cerebral Palsy

- Definition
  - Damage to the immature brain
  - Differences
    - 2yr / 30yr / 80yr
- Abnormalities of muscle tone
  - Ex. Quadriplegic Spastic CP
- Intelligence
  - Variable
- Communication Capacity
  - Variable

Autism: Definition

**Autism:**

- Defined
  - "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child’s educational performance. Other associated behaviors include engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences" [P.L. 108-446]

- Spectrum Disorder (ASD)
  - Mild to Severe

Autism – Peace Officer Responses (Modell & Mak, 2008)

“What does the term Autism mean to you?”

- Themes
  - Appx. 81% incorrectly identified accurate Autism characteristics or did not know
  - Appx. 20% identified Autism as a social interaction deficit and/or communication deficit
  - Many varied responses
    - Over 20 respondents identified mental retardation as an autism characteristic
    - Living in a fantasy
    - Unusual abilities
    - Mental illness
    - Learning Disability
    - Physical Disability
  - "Rain man"
Autism Distinguishing Features

- **Emotion and expressive/receptive verbal disconnect**
  - “I’m happy.”
  - “You make me angry.”
  - Expectation of commensurate facial expressions, voice tone, and body language connected to that emotion
  - Passive monotone voice with unusual pronunciations

- **Facial Expressions**
  - Audience Participation

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Autism Distinguishing Features

- **Rule Governed**
  - Difference between OCD

- **Sensory Integration Disorder**
  - Auditory, Visual, Kinesthetic
  - Multiple inputs (e.g. conversations) and focus
  - Anxiety

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Autism Incidence

United States Average

- 1980: 1 in 10,000
- 2007: 1 in 150
- 2010: 1 in 110
- 2012: 1 in 88
- 2013: 1 in 50
- 1 in 38 est. in South Korea

Most common question?
- Does observed increase in diagnosis represent a true increase?
Autism

What were parents told?
- 1970's (Refrigerator Mother Hypothesis)
- 1980's (Positive Reinforcement)
- Today (fMRI's)

Theories
- Extreme Male Brain Theory
  - Systematizing vs. Empathizing
- Mirror Neuron Theory
  - Mu WAVE suppression on EEG in premotor cortex
  - Bouba / Kiki Test

Autism and Mirror Neuron Systems

Communication

Speech / Language Impairment
Communication

Verbal Repertoire
- Four Basic Types of Communication
  - Expressive vocal verbal (speaking)
  - Receptive vocal verbal (being spoken to verbally)
  - Expressive non-vocal verbal (gestures, facial expressions, body postures, etc.)
  - Receptive non-vocal verbal (understanding gestures, facial expressions, body postures, etc.)

- Use of term “Non-Verbal”
- Issue of “Function” related to Verbal Behavior

Use of the Term “Function”
- Labeling someone as low or high functioning
  - Better to use
    - Level of Independence
    - Support Needs
    - Skill Sets
- Receptive Language versus Expressive Language
  - Bias in the U.S. and all over the World
  - The Story of “Bert”
- Assumptions Pledge
- Use of language
  - Treating People like People

We are not toys…
Interview Techniques

- Communication
  - Pay attention to:
    - Verbal
    - Non-verbal
    - Receptive vs. Expressive Language

- Concrete and Literal
  - "It's raining cats and dogs outside"

- Conversational punctuations
  - Ex. "Really", "You do", "Good", "I see"

- Ask how best to communicate
  - Example

Helen
Interview Techniques

- Interrogative Statements
  - “You like Mr. Steve”

- Questions posed in the Negative
  - “Do you not like going to the doctor?”

- Negative Interrogative Statements
  - “You don’t like Ms. Tammy”

- “I” and “You” confusion
  - Use proper names for people, locations and acts

Interview Techniques: Asking Questions

Ideally, you would be able to ask Open questions

- Open
  - Tell me what happened Thursday?
  - What happened in the bedroom?
  - Tell me more about that?

- Some individuals may only be able to answer YES/NO
  - Leading vs. Not Leading YES/NO questions

- Leading YES/NO
  - Did Mr. Steve touch your penis?
    - (Prior to any previous identification of Mr. Steve)
  - Did Brian hit you?
    - (Same – prior)

- Not Leading YES/NO
  - Did someone hit you?
  - Do you know who hit you?

Interview Techniques

- Resist temptation to fill in the blanks
  - Example
    - Response: “…hurt….head….bad”
    - Question back: “You hurt your head bad?”
    - What if the person is describing what happened to someone else?
    - Example of what not to do:
      - Statement: Paul…touch…penis
      - Question: Paul touched your penis?

