

Co-Occurring Physical and Behavioral Health Conditions in People with Intellectual and Developmental Disabilities

Gary Stobbe, MD

UW Clinical Associate Professor

Medical Director: Adult Autism Clinic)

November 3rd, 2020



Disclosures

- Dr. Stobbe has no conflicts of interest related to this topic.

Objectives

- Become familiar with common co-occurring physical and mental health conditions seen in people with intellectual and developmental disabilities (IDD)
- Identify barriers to evaluation and diagnosis of co-occurring conditions in people with IDD
- Review treatment strategies for common co-occurring physical and mental conditions in people with IDD

Overview

- Increased incidence of medical and behavioral health concerns
- Increased hospitalization and ED visits
- Life expectancy reduced
- Increased healthcare burden often a result of inadequate health care, limited access to services, communication limitations (Krahn, 2006; Gentile, 2015)
- More challenging to identify underlying process due to communication deficits, sensory deficits, difficulty with exam

Case #1

- 18 yo female
- Hospitalized pre-teens for suicidality – dx'ed with OCD, major depression
- Hyperfocused interest in horses
- Trouble reading/writing due to perfectionism
- Very few friends; difficulty sustaining friendships
- Struggled in school until moved to small alternative high school
- Dx'ed with ASD in teens
 - WAIS – full IQ – 102; splintering of sub-tests (50 point difference in working memory and processing speed)

Case #1 (cont.)

- Planning for GED
- Attending vocational school in Fall
 - Vet tech
- Still cutting/suicidal ideation as recently as 6 months prior
 - Benefiting from DBT – “building her tool chest”
 - Current meds – aripiprazole, bupropion, duloxetine
- Exam
 - Blunted affect; flat prosody of speech; very quick response time in answering questions (strongly opinionated); eye contact reduced
 - Positive interaction after examiner asked if the lighting was OK in the exam room

Case #2

- 29 yo male
 - Diagnosed with ASD age 5
 - Minimally verbal
- Age 19
 - Resurgence of aggression and property destruction (symptoms from earlier years returning)
 - Living with mom, sibs off to college
 - Dog phobia
 - Enjoyed going for care rides into Seattle
- Exam – minimally verbal, but better verbal comprehension; responded excitedly during discussion of possible new recreational activities

Case #2 (cont.)

- Age 19-29
 - Added citalopram and later aripiprazole
 - Changed activities with caregivers
 - Started attending classes at the Alyssa Burnett Adult Life Center
 - Started working with behavioral therapist
 - Behaviors have reduced significantly
 - Mom now looking at other living options



Autism: the positives



Understanding, embracing and celebrating different ways of thinking and doing can release the true power of the autistic mind. Here we look at the positive features of autism.



Attention to detail

- Thoroughness
- Accuracy



Methodical approach

- Analytical
- Spotting patterns, repetition



Deep focus

- Concentration
- Freedom from distraction



Novel approaches

- Unique thought processes
- Innovative solutions



Observational skills

- Listen, look, learn approach
- Fact finding



Creativity

- Distinctive imagination
- Expression of ideas



Absorb and retain facts

- Excellent long term memory
- Superior recall



Tenacity and resilience

- Determination
- Challenge opinions



Visual skills

- Visual learning and recall
- Detail-focussed



Accepting of difference

- Less likely to judge others
- May question norms



Expertise

- In-depth knowledge
- High level of skills



Integrity

- Honesty, loyalty
- Commitment

Defining the Population and Terms

- Developmental Disability (DD)
 - A severe, chronic disability with onset before age 22
 - Substantial functional limitations in 3 or more areas of life-activity
 - Self-care, receptive/expressive language, learning, mobility, self-direction, capacity for independent learning, economic self-sufficiency
 - Transition from developmental “delay” to “disability” between age 5-10
- Intellectual Disability (ID)
 - Subset of DD
 - Replaced mental retardation in terminology (*Rosa’s Law* in 2010)
 - Characterized by
 - Significant limitations in intellectual functioning (e.g. reasoning, learning, problem solving)
 - Significant limitations in adaptive functioning (i.e. conceptual, social, and practical skills in everyday life)
 - Onset in childhood (< 18 yo)
- Autism Spectrum Disorder (ASD)
 - Subset of DD
 - Almost 50% (16.7 - 84%) with co-occurring ID (Postorino, 2016)

