Disability and Mental Health

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American Academy of Child and Adolescent Psychiatry (AACAP)

Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders (1999):

Mental disorders occur more commonly in persons with MR than in the general population. However, the disorders themselves are essentially the same. Clinical presentations can be modified by poor language skills and by life circumstances, so a diagnosis might hinge more heavily on observable behavioral symptoms. (p.1)… The principles of psychiatric treatment are the same as for persons without MR, but modification of techniques may be necessary according to the individual patient's developmental level, especially communication skills. Medical, habilitative, and educational interventions should be coordinated within an overall treatment program.(p.8S)

American Academy of Child and Adolescent Psychiatry (AACAP) – update, 2020

Intellectual disability (intellectual developmental disorder) (ID/IDD) is both a psychiatric disorder and a risk factor for co-occurring psychiatric disorders in children and adolescents. DSM-5 introduced important changes in the conceptualization and diagnosis of ID/IDD, and current research studies clarify assessment and treatment of co-occurring psychiatric disorders in this population. Optimal assessment and treatment of psychiatric illness in children and adolescents with ID/IDD includes modifications in diagnostic and treatment techniques, appreciation of variations in the clinical presentation of psychiatric disorders, an understanding of the spectrum of etiologies of behavioral disturbance, and knowledge of psychosocial and medical interventions.

https://www.jaacap.org/article/S0890-8567(19)32223-3/pdf

American Academy of Child and Adolescent Psychiatry (AACAP)

Autism spectrum disorder is characterized by patterns of delay and deviance in the development of social, communicative, and cognitive skills that arise in the first years of life. Although frequently associated with intellectual disability, this condition is distinctive in its course, impact, and treatment. Autism spectrum disorder has a wide range of syndrome expression and its management presents particular challenges for clinicians. Individuals with an autism spectrum disorder can present for clinical care at any point in development. The multiple developmental and behavioral problems associated with this condition necessitate multidisciplinary care, coordination of services, and advocacy for individuals and their families. Early, sustained intervention and the use of multiple treatment modalities are indicated. J. Am. Acad. Child Adolesc. Psychiatry, 2014;53(2):237–257.
https://www.jaacap.org/article/S0890-8567(13)00819-8/pdf

Research

- There is limited research as to the rate of co-occurring neurodevelopmental disabilities and mental health diagnoses.
- Most of the available research is limited individuals with autism spectrum disorder (ASD) due to the Autism CARES Act, first passed in 2006.
- Most of the available research that I have found was conducted after 2010.
- This is a relatively new issue in the field of mental health research and there is little research available to guide treatment.

Recent Meta-study (August, 2019)

Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *Lancet Psychiatry*, August, 2019.

- 70% of people with ASD diagnosed with at least one mental health condition
- 50% of people with ASD diagnosed with more than one mental health condition
- ASD and Co-occurring mental health conditions:
  - 28% ADHD
  - 20% anxiety disorders
  - 13% sleep-wake disorder
  - 12% disruptive, impulse-control, and conduct disorders
  - 11% depressive disorders
  - 9% obsessive-compulsive disorders
  - 5% bipolar disorder
  - 4% schizophrenia spectrum disorders

Comparison to general population

Diagnosis	Autism	General Population
ADHD	28%	7.2%
Anxiety Disorder	20%	15%
Depressive Disorder	11%	8%
Bipolar and related Disorder	5%	3%
Schizophrenia Spectrum Disorders	4%	2%
Obsessive-Compulsive disorders	9%	4%
Disruptive, impulse-Control, Conduct Disorders	12%	7%
Sleep-Wake Disorders	13%	11%

Meta-Study recommendations

"Co-occurring mental health conditions are more prevalent in the autism population than in the general population. Careful assessment of mental health is an essential component of care for all people on the autism spectrum and should be integrated in to clinical practice."

Autism and the Pandemic

- One of the symptoms of Autism Spectrum Disorder is:

  Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
- The pandemic has changed so much of the sameness, routines, and schedules of nearly every aspect of our lives.
- This is stressful to everyone, but is taking an especially high toll on the autism community.
- Long term effects on the mental health of individuals will ASD will likely be experienced for years
- It is important that clinicians treating both children and adults work to learn tools to support this community.

