Understand Mental Health Needs and Challenging Behavior in Intellectual Disabilities & Autism Spectrum Disorders: 
Growing Up Uniquely

Laurie Charlot, PhD
Developmental Psychologist
Clin. Dir NC START East
National START Team Consultant
Asst. Prof., UMass Medical School
Dir. Becket Multidisciplinary ID/MH Evaluation Team
What Leads to Behavioral Health Challenges?

- Communication Problems
- Health concerns
- Anxiety - social anxiety, difficulty with new people, changes can lead to “fight or flight”
- Lack of social awareness
- Sensory issues
- Trauma, Bullying, Loss and Change
AGGRESSION - Other externalizing challenging behaviors

- A final common pathway for distress/discomfort for people who:
  - Have a limited behavioral repertoire
  - Have few ways to express distress
  - Cannot modulate dysphoric states >>> managing anxiety

- Like a *fever* - It means something is wrong
- What is wrong requires *comprehensive assessment*

*This includes examination of the role of Sensory Modulation Challenges*

Charlot, 2018
ASD & Psychiatric Symptoms

- ASD itself can distort the way in which psychiatric disorders present themselves.
- Trauma >>> Social Impairments correlates with increases in behavior problems
- More often exposed to bullying
- May show atypical features

Rates of Psychiatric Disorders in Samples of Individuals with ASDs

- Rates vary widely across studies
- Sample selection
- Methods for case ascertainment
  - Chart reviews or counting from existing databases
  - Informant based
  - Direct patient evaluation
- Critical source of problems relate to symptom identification
National Survey on Child Health (Gurney et al, 2006)

- Children with autism vs. neurotypical children had more:
  - depression or anxiety
  - behavior or conduct problems
  - physician visits
  - treatment for emotional, developmental or behavioral problems (75.4% vs. 7.0%)
  - prescribed medications (51.4% vs. 14.5%)

- Santino & Matson note challenges in identifying comorbid psychiatric disorders in people with ASDs
  - It can be difficult distinguishing symptoms of psychopathology from the core features of ASD
  - Individuals with ASD are a heterogeneous groups
  - Compounded by varying degrees of ID (Matson & Nebel-Schwalm, 2007).

- N = 190 Children with ASD Autism Center
- Retrospective chart review
- Sleep disorders r+ gastrointestinal dysfunction (P < .05) and mood disorders (P < .01)
- Food intolerance r+ gastrointestinal dysfunction (P = .001)
- Ss with mood disorder had more aggressive or self-injurious behs than those w/o mood dxs (P < .05).
Do Individuals with ASD and ID have more psychopathology than individuals with ID (no-ASD)?

- Some controversy

- Some studies do not find differences in rates based on presence of ASD but rather related to functional correlates and level of ID


  > Mental health of adults with autism spectrum disorders and intellectual disability Underwood, Li, McCarthy, J; Tsakanikos, E

► Modified K-SADs
  ► In depth individualized assessment

► N=109 Children

► 5-17 y/o

► 68% FSIQ > 70, mean 83

► Unselected for psychiatric comorbidity

► ADR-I ADOS and DSM-IV-TR criteria for ASD met
Comorbid Psychiatric Disorders in Autistic Children

Frequency of the number of comorbid lifetime DMS-IV psychiatric diagnoses per autistic child.

**Top 3:** Specific Phobia (43%), OCD (37%), and ADHD (31%)

New Onset Psychiatric Disorders with Autism

- Followed 135 Children with ASDs until age 21
- Assessed new onset of psychiatric d/ os
- Direct clinical assessments performed
- 16% had definite and 6% possible onset of a new psychiatric d/o
  - 5 OCD
  - 8 Affective do
  - 1 Anxiety d/o
  - 0 Schizophrenia
- Rates are lower for Bipolar d/o and Psychosis \( v \) studies using less rigorous methods and sample with < cognitive impairment
Differential Diagnosis of Psychiatric Disorders in ASD is Complex  Bradley et. al., 2013

▶ “It can be anticipated that mental health disturbances in those with atypical neurofunctioning may be both different as well as similar to those with typical neuro-functioning.”