Neurodevelopmental Disorders – DSM-5

- Category in DSM-5 includes a group of often co-occurring developmental conditions, including –
 - Intellectual Developmental Disorder (IDD) – better known as *intellectual disability*
 - Autism Spectrum Disorder (ASD)
 - Attention Deficit Hyperactivity Disorder (ADHD)
 - Communication disorders
 - Includes *language d/o, speech sound d/o, childhood-onset fluency d/o (stuttering), and social (pragmatic) communication d/o*
 - Motor disorders
 - Includes *developmental coordination disorder, stereotypic movement disorder, and tic disorder (including Tourette Syndrome)*
 - Learning disorders
 - Including *specific math and reading learning d/o*

Examples of DD without ID?

- Some genetic syndromes
- Some individuals with cerebral palsy
- Some individuals with other acquired early brain insults (premature birth, drug/toxin exposure, TBI, etc.)
- Some individuals with ASD
 - Note, however, some individuals with ASD without ID still have severe adaptive deficits due to the ASD core deficits
 - *Yet may not qualify for services from WA State Developmental Disabilities Administration)*

Co-Occurring Health Conditions in ID/DD

- **Physical health**
- **Mental health**
- Sensory disorders
 - Hearing loss (Herer, 2012)
 - Vision impairment (Warburg, 2001)