Intellectual Disability and Co-occurring mental health diagnoses

- According to a 2013 review of studies from 2003 to 2010, 13.9% to 74% of individuals with ID have a co-occurring mental health diagnosis.
- Why are the numbers so broad?
  - Lack of data
  - Lack of consistency on diagnosing and tools used

Buckles, J., Luckasson, R. & Keefe, E. (2013). A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003-2010. *Journal of mental health research in intellectual disabilities.*

"While the exact prevalence is unknown, most professionals accept that roughly 35% of people with intellectual disabilities also experience mental health challenges." - National Association for the Dually Diagnosed (NADD) www.thenadd.org

Individuals with disabilities are a vulnerable population

- Individuals with disabilities are involved in the legal system both as victims and criminals more than the average population.
- Individuals with disabilities are 2 times more likely for violent crimes and 4-10 times for abuse and other crimes.
- Children with disabilities are 3.4 times more likely to be abused.
- Individuals with disabilities, both male and female, are 7 times more likely to be sexually assaulted than the general population.
- Individuals with disabilities make up about 2-3% of the general population.
- Individuals with disabilities make up about 4-10% of the prison population
- Students with disabilities are 2.96 times more likely to be arrested while at school than students without disabilities; and 2.91 times more likely to be referred to law enforcement while at school than students without disabilities

From: www.thearc.org, http://www.nbcnews.com/news/us-news/kids-cuffs-why-handcuff-8-year-old-student-disability-n722451, https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about

Services available to Idahoans

- Individuals with dual diagnoses have two types of services available
  - Developmental Disability (DD)
  - Mental Health (MH)
- These services have different qualifying criteria and purpose
  - DD services are designed to help develop skills, to make gains in functioning, and to help the individual catch up developmentally with their same age peers
  - MH services are designed to help develop coping skills for mental health diagnoses

Services available to Idahoans

- Qualifications for DD services for Children (up to age 21)
  - developmental disability such as cerebral palsy, epilepsy, autism, or intellectual disability
  - disability results in substantial functional limitations in three or more of the following areas:
    - self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living or economic self-sufficiency
  - Reflect the needs for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of life-long or extended duration and individually planned and coordinated

Services available to Idahoans

- DD Services for children include
  - Children's Habilitative Intervention Services
    - Habilitative Skill
      - delivered by someone with at least a HS diploma, overseen by BCBA
    - Behavioral Intervention
      - delivered by someone with at least a bachelor's degree, overseen by a BCBA
    - Family training
    - Crisis Intervention
    - Respite
  - Applied Behavior Analysis (ABA)
    - Board Certified Behavior Analysist (BCBA), individual with a master's in ABA and additional supervision and certification
    - Registered Behavior Technician (RBT), no degree requirement, individual with specialized training overseen by a BCBA
  - Katie Becket Waiver
- All children with Medicaid can access behavioral interventions if they meet qualifications

Services available to Idahoans

- Qualifications for DD services for Adults(18 and over)
  - Must meet the definition of developmental disability according to Idaho State Code 66-402, which includes among other requirements that an individual have an IQ of 75 or lower
  - Additional requirements can be found at: https://healthandwelfare.idaho.gov/Medical/DevelopmentalDisabilities/tabid/120/Default.aspx
  - Individuals must also meet financial criteria

Services available to Idahoans

- DD Services for Adults include
  - Developmental Therapy
    - delivered by someone with at least a bachelor's degree
  - Community Support worker
    - delivered by someone with at least a HS diploma
  - Community Crisis Supports
  - Supported Living or Certified Family Home
    - approved through Health and Welfare
    - must be 18 and have a HS diploma
  - Targeted Service Coordination
    - delivered by someone with a bachelor's degree
  - Vocational Rehabilitation
    - delivered by someone with a bachelor's or master's degree depending on service
  - Other services such as specialized medical equipment or delivered meals

Services available to Idahoans

- MH Services for children (17 and under)
  - Mental health therapy, both individual and family
    - (master's degree)
  - Family Support Partner
    - (have a child with a mental health dx and specialized training)
  - Case Manager
    - (bachelor's degree)
  - CBRS
    - (bachelor's degree)
  - Respite
    - BPA respite
    - Agency based respite (YES class member)
  - Behavioral Interventions
    - (bachelor's degree)
  - Peer support partner (13+)
    - (mental health dx and specialized training)
  - YES program services
    - Targeted Care Coordination
    - Wrap-around
  - Flex funds – varies by region

Services available to Idahoans

- MH Services for adults(18 and over)
  - Mental health therapy, both individual and family
  - Peer support
  - Case Manager
  - CBRS

Services available to Idahoans

- Mental Health and Developmental Disability Services are very different.