▶ ...Understanding how people with autism experience the world differently from the general population may illuminate more accurately the nature of the mental health disturbances they experience, the extent to which these overlap and are different from the general population, as well as provide opportunities for more targeted interventions and treatment.” p.253
ASD, Trauma and Anxiety

- Anxious hypervigilance and hyper focus
- Poor regulation of negative arousal states
- Perseveration on perceived threatening stimuli
- Some people with ASD overreact to aversive sensory stimuli because they are more likely to attend to them and have difficulty disengaging from them (set shifting)

- Why did Angela always assault Maribel?
  - Maribel never smiled

Charlot, 2018
Trauma Symptoms & Sensory Challenges

- Participants with post traumatic stress symptoms “vacillated between sensory sensitivity, sensation avoiding, and low registration.”

- Low registration is caused by avoiding in some cases

Understanding Emotional Challenges in ASD

- **Anxiety and low mood** may be worsened by stressful experiences, health challenges and - a lack of meaningful engagement
  - a lack of happiness
- **Challenging behaviors** may be provoked or worsened by anxiety
  - “meltdowns” and outbursts > often based in anxiety
Gillott A. Standen PJ (2007) Levels of Anxiety and Sources of Stress in Adults with Autism..


- 34 adults- ASD 20 adults ID
- Informant-based measures of anxiety and stress
- Groups matched by age, gender, level of ID
- **ASD Ss @ 3 X’s more anxious v ID Ss.**
- ASD Ss had > scores on subscales: panic and agoraphobia, separation anxiety, OCD, GAD
- Stress (ability to cope with change, anticipation, sensory stimuli and unpleasant events)
- r+ with high anxiety levels for ASD grp, “....the more anxious the individual with autism, the less likely they were able to cope with these demands.”
Sources of ANXIETY in ASD

5 groupings emerged:
(a) the environment
(b) interactions with others
(c) concern for other
(d) fearful anticipation of an event or outcome
(e) disappointment


Sound and light sensitivities
Crowds
Uncertainty/making decisions
Delays (e.g., transport)
Anticipation and disappointment
Unexpected or sudden change
Health concerns (germs)
Public speaking
Communicating with others
Perceived injustice to self or others
Authority (e.g., police, security)
News reports and other media
Meeting deadlines
Making eye contact
Losing things
Bullying and gossip
Managing finances
Perceived surveillance of self
Explaining diagnosis
Charlot, 2018
Missing Anxiety?

- Some research suggests that anxiety is more common in children with higher IQs.
- BUT, do we simply miss it when people are less able to communicate?
- Do people see aggression and externalizing behaviors as always = Irritability, anger?
  - Missing Fight or Flight
  - Things are not always what they seem at first glance

Charlot, 2018
AGGRESSION = FIGHT OR FLIGHT

- Irritability may co-occur
- Instrumental aggression
  - Less often but may be to get help or avoid aversive sensory experiences
- Affective aggression
  - Reactive, ”panic” self-protection

Charlot, 2018
Anxiety

- May be missed and mistaken for other psychiatric problems (ie mania)

- Severe anxiety and panic may drive escape based agitated behaviors
  - give appearance of more “severe” d/o
  - increased in adolescents at times dt size and strength
Phenomenology of Anxiety

- TYPICAL
  - Tense facial expression
  - Saying I am afraid or worried other verbalizations
  - Hand wringing, pacing
  - Freezing
  - Withdrawing
  - Crying
  - Tantrums

- ASD
  - Flat facial expression
  - Rarely telling others feelings -
  - Same
  - Same
  - Same
  - Less common?
  - May be more common and severe

Charlot 2019
Developmental Effects on Psychiatric Disorder

- Individuals may present with **neurodevelopmental features similar to younger neurotypical children**

- To establish psychopathology, departure from usual behavior for the individual (i.e. sleep)
  - AND usual for developmentally driven expected behavior

- This may be variable even between domains of functioning
  - Socially may present like much younger Individual while able to perform complex cognitive tasks
    - Computer skills at adult level
    - Socially similar to preschool aged Individual
When associated with ID

- Consider what would be developmentally expected for a neurotypical child functioning in the same manner
  - Using the same info processing tactics
  - With similar social-emotional developmental profile
  - Identifying with heroes
  - Not recognizing differences between fantasy-reality
People with ASD (and other people with ID) will respond to trauma triggers by becoming agitated, aggressive or self-injurious.