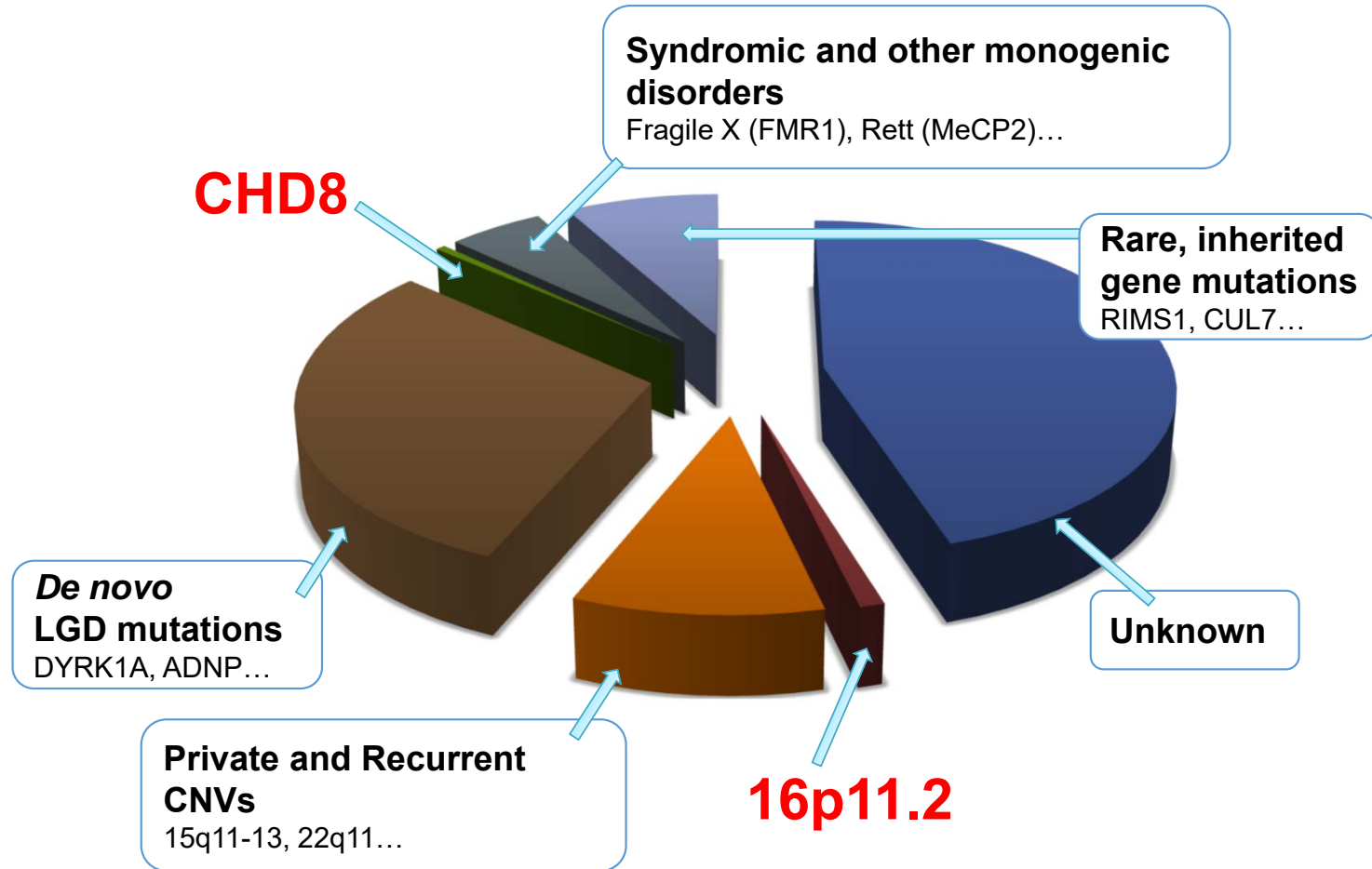
Physical Health in IDD

- Genetic syndromes
- Sleep
- Epilepsy
- GI
- other

Genetic Syndromes – Basic Principles

- Genetic variants often predict multi-organ system involvement
 - Can effect extent of workup for new onset behavioral symptoms
- Need to consider other organ involvement in “syndromic” cases
 - Dysmorphic features, gross motor delay, early-onset seizures
 - Consider even when genetic testing is negative (“cryptogenic”)
- Certain genetic syndromes predict specific organ involvement
 - E.g. – Down syndrome (cardiac involvement, Alzheimer’s, OSA, Moyamoya, endocrine, ENT, spine)

Genetics and Autism



CHD8 Gene Mutations – Predicts a Phenotype

- Increased head size
- Rapid, early post-natal growth
- A facial phenotype marked by prominent forehead, wide set eyes, and pointed chin
- Increased rates of gastrointestinal complaints
- Marked sleep dysfunction.

Bernier, 2014



Sleep in IDD

- Sleep disorders more common in IDD than general population (Esbensen, 2016)
- Sleep disorders more common in ASD than other DDs (Mazurek, 2019)
 - 80% of preschoolers
 - Greater in those with sensory sensitivities
- Sleep disturbance independent variable for psychiatric hospitalization (Righi, 2018)
- Problems in **sleep onset, duration, night time awakenings and sleep fragmentation** are common
 - Melatonin often beneficial especially when sleep onset disrupted
- Less common but important to consider include sleep apnea (obstructive and central), RLS and or parasomnias
 - Formal sleep studies can find abnormalities but studies can be difficult to perform
 - Behavioral strategies for sleep study prep - vkc.mc.vanderbilt.edu/assets/files/resources/sleepstudy.pdf