- In Idaho's current mental health system, individuals who are dual diagnosed are generally enrolled in DD services, but may not receive the mental health care that they need.
- This may be due to
  - Lack of knowledge or education of family, caregivers, or service providers
  - Lack of available mental health providers comfortable serving this community
  - Perceived pressure from managed care system

Advocacy and Education

- There is a huge need for advocacy for individuals with dual diagnoses and education for service providers
- Many individuals with developmental disabilities are vulnerable and struggle with communication and self-advocacy.
  - Need for behavioral services, speech, occupational therapy, physical therapy, other medical issues requiring specialists, etc.
  - Independence and autonomy vs. individual safety
  - Educational or job training needs
  - These issue often puts mental health low on the list of priorities
- There is a lack of knowledge of dual diagnoses across disciplines.
  - Mental health providers
  - Developmental disability providers
  - Educators

Advocacy and Education

- This lack of knowledge can lead to
  - Misunderstanding of mental health symptoms as 'misbehaviors' or as symptoms of their disability.
    - Avoidance of unpleasant task vs avoidance due to anxiety
    - Misunderstandings can lead to interventions that are counter-indicated
      - Example: sensory aversions vs OCD triggers
  - Lack of access to appropriate care/interventions
    - Example: young adult with MDD
- A study in Japan found that while 60% of individuals with ID and MH diagnoses received medication, only 6% received therapy. (Journal of Intellectual Disability Research, Nov. 2018)
- A study in Australia found that only 9% of children with ID and MH diagnoses received treatment from professionals with experience in both diagnoses and that 47% received no help at all. (Journal of mental health research in intellectual disabilities, 2018)

All individuals deserve access to mental health care

- Not all individuals with dual diagnoses are appropriate for mental health services
- It is often unclear if mental health services will be helpful when a therapist first sees a client for services
  - Case examples
- These individuals deserve at minimum a chance to receive therapy for a period of time in order to see if they will benefit
- Many individuals who are 'neurotypical' do not benefit from mental health therapy, but are not denied access to services
- This is a human/disability rights issue

Treatment Strategies

When treating clients, you meet them where they are at, regardless of disability status.

- **What is their stage of change?**
  - precontemplation, contemplation, preparation, action, maintenance
- **What is their emotional level?**
  - This can be affected by
    - Life experience
    - Abuse history
    - Substance use
    - Disability
- **Cognitive level**
  - This can be affected by
    - Life experience
    - Abuse history
    - Substance use
    - Disability
- **Chronological age**

In this way, treating a person with a disability is not any different than the work that you are already doing with clients. We as clinician's meet the client where they are at.

Adaptations for individuals with disabilities:

The primary adaptations that I use with individuals with disabilities:

- Simplify concepts
- Break concepts down into smaller steps
- Relate concepts to the person's specific interests
- Increased visuals
- Treat symptoms NOT diagnoses, i.e. don't get hung up on which diagnosis is causing the behavior
- Increased repetition of concepts
- Increased family involvement with client's permission (even if the client is not their own guardian)
  - Natural family
  - Supported living staff
    - Note: except in very special circumstances, I do not allow supported living staff in sessions. I will however give copies of visuals and have family meetings to discuss presenting problems with the client's (and guardian's) permission
  - This strategy is dependent on having supports who have a strong relationship with the individual, is able to understand the tools themselves, and provide significant emotional or concrete support in practicing the tools.
- Individuals with disabilities will often require increased systems work compared to the average individual.
- This requires a system that is willing to coordinate

Adaptations for individuals with disabilities:

- Thinking of autism as a culture, i.e. approaching individuals on the spectrum as students of neurotypical culture
- Treating autism, ADHD, etc. as neurodiversity rather than disability
- Full physical assessment from a PCP, i.e. are there physical health explanations for symptoms?
- When assessing for a mental health diagnoses, I look more for symptoms such as psychomotor agitations, insomnia, behavior changes than on reports of emotions
- I often given more general diagnoses initially such as 'other specified depressive disorder,' and then gather additional qualitative data during treatment

Adaptations for individuals with disabilities:

Learning Styles

Different kinds of thinking

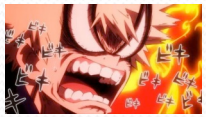
Dr. Temple Grandin

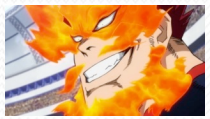
1. Photo Realistic Visual Thinking – Poor at algebra
2. Pattern Thinker Music and Math – Poor in reading
3. Verbal Facts Language Translation – Poor at drawing
4. Auditory Thinker – Visual perception fragmented

