

Autism/IDD and Catatonia

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ECHO IDD Complex Behavior

***Disclosure:** The speakers have no relationships with any commercial firms having products related to topics discussed today. Actual disclosure forms are available upon request.*

Objectives

- Review what we know about catatonia and autism/IDD
- Review clinical features of catatonia presentation, evaluation, and treatment
- Discuss long-term outcomes in catatonia associated with autism/IDD and future directions

Catatonia in ASD/IDD

- Emerging science and awareness - *prevalence estimates as high as 12-20%*
 - Higher risk in “syndromic” forms of autism/rare gene disorders?*
 - Down Syndrome Regression Disorder – may be a form of psychosis/catatonia, or is catatonia a symptom of DSRD?*
- Underlying trigger may be medical/neurologic/psychiatric
 - Medical/neurologic causes typically present more acutely*
 - In autism/IDD, onset is often sub-acute/chronic (psychiatric?)*
- Psychosis/thought disorder felt by most autism/IDD experts to more often stem from a primary affective disorder (depression, mania, OCD, PTSD)
- Can present as “hyperkinetic” (difficult to differentiate from “self-stim”)
- Consider with **unexplained new onset weight loss, incontinence, and new disruptive behaviors**
- Anti-psychotic class can sometimes worsen catatonic symptoms*

Hasan S, Hussain I, Chadwick L, et al. *J Autism Dev Disord*, 2025: <https://doi.org/10.1007/s10803-025-06855-3>

Smith JR, Lim S, Bindra S, et al. *MedRxiv*, <https://doi.org/10.1101/2024.09.05.24312724>.

Catatonia in ASD/IDD – rare gene disorders

A wide range of neurodevelopmental genetic syndromes and rare gene disorders have been associated with **psychosis and/or catatonia**. Two recent systematic reviews identified **47–78 distinct genetic conditions** reported in association with catatonia alone.

Of the chromosomal microdeletion/duplication syndromes, those most commonly associated =

- 22q11.2 deletion syndrome (DiGeorge/velocardiofacial syndrome) — The most common and best-studied genetic cause of psychosis; ~25% develop schizophrenia or schizophrenia-like features. Also the second most commonly reported genetic syndrome in catatonia.

Phelan-McDermid syndrome (22q13.3 deletion / SHANK3 mutations) — The most frequently reported genetic condition in catatonia. Also associated with psychosis, bipolar features, and regression, particularly from adolescence onward.

1q21.1 deletion and duplication — Both associated with schizophrenia.

15q11.2 deletion (Burnside-Butler syndrome) — Associated with schizophrenia.

15q13.3 deletion — Strongly associated with schizophrenia and epilepsy.

15q11-q13 duplication (Prader-Willi/Angelman region) — Duplications at this locus carry among the highest risk for ASD and are also associated with psychosis.

16p11.2 deletion and duplication — Both associated with schizophrenia.

3q29 deletion — Associated with a very high risk of schizophrenia.

NRXN1 deletion — Deletions of the neurexin-1 gene are associated with schizophrenia and ASD.

7q11.23 duplication (Williams syndrome region duplication) — Associated with schizophrenia risk.

17q12 deletion — Associated with schizophrenia and ASD.

17p13.3 microduplication - Recently reported in association with recurrent catatonia.

What is catatonia and why is it difficult to diagnose in autism?

- Catatonia is categorized as a sub-type of schizophrenia (DSM-5)
 - Cluster of mood, motor, vocal, and affective symptoms
 - Can be “malignant” and life-threatening with autonomic symptoms (HR, temp, breathing)
 - Pre-frontal/anterior cingulate circuitry implicated
- Prevalence in autism unknown and difficult to recognize
 - Overlap of catatonia symptoms and features of autism
 - Variability in catatonia symptoms from day to day and moment to moment (hyperkinetic and hypokinetic)
 - No biomarkers in majority of cases
 - Onset is often sub-acute/chronic
- Additionally
 - Psychiatric providers unfamiliar with neurodevelopmental disorders
 - Psychiatric evaluators often don't know the pre-onset baseline