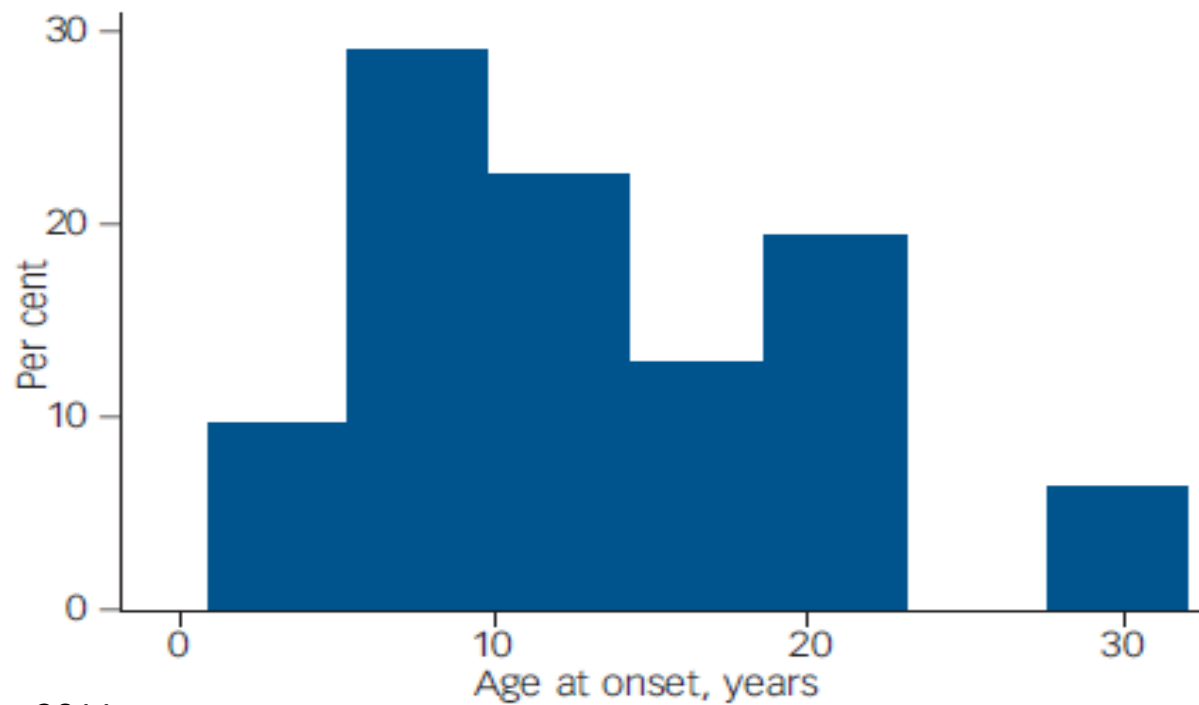
Medications For Sleep

- Melatonin – long-acting in Phase III trials
- Anti-histamines - (diphenhydramine, hydroxyzine) no studies; safe and effective; SE common
- Alpha-agonists – (clonidine, guanfacine) no studies; BP/CV effects are most common SE
- Trazodone - no studies in pediatric ASD populations; SE common; risk of priapism (rare) harder to manage due to communication deficits.
- Atypical anti-psychotics NOT recommended exclusively for sleep
- Gabapentin (Neurontin)

Epilepsy in IDD

- Higher frequency of epilepsy with increasing neurologic disability (Devinsky, 2015)
- 22% of adults with autism (Bolton, 2011)
- All seizure types (GTC and CPS most common)
- EEG abnormalities common
 - In ASD - 44% focal, 12% generalized, 42% mixed (Ekinci, 2010)
- Early onset around time of Dx – increased likelihood of underlying genetic syndrome
- AED choice influenced by side-benefit of improved behavior
 - Lamotrigine, valproic acid, oxcarbazepine
 - Note - Levetiracetam can increase irritability

Epilepsy in Autism – Age of Onset



Bolton, 2011

GI Dysfunction in Autism

- Functional disorders more common (Ibrahim, 2009)
 - Constipation 2x more likely
 - Feeding issues/food selectivity 1.5x more likely
- Research inconclusive but suggests possible brain-gut-microbiome connection in ASD (Luna, 2016)
- CHD8 gene mutation
 - Example of genetic condition with both ASD and GI symptoms (Bernier, 2014)

Motor Disorders

- Complex motor tics more common in ASD
- Onset typically in childhood or adolescence but can also occur in adult years
- Difficult to differentiate from stereotypies
 - Tics more likely worsened by stress/anxiety
- Partial seizures also in differential

...but that's not all!

- Increased risk for many chronic health conditions in adults with ASD (Croen, 2015)

- GI disorders (34.7% vs 27.5%)
- Sleep disorders (17.6% vs 9.6%)
- Seizures (11.9% vs 0.73%)

AND

- Allergies (36.3% vs 28.7%)
- Obesity (33.9% vs 27.0%)
- Hypertension (25.6% vs 15.6%)
- Dyslipidemia (22.8% vs 15.1%)
- Autoimmune conditions (13.9 vs 10.8% in control group)
- Diabetes (7.6% vs 4.3%)
- Thyroid disease (7.0% vs 3.1%)
- Rare conditions (stroke, Parkinson's, vitamin deficiency, hearing and vision impairments, genetic disorders)

“Autistic Burnout”

- Cognitive fatigue from “masking”
 - Reduces potential for FT employment
- Autistic Burnout: An Interview With Researcher Dora Raymaker, PhD
 - <http://www.thinkingautismguide.com/2019/08/autistic-burnout-interview-with.html>
 - Similar phenomenon of cognitive fatigue seen with acquired central nervous system conditions (TBI, multiple sclerosis)