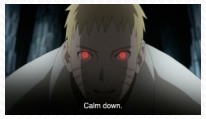
There can be mixtures of these thinking types

Adaptations for individuals with disabilities:

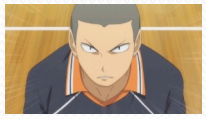
- Many individuals with disabilities have difficulties with verbal processing. For this reason, my primary adaptation is to increase the amount of visuals that I use.
- This includes visuals of concepts as well as visuals of our actual conversations
- If they can draw, use their drawings

5  Explosion

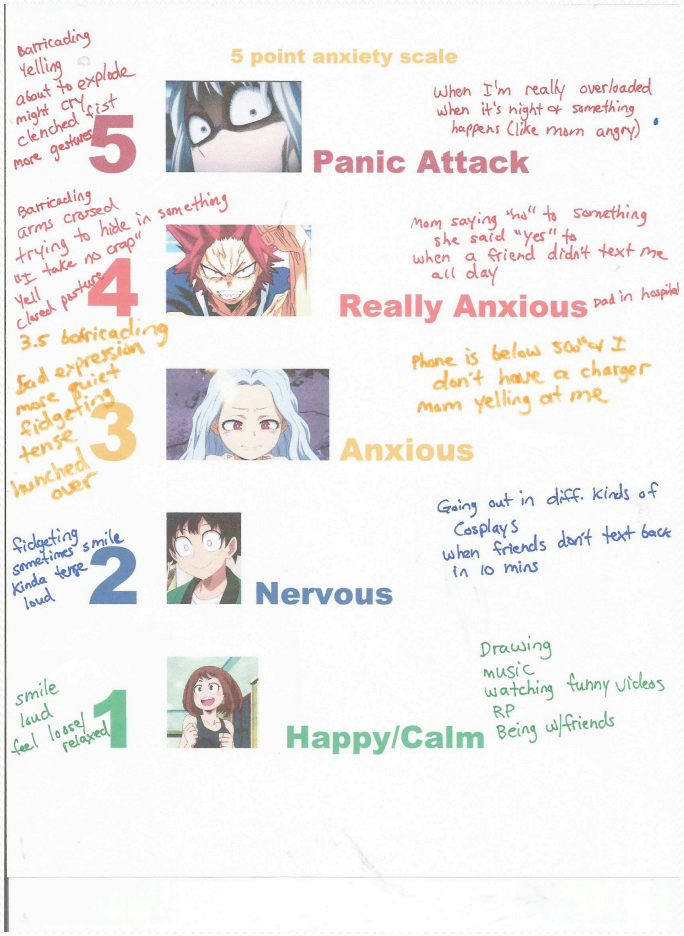
4  Really Mad

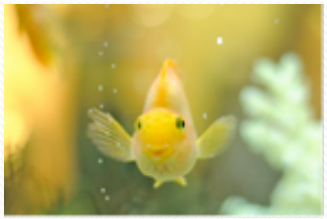
3 

Mad

2  Irritated

1  Happy





Happy

Mad

Sad

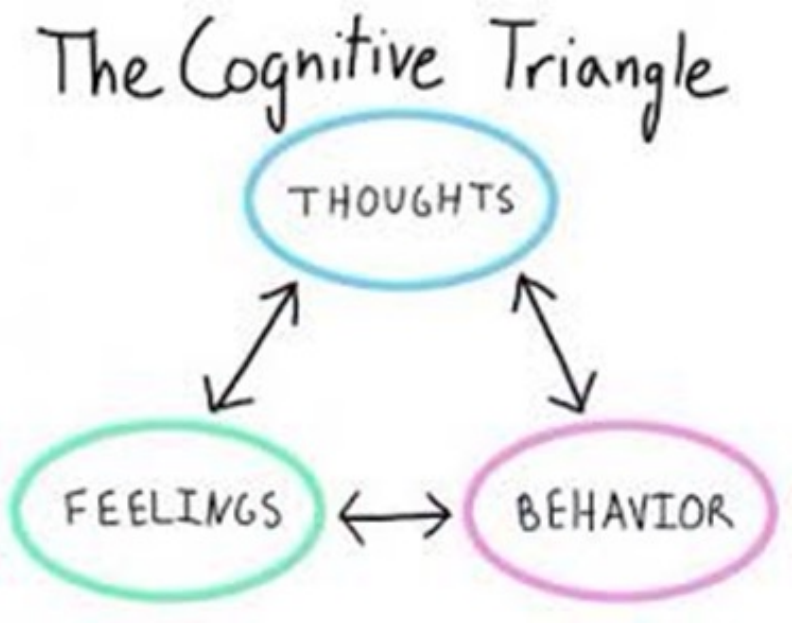
Excited

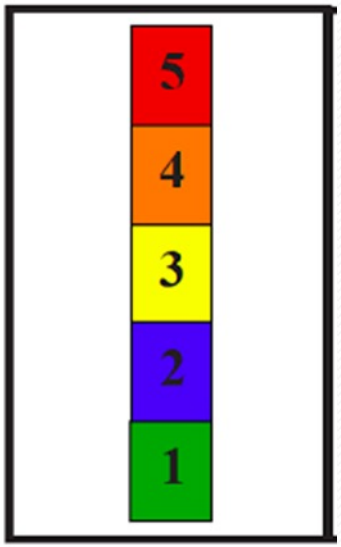
Worried

Bored

Frustrated

Frightened


The Cognitive Triangle
THOUGHTS
FEELINGS
BEHAVIOR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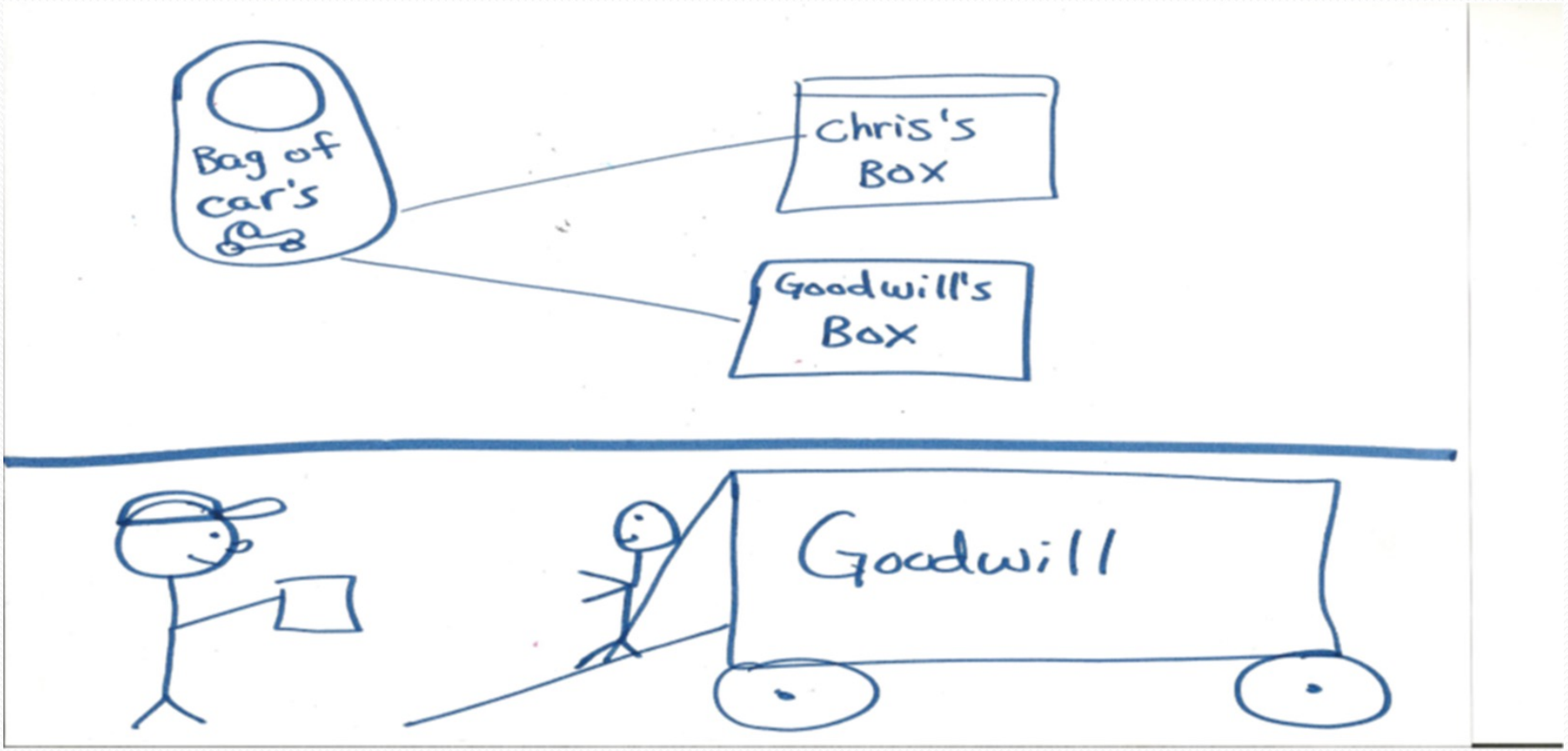
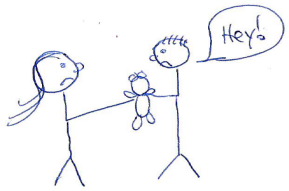
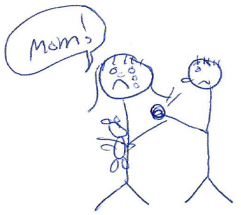