May not display typical features of anxiety, while anxiety is the most common mental health symptom.

Psychosis is rare and difficult to accurately diagnose.

Individual observed parent being physically abused.
Personality Disorders & ASD

- Personality Disorders.... Rare
- Clinical awareness, a careful developmental history, and genuine knowledge about ASD are key to differential
- For the individual patient, a “‘redefinition’ from PD to an ...ASD will often provide a basis for a better understanding of the core problems faced by the individual with social communication impairment”

ADHD

- Common comorbidity or core feature?
- Confusion may arise due to capacity to attend to preferred or obsessive interests when also presenting with extreme challenge attending to other tasks (i.e., academic tasks)
- Problems tolerating or filtering out extraneous stimuli and tendency to become easily over-aroused
  - Exaggerated under stress leading to intensity suggestive of d/o
  - Unclear if pathophysiology is same as when seen in non-ASD Individuals

Charlot 2019
Depression

- Similar in ASD with and without ID
- Also see “baseline exaggeration”
- Like all persons with ID, ASD + DEP:
  - Anhedonia and irritability > classic depressed mood
  - Detected and reported > with milder ID
  - > psychomotor agitation
  - Withdrawn behavior
  - Comorbid anxiety symptoms
“Differentiating between the core symptoms of PDD and psychosis can be very difficult, as not only misinterpreting autistic behaviors as psychosis but also being unable to diagnose psychosis because of communication difficulties can occur.”
MISDIAGNOSIS of PSYCHOSIS

- Odd use of words (or even made up words) when associated with externalizing behaviors can be confused as psychosis
- “Scripted speech”
- Conversation lacks give and take and speech content is idiosyncratic, worsened by stress or anxiety
  - “Tangential thinking”
  - “Flight of ideas”
PSYCHOSIS


- Thought disorder and bizarre behavior are unreliable due to the fact that they are also core PDD symptoms.
- Delusions are more reliable but cautiously useful as “unusual world view” and idiosyncratic obsessions also seen commonly in ASDs (AS).
- Auditory hallucinations should be differentiated from self-talk or pseudohallucinations.
Examined multiple clinical groups and controls

- Autistic Disorder
- PDD nos - MCDD
- Anxiety d/os
- ADHD
- Controls

Thought disorder was associated with verbal abilities

- Highlighting the impact of developmental effects
CASE EXAMPLE  JAY

- Abilify 5 mg po qhs
- Effexor 150 mg po BID
- Depakote spkles 500 mg po BID
- Ativan 0.5 mg po qAM, 1 mg po qPM, 1 mg po qhs
- Trazodone 300 mg po qhs
- Nexium 40 mg po BID
- Zantac 150 mg po qhs
- Simvastatin 20 mg po daily
- Feosol 45 mg po daily
- Genteal 1-2 drops to right eye TID

- 40 y/o male with CdL
- Obesity
- Constipation
- GERD
- Hiatal Hernia
- ? Fe def anemia
Cornelia DeLange Syndrome (CdLS): J.

- Very high rate of GI problems including GERD
- Skin problems
- Vision and hearing problems
- ASD
- Anxiety/phobias
- Attention problems
- Compulsions
- SIB

Charlot 2019
“I think I swallowed battery acid”
Things are not always what they seem to be......