Mental Health in IDD

- Disruptive behavior
- Anxiety
 - trauma
- Depression
- Impulsivity/ADHD
- Psychosis/mania
- Catatonia

Conceptualizing Mental Health COD in ASD/DD With or Without ID

- ASD/DD as a “**neurodevelopmental substrate**”
 - enhancing likelihood of co-occurring mental health conditions
- Without ID
 - **Overlap of ASD core features and symptoms of other mental health disorders**
 - Often delays recognition and treatment of mental health disorder (Bakken, 2010)
 - Or the reverse – psych dx can delay recognition of ASD
- With ID
 - Atypical symptom manifestation
 - Self-injury, irritability, aggression, new and unusual movements/behaviors
 - Communication barrier can limit interviewing
 - Many above symptoms could be functional (method of communicating)

Redefining Mental Health in IDD – DSM View

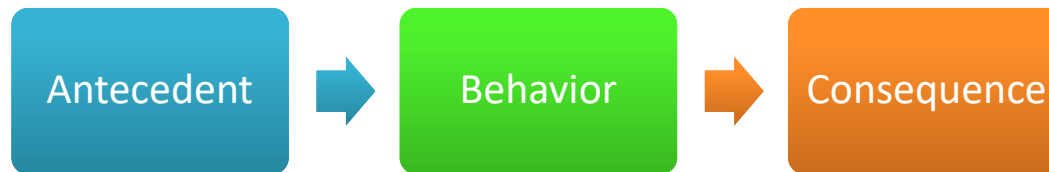
- NADD
 - 2007, collaborated with American Psychiatric Association on the publication of *Diagnostic Manual – Intellectual Disability (DM ID)*
 - A text guiding diagnosis of mental disorders in persons with ID
 - Updated version developed after DSM-5 released

Before reaching for the prescription pad...

- Is the “disruptive” behavior functional (i.e. serving a purpose)?
- Are there environmental factors influencing the disruptive behavior, and, if so, can they be modified?

Applied Behavior Analysis (ABA)

- ABA forms the foundation of many comprehensive behavioral treatments for ASD
 - Focus on acquisition of skills or decreasing disruptive behavior
- Strong evidence base for addressing core deficits of ASD



- Early intensive behavioral intervention (EIBI) draws from ABA principles
- ABA is appropriate for a wide age range, but is particularly emphasized in early childhood

Overview of Psych Meds in Adult ASD

- **Systematic evidence of benefit lacking** (Dove, 2012)
 - No FDA approved med for adults
 - **Aripiprazole and risperidone** only meds approved in children
 - Lack of empirical evidence allows for “choosing your favorite”
 - Family history to medication response may influence choice
- Despite lack of evidence, **psych med use is common**
 - **Atypical antipsychotics, SSRIs, and stimulants** most commonly used (Esbensen, 2009)
 - 80% of all adults on psychotropics
 - Steady increase in use of psychopharm agents with age
 - Once on psychotropic, likely to stay on
- **Poly-pharmacy is common** (Tsiouris, 2013)
 - Mean – 1.51 meds in adults with ID/autism

Challenging Aspects of Psych Med Treatment in IDD

- **Identify the target symptom** before starting treatment.
 - Narrow target symptom(s) and expectations
- **Measuring response** is challenging.
 - Subjective (often from observer) assessment of benefit
- **Adverse events** are common.
 - Idiosyncratic responses are more common
 - Adverse events can be reported as increase in core symptoms or target symptom
- Beware of **regression to the mean**.
 - Sometimes inappropriately attribute improvement to the medication.

Basic Principles of Psych Meds in IDD

- Maximum dose is often less than prescribed to typically developing individuals.
- Start LOW and go SLOW!
- Avoid polypharmacy if possible.
- Common pitfalls:
 - Misattribution of med effect due to other life changes
 - Positive response could be “regression to the mean”
 - Reporting by caregiver strongly influenced by placebo effect/belief system
 - Leaving medication on board when only minimal benefit is seen
 - Benefit/failure at young age not always predictive of response at later age

