

DOWN SYNDROME REGRESSION DISORDER (DSRD)

Information for Educators

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When students experiencing DSRD are in school (or work) settings, the impact of their symptoms can often be overwhelming. Information and strategies that may be helpful are provided here. The most important thing an educator can do is to UNDERSTAND the condition as much as possible, and work collaboratively with families to create plans that allow students to stay in school while they battle the condition.

What is DSRD?

Down Syndrome Regression Disorder (DSRD) is a rare but serious disorder that occurs in individuals with Down syndrome, usually in the adolescent or young adult years. The term regression refers to the loss of skills an individual has previously mastered. These skills can be daily living, language, movement or social skills. The loss is often sudden, occurring over a period of weeks to months.

NDSS.org

The exact cause of DSRD is unknown, but current medical research points to immune system dysfunction, leading to the body mistakenly attacking healthy brain tissue, resulting in inflammation. Psycho-social stressors, medical conditions, and genetic variants may also play a role. Treatments may include immunotherapy and/or psychiatric medications.



Symptoms of DSRD include:

- Behavioral changes
- Changes in thinking
- Changes in processing
- Loss of functional skills
- Loss of social skills
- New neurological deficits
- Difficulty sleeping
- Irregular sleeping patterns
- Language difficulties
- Irregular movements
- Anxiety
- Delusions
- Hallucinations
- Depersonalization
- Obsessive-compulsive tendencies

DSRD and Catatonia

Many students with DSRD display behaviors of catatonia.
Below are typical behaviors that you may see in the classroom.
There are two types of catatonia.
Students may have one or the other, or a combination of both.

Stuporous Catatonia	Excited Catatonia
Immobility Lethargy Lack of responsiveness Mutism Refusal to eat	Excessive movement Agitation Violence Disorganized behavior Hallucinations or delusions

Everyone concerned with the affected individual needs to understand that the difficulties of movement, activity and participation are not under the individual's voluntary control. The individual is not being deliberately manipulative, stubborn, willful, obstructive or lazy. The condition causes severe distress and frustration to those affected and **they need a sensitive, sympathetic and understanding approach.**

-Dr. Amita Shah (British Psychological Society)

Strategies for Working with Students

DO

- Ask questions and seek to understand
- Gently encourage participation in activities
- Increase use of visual and verbal prompts
- Keep to the typical schedule as much as possible
- Reduce task demand when behaviors escalate
- Provide a space for de-escalation and calm
- Consider a primary care giver in the school setting
- Develop a safety plan for staff and students
- Communicate regularly with family about any negative or positive behavior changes. A team approach is always best

DON'T

- Jump to the assumption that the behaviors are intentional
- Punish the student
- Insist the student complete an assigned task
- Assume that traditional behavior management techniques will be effective
- Search for 'triggers' or 'functions' of the behavior as you will likely not find them
- Insist the student be sent home when he/she misbehaves
- Chastise the student or family because of the behavior
- Speak about the student in front of them; they are likely hearing you even if they do not react

For more information about DSRD:

National Down Syndrome Association
ndss.org

Down Syndrome Medical Interest Group
dsmig-usa.org

What You Need to Know About Catatonia
[Web MD](#)

CARE Down Syndrome
careds.org

Information on Down Syndrome Regression Disorder
<https://www.facebook.com/DownSyndromeRegressionDisorderInformation>

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