- Positive swallow study - aspiration precautions in place
  - History of GERD and frequent c/os of chest pain
- Positive for constipation (marked) on PE at eval
- Unusual gait as noted
- Skin problems
- Fatigue and day time sleeping
- Side effects/Medical Screening informant reports “No” problems for all of the above areas
PSYCHOSIS

Konstantareas and Hewitt

- Compared adult males
  - 14 - schizophrenia and 14 ASD
- 50% of ASD group met criteria for schizophrenia
- Differences in symptoms noted between the two groups.
  - ASD group had limited language (affecting assessment)
  - 4/7 - bizarre behavior
  - 1 - formal thought disorder
  - 6 - negative symptoms
  - 0 - hallucinations or delusions.
  - 2 - ? delusional without corroboration then found that both were “merely stating accurate information in an immature way”

Mania

- May be over-diagnosed
- Missed medical problems and anxiety?
- When present - delusions may be simpler
- Associated with extreme obsessionality and/or high levels of anxiety
- ? Of chronicity in early onset given hallmark of episodicity in the syndrome
  - Is “chronic mania” really the same syndrome?
OCD

- Some controversy re whether to diagnose due to symptoms being evident as core features of ASD
  - Some individuals have classic O-C features
  - Others have more intense RRBs raising the concern to a higher level
- Most frequent phenomenology differs between people with and without ASD
OCD: Most to Least Freq
Compulsions
Unpublished Data from Charlot

- NON-ASD
- Cleaning
- Checking
- Symmetry
- Hording

- ASD
- Symmetry
- Hording
- Checking
- Cleaning

Charlot 2019
Compulsions and obsessions less sophisticated in children with ASD v OCD.

Sameness behavior - more prevalent in younger Children with OCD,” but for children with ASD, age was not significantly related to sameness behavior, repetitive movements, compulsions, or obsessions.”
Some Syndromes Associated with ID and ASD May Increase the Risk of Psychiatric Disorders or Behavioral Phenotypes
Genetic Factors Contribute to Multiple Forms of Risks

- Specific brain and neural circuitry aberrations
- Behavioral and emotional disorder (Behavioral Phenotypes)
- Health problems
- Adverse Drug Events (ADEs)
  - CYP 450 polymorphisms >> 2D6
  - Person with congenital abn in Fronto-Basil Ganglia neural circuits > risk of EPS
  - Patient with VCF develops a urethral stricture
  - Down syndrome patient develops serious OSA
  - Patient with birth “defects” causing dystonia rapidly develops dysphagia when treated with an AP drug
Genetic Syndromes:
Ex. Fragile X (FXS)
- Most common inherited cause of ID
- ABNORMALITY in the FMR1 GENE
- Expansion of a triplet repeat -CGG
  - > 200 repeats = full mutation
    - normal = about 40 or less
- Silencing of FMR1 leads to < FMRP
  - Fragile-X Mental Retardation Protein
  - FMRP important for normal development of neural connections
- Some other gene problems can also cause FXS
- There is marked heterogeneity in FXS so now called the FXS Spectrum
Genetic Syndromes:
Ex. Fragile X (FXS)

- May contribute to risk of mental health disorders or temperamental tendencies
- ALSO, confer risk for health problems
- May add risk for adverse drug events altering typical responses to medications

FXS AND HEALTH

- Multiple associated physical problems
- Most s/t loose connective tissue:
  - hypotonia
  - hyperflexibility
  - high arched palate
  - flat feet
  - recurrent ear infections
  - mitral valve prolapse
  - seizures
  - precocious puberty
  - ophthalmic issues

Charlot 2019
PSYCHIATRIC DISORDERS IN FXS

- Highly associated with ASD, or ASD features
  - Hypersensitivity to sensory stimuli
  - Low habituation to repetitive stimuli
- Childhood
  - ADHD, anxiety
- Adults
  - Anxiety and Depression (> 50% of adults anxiety)
- Hallmark >>>> Social Anxiety
COMMON FEATURES

- ANXIETY
- Shyness
- Perseveration
- Hyperactivity-Attention problems
- Mood instability (Difficulty managing emotions)
- Gaze aversion
- Stereotypies
  - Hand flapping
  - Hand biting
Knockout Mouse Gives us Clues

- A knockout mouse is genetically engineered
  - Researchers inactivate or knock out an existing gene
- Replace or disrupt it w/ artificial DNA
- Loss of gene activity causes altered “phenotype”
  - Changes in appearance, behavior, physical characteristics etc
- Animal Models allow us to look deeper at at the “molecular level” and give us clues about ASD
- New treatment targets are being identified that alter pathways disrupted by genetic effects on protein synthesis