Catatonia in ASD/IDD – Clinical Characteristics

- 6 primary symptoms clusters – *(examples not all inclusive list)*
 - **Psychomotor activity**
 - Freezing AND new onset repetitive/purposeless
 - **Speech disturbances**
 - Mutism AND new echolalia
 - **Change in behavior/skills/function**
 - Loss of self-help skills including toileting, eating/drinking
 - **Mental health symptoms**
 - Aggression/self-injury, agitation/restlessness, loss of interests/social withdrawal
 - **Physiologic symptoms**
 - Sleep/insomnia, fever, increased pupillary size, diaphoresis, incontinence
 - **Symptoms related to arousal and awareness**
 - Thought disturbances

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Catatonia in ASD/IDD – Treatment Considerations

- **Baseline Bush-Francis Catatonia Rating Scale is elevated at baseline** in autism without catatonia
 - Assessment more challenging if the clinician did not know the person prior to catatonia symptom onset
- **Variability** from day to day, hour to hour, can impact the evaluation
 - Videos of observed behaviors outside of clinic can be valuable
- Treatment most effective – **benzodiazepines and ECT**
- **“Lorazepam challenge”** with pre- and post-measurement of symptoms often necessary to confirm dx
 - Inpatient and outpatient protocols (“playbook” of inpatient is to push dose to sedation)
- Treatment with **benzodiazepines often requires very high dose**
 - Challenging for providers and families to accept
- Treatment with ECT on outpatient basis in WA State **requires judge/court approval**
- Long-term outcomes suggest **incomplete recovery** in majority of cases

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Catatonia and Autism/IDD – Long-Term Outcomes and Family Perspective

- Carol Allread, LEND fellow, parent and family advocate

Future Directions

What We Need

- A biomarker beyond just the lorazepam challenge to assist in diagnosis
- Improved early recognition along with studies of the impact of early treatment on long-term outcomes
- Explore both pharmacological and neuromodulatory novel and innovative therapies targeted at treatment early in condition

Resources

[Catatonia in Autism - Family/Caregiver Information Sheet](#)

[SPACES Webinar Series](#)

Autism Science Foundation
“Let’s talk about catatonia.”
Podcast, March 31, 2025

<https://asfpodcast.org/archives/1850>

The Catatonia Foundation
“Catatonia in autism and other neurodevelopmental disorders.”
<https://www.thecatoniafoundation.org/catatonia-in-autism>

Catatonia in Autism



WHAT FAMILIES AND CARE PARTNERS NEED TO KNOW



What is Catatonia?

Catatonia is a serious but treatable condition that affects movement, speech, behavior, and autonomic functioning (breathing, heart rate, temperature regulation). Often linked to mental health disorders, catatonia can also affect people with autism—and it’s more common than you might think.

Up to **10%** of autistic individuals may experience catatonia symptoms at some point across their lives

Features of Catatonia in Autism

- Catatonia in Autism can show up gradually or all at once
- Symptoms may come and go
- There are two forms: Hypokinetic (Shutdown) and Hyperkinetic (Excited)*
**People may alternate between these two states (mild-extreme stillness to mild-extreme agitation)*



Watch for and note the following changes, especially if they present as a loss of previously acquired skills:

HYPOkinetic

- Movement – “freezing”, moving very slowly, or requiring prompting to move
- Trouble crossing thresholds or completing physical movements
- Staring or fixed gaze*
- Mutism or reduced speech/communication*
- Refusal to eat/drink, eating with hands, requiring significant encouragement to eat/drink
- Loss of self-care/daily living skills
- Social withdrawal
- New or worsening urinary incontinence*

HYPERkinetic

- Echolalia, Echopraxia* (echoing others’ words or movements) - new onset
- Repetitive/purposeless movements* (Increased or new onset)
- Posturing - holding body in unusual positions
- Nudism* (removing clothes)
- Agitation/Restlessness*
- Aggression/Self Injury*
- New or worsening urinary incontinence*

*Autism symptom overlap

In rare cases, catatonia can become life-threatening (called Malignant Catatonia) with high fever, rapid heart rate, and trouble breathing. This is a medical emergency!

Questions and Discussion

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