- Expect to take more time

- Ideally, you would just be able to ask a question and get a response
Interview Techniques

- However, sometimes an initial question can be too difficult or the person is not oriented to answering questions

- For this, use Reverse Scaffolding

- Ex. Mary

Reverse Scaffolding

- Ex. “Pick up the paper”
  - “Raise your hand”
  - “Touch your nose”
    - “Give me a high five”
    - “Go pick up the paper”

High Probability (HP) Instructional Sequence

- Building momentum and increasing response effort
  - Physical Response
  - Verbal Response

HP Sequencing Examples
**Interview Techniques**

**Echolalia**
- Repeating of words spoken by others
- Normal in children as a developmental process
- Not random speech
- Taking his “turn” in the conversation

**Strategies**
- Time
- Reduction of Anxiety
- Patience

**Perseveration**
- Hyperfocus on a particular topic or subject unrelated to the topic of discussion

**Strategies**
- Re-direct the victim if they perseverate off topic
- Re-frame the question if it elicits an off topic discussion

**Example**

**Justin - Perseveration**
Interview Techniques

Influenced Responses

- Individuals with disabilities are taught to “get along” with other people and respect those in authority
- As a result, they may change their responses if they think you don’t like their answer

- Research suggests individuals with intellectual disabilities can be as accurate as individuals without disabilities, but are significantly more suggestible
  - (Henry & Gudjonsson, 1999)

Mary

How to avoid influenced responses?

- Keep your body language and voice tone neutral
  - Examples
    - Nodding or shaking of head during responses
    - Interrogative statements

- Avoid conversational punctuations
  - “Good”

- Resist temptation to be helpful and supportive
  - Balance between overly helpful, friendly and cold

Video Clip courtesy of Barbara Wheeler, Ph.D.
Director, Center for Disability Studies and Community Inclusion
USC University Center for Excellence in Developmental Disabilities Research, Education and Service (USC UCEDD)
Interview Techniques

- Saliency
  - Emotional “strength or pull” of an experience
  - Helps all people remember things – good or bad
    - Lunch 2 Wednesdays ago?

- The saliency of common events may be greater for individuals with disabilities

- Salience Landscape Theory
  - Perceptions of emotional significance

Keith: Saliency

Communication Disorders
Communication Disorders

- Time
- Patience
- Communication is a two way street

- With difficult to understand speech
  - Use yes/no format as appropriate
  - Repeat and paraphrase – wait for confirmation
  - Don't be afraid to say: "I didn't understand, could you repeat"
  - Example ...........

Sharon

Communication Disorders

- With difficult to understand speech
  - The more you are around an individual with a speech disorder – the easier it is to understand
- Expect to take more time
- Sometimes you cannot understand what a victim is saying verbally
  - Example
Michael: Unintelligible Speech

What do you do with unintelligible speech?
Create yes/no communication
Validation:

If capable, ask to:
- Write their response
- Draw their response
- Show you
  - Ex. “Assa Pa”

Ask support person how they communicate
- They may be able interpret victim’s speech
- Can verify with victim for accuracy (yes/no)
  - May not be admissible

Use of pictures or other AAC
AAC (Augmentative and Alternative Communication)
- Processes or devices that augment or replace an individual’s method of communication
Augmentative and Alternative Communication (AAC)

- Manual signing, gestures, facial expressions, pantomime, pointing, and/or eye gaze
- American Sign Language (ASL)
  - Use professional interpreter
  - Learning basics for rapport
- Low tech
  - Picture Exchange Communication System (PECS)
  - Ex. Picture board
- High tech
  - iPad
  - Computer

PECS

Picture Board
Communication Device: iPad

Massachusetts Supreme Court
- Ruby McDonough, sexually assaulted, 10 years earlier stroke
- Verbal Behavior
  - Reliably answer “yes” and “no” questions
  - Point to pictures and objects to make her needs known
- Court Ruled
  - Ruby’s rights had been violated when she was deemed incompetent to testify
  - Established brand new rules to ensure that the rights of all crime victims with disabilities will be better protected
  - Individuals with disabilities not only have a right to physical accessibility (e.g., wheelchair ramps to ensure they get IN to the courthouse), they have a right to accommodations that will enable their “full and equal” testimonial and participatory rights as witnesses in criminal cases

Alternative Communication Testimony
- MA Supreme Court
  - Allowed Ruby to use gestures and answer only “yes” and “no” style questions
- Ohio
  - Ricardo Woods, 35, was convicted of fatally shooting David Chandler
  - Police interviewed Chandler while he was hooked up to a ventilator, paralyzed after being shot in the head and neck as he sat in a car. He was only able to communicate with his eyes and died about two weeks later.
  - Prosecutors showed jurors a videotaped police interview in which they say Chandler blinked three times for “yes” to identify a photo of Woods as his shooter.
  - Judge Myers watched the video and said that she found the identification reliable
  - She noted that Chandler’s identification was made by pronounced, exaggerated movement of the eyes and not by involuntary movements.
  - A doctor who treated Chandler also testified that Chandler was able to communicate clearly about his condition
AAC Summary
- Do not assume people who use AAC have intellectual disabilities
- AAC may be one of several ways a person communicates
- No special training is needed to communicate
- Speak directly to the AAC Device user
- Try not interrupt when they are using their device
- Be comfortable with silence
- “Voice” from Carrie-Lynn

Carrie-Lynn

Final Considerations
- Range of communication abilities
  - Both receptive and expressive
- No assumptions of intelligence based on physical appearance and/or VVB
- Anxiety / Stress
  - Increases in maladaptive behaviors
    - Perseveration
    - Echolalia
    - Responses to sensory input
- Increase your experience
- Be Cool
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