Bag of car's
Chris's Box
Goodwill's Box
Goodwill

What happened...

My sister took my toy.



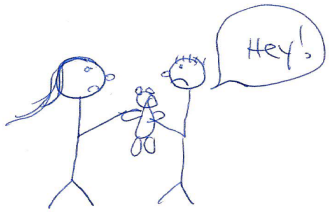
So I hit her...



Anger level 4!

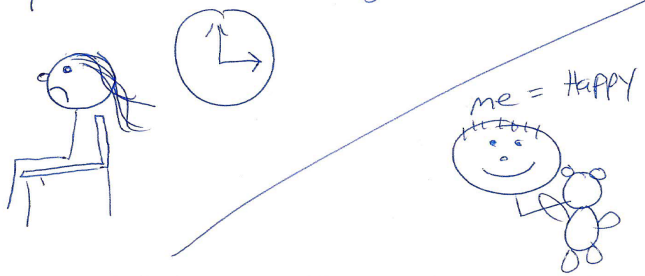
And got time out.

What if I would have...



Told mom instead:

My sister would get time out.



Therapy resources that I use

- *Incredible 5 Point Scale* by Kari Dunn Buron and Mitzi Curtis
- *The Emotion Regulation Skills System for Cognitively Challenged Clients* (DBT) by Julie F. Brown
- *Whole Brain Child* by Dan Siegle
- Healthy Relationships Workbook from Arc of Spokane
- *Social Thinking* by Carol Gray
- *Taking Charge of ADHD, Fourth Edition: The Complete, Authoritative Guide for Parents* by Russell A. Barkley

Meltdowns

- Why are they having a meltdown?
- Instinctive ‘fight or flight’ behavior
  - No evidence of cognitive functioning
  - No ability to bargain
- Overwhelmed either cognitively or sensory or both
- Involuntary physiological response. This is NOT a tantrum.

- Patricia McGuire, M.D., FAAP

Meltdowns

- How are YOU feeling?
- What are you thinking?
- How are you responding?
  - Empathy?
  - Criticism?
- What actions are you taking?
- What can you do to keep yourself calm?
- Reduce amount of sensory stimulation
- Repair communication, once the individual has calmed down.
- Problem solve triggers (positive behavior support)
- Teach self-soothing strategies
- Use the SCARED technique to help create a long term intervention plan

Meltdowns

- Be patient
- Do not to try speak to the individual unless it is necessary or they have started to calm down
- If speaking, look at the person before you speak and say his or her name often (don't expect or force eye contact)
- Keep sentences slow, short, and clear
- Use simple language
- Give direct instructions, two words are best, "Stand up." or "Come here."
- Avoid touching the person unless necessary to keep the person from injuring themselves, you, or someone else
- Don't try to stop behaviors which may the person's way of self-calming (rocking, rubbing, etc.)
- Sometimes just having a third party enter the situation can help individuals with disabilities calm down.

Meltdowns
SCARED calming technique

- **S** - SAFE (help them feel safe)
- **C** - CALM (stay calm so they absorb our calmness)
- **A** - AFFIRMATION (confirm reason for stress)
- **R** - ROUTINE (what helps them calm down?)
- **E** - EMPATHY
- **D** - DEVELOP INTERVENTION PLAN

Developed by Debra Lipsky & Dr. Will Richards, **Managing Meltdowns: using the S.C.A.R.E.D. calming technique with children and adults**

Questions?

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