

# Nothing About Me Without Me...

...responding sensitively and effectively to the needs of neuro-atypical children

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# Introduction / Welcome

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Parent

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# An Opening Conversation

- What disabilities / neuro-atypical presentations have you seen in the course of your careers?
- What kinds of challenges have these situations created?
- • •
- My presentation title, “Nothing About Me Without Me” is an ethical principle about *inclusion*. Please think of examples of how this might be applied in your own professional role, and share near the end of our time together today.

# Flight Plan for Today

- Cultural Competency
- Facts and Definitions
- Vulnerable Population
- People First Language
- Considerations for Communication
- Advocacy Resources
- Q & A / Wrap-Up



# Cultural Competency

All the tools you need to be competent to help kids with disabilities are the ones you have developed to become *culturally competent*.

...



# Cultural Competency

- Knowledge
- Self-Awareness
- Attitude

...



# Developmental Disabilities

**1 in 6 children ages 3 – 17 years have one or more developmental disabilities**



DEVELOPMENTAL DISABILITIES INCLUDE:

INTELLECTUAL  
DISABILITY

LEARNING  
DISABILITY

VISION  
IMPAIRMENT

HEARING LOSS



ADHD

AUTISM SPECTRUM  
DISORDER

CEREBRAL PALSY

AND MORE

# Intellectual Disabilities

## DIAGNOSIS OF AN INTELLECTUAL DISABILITY REQUIRES:

01

### **IQ SCORE BELOW 70**

Mild cognitive disability: IQ 55-70  
Moderate cognitive disability: IQ 30-55  
Severe cognitive disability: IQ under 30



02

**DEMONSTRATED  
DIFFICULTIES WITH  
2+ AREAS OF  
ADAPTIVE BEHAVIOR**

03

**ONSET OF DISABILITY  
BEFORE AGE 18**

@HIEHELPCENTER

# Autism Spectrum Disorder



## 10 SYMPTOMS OF AUTISM

**Developmental learning delays**



**Difficulty communicating**



**Difficulty in social situations**



**Attachment to unusual interests**



**Difficulty understanding emotions**



**Over or under sensitivity to light, sound, touch or taste**

**Repetitive movements and behaviors**

**Trouble with transitions**

**Recurring sleep problems**

**Insufficient impulse control**

# Common Types of Disabilities:

## ● Visible

- Blindness
- Speech impairment
- Cerebral Palsy
- Mobility
- Paralysis of part of body
- Use of wheelchair, walker, cane, or other adaptive equipment

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## ● Invisible

- Autism Spectrum Disorder
- Hearing disabilities
- Intellectual disabilities
- Learning disabilities
- Mental health disabilities
- Traumatic Brain Injury
- Chronic pain or spasticity.

# Victimization of children with disabilities

- Disabled children are more vulnerable because of a variety of situational factors:
  - Dependence on caregivers for meeting their basic needs
  - Limited understanding about sexual issues
  - Frequent isolation from conventional social environments
  - Limited social and communication skills

# Victimization of children with disabilities

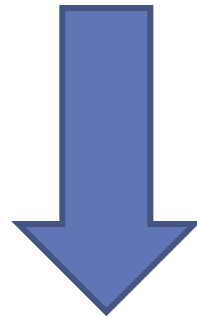
- Often, the person's specific disability is used as part of the abuse
- Caregiver takes advantage of person's disability to withhold necessities like personal care, food, medication, communication

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# The Cascade of Injustices

- The child may not be understood or believed
- Reports not investigated
- ...
- No trial
- No conviction
- No therapy or inappropriate therapy



# Myths about clients with neuro-atypical presentations

- Cannot remember past events with any accuracy
- Make up stories to get attention
- • •
- Are so suggestible that their statements cannot be trusted
- Can not distinguish truth from lie

# Myths about clients with neuro-atypical presentations

- Don't have communication strategies to share experience
- Cannot testify in court
- ...
- Won't remember abuse experience
- Are asexual

# People First Language



# Disabilities and Abilities

- Are we not all “differently-abled?”
- Do we not all have “li-abilities?”  
• • •
- Are we not more alike than different?
- Can anyone ultimately identify the limits of another’s potential?

# Person-First Language

- Let's practice replacing old language with more accurate and person-centered language.
  - "I'm pretty sure he's Autistic"
  - 
  - "Jane suffers from Cerebral Palsy."
  - "Taylor is now wheelchair bound."
  - "She's handicapped."