Commonly Used Psych Med Classes in IDD

- **Antidepressants**
 - SSRIs most common
- **ADHD Meds**
 - Stimulants – long acting preferred
 - Non-stimulants (alpha-agonists, atomoxetine, amantadine)
- **Antipsychotics**
 - Risperidone and aripiprazole most studied
- **Anxiolytics**
 - Benzodiazepines (more commonly “prn” use; lorazepam for catatonia)
 - Beta-blockers
- **Mood stabilizers**
 - AEDs (lamotrigine, valproic acid, carbamazepine) and lithium

Anxiety and IDD

- Incidence **increases with improving self-awareness**
 - Can emerge as developmental progress is occurring
- Often provoked by changes in routines, new social situations, difficult task demands, etc.
- **Presentation variable**
 - Fearfulness, irritability, tantrums, self-injurious behaviors, aggression, obsessive questioning, repetitive behaviors, etc.

Targeting Anxiety in IDD

- SSRIs most commonly used
- SNRIs also used
- Consider buspirone
- Avoid benzodiazepines if possible
 - Effective as “prophylactic prn” for blood draws, dental visits, etc.
 - Consider hydroxyzine as first line alternative
- Consider alpha-agonists or beta blockers as these might be therapeutic for “hyperarousal”
- Don’t forget importance of **physical exercise, physical health, and sleep!**

Depression and ASD

- As with anxiety, **increased in ASD** vs. other DDs (especially *ASD without ID*)
 - Developmental progress in **self-awareness** can contribute
 - Increasing academic and social demands
- Again, **ASD can mask** and/or compound symptoms
 - social withdrawal, constricted affect, irritability, increased insistence on routines, disorganization, inattention.
- Suicide attempts 4-fold increase in ASD (Croen, 2015)
 - **10-fold increase in “high-functioning” ASD (without ID)**
 - LGBTQ+ identity may increase risk

Targeting Hyperactivity, Impulsivity and Inattention in IDD

- Co-occurring ADHD in IDD estimated anywhere 30-85%
 - Symptom overlap confounds prevalence numbers
- Most common treatment is **medication**
 - Psychostimulants most common – long-acting preferred
 - Some evidence for alpha-2 agonists (guanfacine, clonidine).
 - Limited studies of atomoxetine
- Don't forget interplay between inattention and anxiety/mood
- Also, don't forget importance of **physical exercise, physical health, and sleep**

Antipsychotics and IDD

- Primary target is “**behavioral dysregulation**”
 - Irritability, aggression, self-injury, tantrum behaviors
- Secondary targets can include
 - Mood, sleep, tic behaviors, compulsive behaviors
 - Hallucinations/psychotic features
- **Typically reserved as “2nd line”** due to side effect profile
 - Although can sometimes be highly therapeutic
 - Safety blood test monitoring may be challenging
- Evidence supports **benefit at low dose**
 - Safety blood test monitoring may be challenging

Other Conditions to Consider in ASD

- **Bipolar**
 - Consider when cycling of behavior/mood is seen
 - Cycling can be very rapid
 - Consider with **unexplained new onset insomnia**
 - Treatment combining antidepressant with mood stabilizers
- **Obsessive Compulsive**
 - Gray line between repetitive behaviors/OCD
 - Consider with new onset repetitive behavior
 - Treatment combining SSRI and anti-psychotics
- **Catatonia**
 - Seen more commonly in “syndromic” forms of autism
 - Can present as “excitable” form (difficult to differentiate from “self-stim”)
 - Consider with **unexplained new onset weight loss**
 - Treatment with high dose benzodiazepine
- **Tic Disorder**
 - Can emerge at later onset in ASD
 - Difficult to differentiate from “self-stim” behavior
 - Treatment with alpha agonists and anti-psychotics

Advice from Self-Advocates – “*Don’t Just Focus on the Weaknesses*”



Hyperfocused vs. Preferred Interests – When is it a Good Thing?