# Nothing About Me Without Me

**Please share examples of how this might be applied in your own professional role ...**

# Advocacy

- Seek out and develop professional relationships with experts and advocates
- Identify partners with expertise in kids and adults with disabilities
- • •
- Stay abreast as to legislative initiatives relevant to child abuse and kids with disabilities
- Maintain a strengths perspective



# Considerations for Practice

- Background information from school
  - Individualized Education Plan (IEP)
  - Psycho-educational Evaluation every three years
  - Input from caregivers, teacher, therapists, etc.
- What are areas of interest for child?
  - • •
- What is child's routine? Any "best time" for communicating?

# Considerations for Communication

- Talk directly to the individual with the disability
  - Don't discuss aspects of disability that may cause undue stress
  - Normalize the experience without ignoring special circumstances
- • •



# Considerations for Communication

- For Children Who Have Intellectual Disabilities:
  - Preferred terms : cognitive impairment, or neuro-atypical
  - Use appropriate level of concrete language and phrasing
  - Check for comprehension, and the tendency to say “yes” as an acquiescent response
  - Avoid slang, analogies, etc.



# Considerations for Communication

- For Children who Have Autism Spectrum Disorder(s):
  - Intellectual impairment varies greatly (Ex. Asperger's)
  - ...
  - Be alert to communication flow
  - Be concrete
  - Rapport may be difficult to establish depending on child

# Self Advocacy

Dear Ann Coulter,

Come on Ms. Coulter, you aren't dumb and you aren't shallow. So why are you continually using a word like the R-word as an insult?

I'm a 30-year-old man with Down Syndrome who has struggled with the public's perception that an intellectual disability means that I am dumb and shallow. I am not either of those things, but I do process information more slowly than the rest of you. In fact it has taken me all day to figure out how to respond to your use of the R-word last night.

After I saw your tweet, I realized you just wanted to belittle the President by linking him to people like me. You assumed that people would understand and accept that being linked to someone like me is an insult and you assumed you could get away with it and still appear on TV.

# Self Advocacy

I have to wonder if you considered other hateful words but recoiled from the backlash.

Well, Ms. Coulter, you, and society, need to learn that being compared to people like me should be considered a badge of honor.

No one overcomes more than we do and still loves life so much.



Come join us someday at Special Olympics. See if you can walk away with your heart unchanged.

A friend you haven't made yet,

John Franklin Stephens

Global Messenger

• Special Olympics Virginia



# Your Questions / Feedback



# References

- Moving Mountains: Enabling Children, Disabling Child Abuse (Butler Child Advocacy Center at the Children's Hospital at Montefiore, NY)
- Child Abuse Victims with Disabilities: A Curriculum for Law Enforcement First Responders and Child Protective Services Frontline Workers (Child Abuse and Neglect Disability Outreach Program of Arc Riverside, CA)  
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- Project Ability – Demystifying Disability in Child Abuse Interviewing (CARES Northwest in Portland, OR)
- Responding to Maltreatment of Children with Disabilities: A Trainer's Guide (Child Development and Rehabilitation Center at Oregon Health & Science University)

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- Alriksson-Schmidt, A. I., Armour, B. S., & Thibadeau, J. K. (2010). Are adolescent girls with a physical disability at increased risk for sexual violence? *Journal of School Health, 80(7)*, 361-367.
- Sedlak, A.J., Mettenburg, J., Basena, M., Petta, I., McPherson, K., Greene, A., and Li, S. (2010). Fourth National Incidence Study of Child Abuse and Neglect (NIS-4): Report to Congress. Washington, DC: U.S. Department of Health and Human Services, Administration for Children and Families.
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- Rand, M. R., & Harrell, E. (2009). Crime against people with disabilities, 2007. The Bureau of Justice Statistics. U. S. Department of Justice.
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- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, 24(10)*, 1257-1273.
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- McCormack, B., Kavanagh, D., Caffrey, S., & Power, A. (2005). Investigating sexual abuse: Findings of a 15- year longitudinal study. *Journal of Applied Research in Intellectual Disabilities*, 18(3), 217-22.                      • • •
- Crosse, S.B., Kaye, E. & Ratnofsky, A.C. (n.d.). A report on the maltreatment of children with disabilities. Washington, D.C.: National Center on Child Abuse and Neglect, DHHS

# The Partnership for People With Disabilities

- Based at Virginia Commonwealth University
- I-CAN! Accessibility Project
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- Abuse & Neglect of Children with Disabilities: A Collaborative Response
- Virginia Positive Behavior Support Project



# Advocacy Resources

- Parent Educational Advocacy Center (PEATC)  
[www.peatc.org](http://www.peatc.org)
- Council of Parents, Attorneys and Advocates (COPAA)  
[www.copaa.org](http://www.copaa.org)
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- Wrightslaw: Special Education Law and Advocacy  
[www.wrightslaw.com](http://www.wrightslaw.com)
- Legal Aid Justice Center: JUSTChildren Program  
[www.justice4all.org](http://www.justice4all.org)