- “Special interest areas”
- Sciences, history & culture, animals, information and mechanical systems, belief systems, machines and technology
- Improves joint attention, social interaction, and anxiety
- 62% of adults feel focusing on preferred interests has helped not hindered success (majority of these individuals were high functioning and diagnosed as an adult)
- Only 10% felt their teachers were supportive of their preferred interests

Koenig, 2017

Thanks!

gastobbe@uw.edu



Party Boy by Wil Kerner



Questions and Answers



Day 2 Agenda

November 4 1:00 - 4:00 PM

| Session Title | Time |
|--|-------------------|
| Care Coordination and Shared Care Planning | 1:00 PM - 1:55 PM |
| Break | 1:55 PM - 2:00 PM |
| Leveraging Telehealth to Advance Integrated Care | 2:00 - 2:55 PM |
| Break | 2:55 PM - 3:00 PM |
| Can Value-Based Payment Sustain Integrated Care? | 3:00 - 4:00 PM |

Register through GoToWebinar:

<https://attendee.gotowebinar.com/register/6284981497673468944>

References

- Bakken TL, Helverschou SB, Eilertsen DE, et al. Psychiatric disorders in adolescents and adults with autism and intellectual disability; a representative study in one county in Norway. *Res Dev Disabil*, 2010, 31(6):1669-77.
- Bernier R, Golzio C, Xiong B, et al. Disruptive CHD8 mutations define a subtype of autism early in development. *Cell*, 2014 Jul 17; 158(2):263-76.
- Bolton PF, Carcani-Rathwell I, Hutton J, et al. Features and correlates of epilepsy in autism. *British Journal of Psychiatry*, 2011, 198: 289-94.
- Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. *Autism*. 2015;19(7):814–23.
- Devinsky O, Asato M, Camfield P, et al. Delivery of epilepsy care to adults with intellectual and developmental disabilities. *Neurology*, 2015 Oct 27; 85(17):1512-1521.
- Dove D, Warren Z, McPheeters ML, et al. Medications for adolescents and young adults with autism spectrum disorders: a systematic review. *Pediatrics*, 2012, 130: 717-26.
- Ekinci O, Aman AR, Isik U, et al. EEG abnormalities and epilepsy in autistic spectrum disorders: clinical and familial correlates. *Epilepsy Behav*, 2010, 17: 178-82.
- Esbensen AJ, Greenberg JS, Seltzer MM, et al. A longitudinal investigation of psychoactive and physical medication use among adolescents and adults with autism spectrum disorders. *J Autism Dev Disord*, 2009, 39:1339-49.
- Esbensen AJ, & Schwichtenberg AJ. Sleep in neurodevelopmental disorders. *Int Rev Res Dev Disabil*, 2016; 51: 153-191.

References (cont.)

- Gentile JP, Cowan AE, & Smith AB. Physical health of patients with intellectual disability. *Advances in Life Sciences and Health*, 2015; 2(1): 91-102.
- Herer GR. Intellectual disabilities and hearing loss. *Communication Disorders Quarterly*, 2012; 33: 252-260.
- Koenig, KP & Williams, LH. Characterization and utilization of preferred interests: a survey of adults on the autism spectrum. *Occupational Therapy in Mental Health*, 2017, DOI: 10.1080/0164212X.2016.1248877.
- Krahn GL, Hammond L, & Turner A. A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*. 2006; 12:70-82.
- Ibrahim SH, Voigt RG, Katusic SK, et al. Incidence of gastrointestinal symptoms in children with autism: a population-based study. *Pediatrics*, 2009 Aug; 124(2):680-6.
- Luna RA, Savidge TC, & Williams KC. The brain-gut-microbiome axis: what role does it play in autism spectrum disorder? *Curr Dev Disord Rep*, 2016 Mar; 3(1):75-81.
- Mazurek MO, Dovgan K, Neumeyer AM, et al. Course and predictors of sleep and co-occurring problems in children with autism spectrum disorder. *J Autism Dev Disord*, 2019 May; 49(5):2101-15.
- Postorino et al. Intellectual disability in autism spectrum disorder: Investigation of prevalence in an Italian sample of children and adolescents. *Research in Dev Dis*, 2016; 48: 193-201.
- Righi G, Benevides J, Mazefsky C, et al. Predictors of inpatient hospitalization for children and adolescents with autism spectrum disorder. *J Autism Dev Disord*, 2018 Nov; 48(11):3647-57.
- Tsioris JA, Kim SY, Brown WT, et al. Association of aggressive behaviours with psychiatric disorders, age, sex, and degree of intellectual disability: a large-scale survey. *J Intellect Disabil Res*, 2011, 55(7): 636-49.
- Warburg M. Visual impairment in adult people with intellectual disability: Literature review. *J of Int Dis Res*, 2001; 45: 424-438.