





JOHNS HOPKINS

The Early Years: Naughty to Nice Behavior

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Behavior

Although many children with CdLS have no significant behavioral problems, there are some conditions that make challenging behavior more likely to occur. They may also have strong reactions to ordinary stimuli that continue long after the stimulus is gone. Individuals with CdLS may also have irregular patterns of behavior in the areas of eating, sleeping and emotional response.

Lack of sensitivity to pain and/or heightened sensitivity to touch suggests some individuals may have neurological impairment. They may also be prone to behavioral problems such as hyperactivity, short attention span, and oppositional or repetitive behavior.

Behavioral Issues

People with CdLS may exhibit a number of behavioral problems such as selfinjury (head-banging, hand-biting, etc.), compulsive repetition, and/or autisticlike behaviors. Anxiety, Obsessive Compulsive Disorder, Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder have also been noted.

Objectives To identify behavioral issues commonly seen in CdLS

To assist caregivers of individuals with CdLS to identify common medical causes of behavior issues

To identify potential environmental triggers to challenging behaviors

To explore various treatment options

Important Points

- The answers are not quick and easy.
- Problem behavior is not like a disease with one clear treatment path. The causes vary greatly. Therefore, the treatment will vary.
- Assessment takes time.
- Need to understand as much as possible about the behavior and the functions to understand how to intervene.
 Treatment evaluation takes time.

WHAT ARE THE MOST COMMON BEHAVIORAL ISSUES SEEN IN INDIVIDUALS WITH CdLS?

Previous Research

Prevalence rate of 55.6% for significant self-injury (SIB) in people with CdLS (Oliver, Sloneem, Hall, & Arron, 2009)
 32% had physical aggression

• 41% had destruction of property

Examples of SIB in CdLS

Head banging Head hitting Self biting: fingers Hair pulling Eye poking Self scratching Skin picking Ear poking Face poking

Strongest risk factors for developing SIB are degree of intellectual disability, presence of a genetic syndrome, expressive communication deficit and age

Greater the degree of intellectual disability, the more self injury. Self-Injurious behavior is 4 times greater with severe-profound than mildmoderate intellectual disability.

Examples of other challenging behaviors in CdLS

- Aggression: hitting, kicking, biting, scratching, head butting, pinching, slapping, choking, hair pulling
- Property destruction: ripping, breaking
- Disruptive behavior: throwing objects, screaming, yelling, banging on surfaces
- Pica: ingesting inedible items
- Elopement: running from designated/supervised area
- Incontinence
- Noncompliance: passive refusal
- Dangerous behaviors: climbing, standing on furniture

What do we do about problem behaviors?

IT DEPENDS

Rule out medical/ physiological problems first

If there is pain/discomfort, treat the pain/discomfort

Safety Concerns

Risk of tissue damage

Risk of head injury

Risk of permanent damage from head directed SIB

Safety Precautions

Protective Equipment: not the only component of the treatment, seek professional input, develop a fading plan

Modified equipment

Medical Evaluations prior to assessment

New or Mild Problem Behavior

Add stimulating activities to the individual's schedule to rule out boredom as a factor

Identify how you are responding to the mild/new problem behavior

For chronic, ongoing problem behaviors.....

Why is the child engaging in the problem behaviors?
 One cause of increased problem behaviors is physical health conditions associated with pain and discomfort

Other potential factors influencing problem behaviors:

 attention, access to preferred items, escape from a demand, self -stimulation, anxiety, communication

MAY BE OTHERS AS WELL

Why is function important?

Understand why it's happening, so you don't make accidental mistakes

- Example 1. Yelling may make the behavior worse when the child just wants your reaction.
- Example 2. Time-out may make the behavior worse if the child just wants to get out of doing something

How do we figure it out?

Assessing the Function of Problem Behavior

Use techniques of Applied Behavior Analysis (ABA)

Functional Assessment

Develops hypothesis of function of problem behavior

Possible Hypotheses

- Self-Stimulation
- Access to Positive Social Reinforcement
- Access to Positive Tangible Reinforcement
- Reinforced by the removal of something

Functional assessment questions When does the behavior always occur? When does the behavior never occur? What happens before the behavior? What happens after the behavior? What is the individual trying to communicate to you? Does the individual seem to want a reaction from you following the behavior?

Does the individual use the behavior to get out of doing things?
 Does the individual have more of the behavior when he/she needs to wait for something?
 Does the individual engage in the behavior when he/she hereds to here the individual engage in the here there the here

behavior even if no one else is around?

Does the individual engage in the behavior in a repetitive fashion?

Functional Assessment

- Indirect Functional Assessments
 - Interviews
 - Functional Analysis Interview (O'Neill and Horner)
 - Questionnaires
 - Motivational Assessment Scale (MAS)
 - Questions About Behavioral Function (QABF)
- Direct Observation
 ABC data
 Scatter plot

What do we do now?

Define the behavior
 Clear
 Concise
 Observable

Example
 Aggression: hitting, kicking
 Self-injury: arm biting, hand biting

Measurement and Data Collection

<u>direct</u> measurement (*assess in actual situation*)

repeated measurement (evaluate change; don't continue ineffective program; don't discontinue effective program prematurely

Types of Data Collection

Frequency

record each occurrence of the behavior

Best Practice: convert to rate
 total behaviors/total time

 Ex. Aggression per hour, self-injury per day

can compare each day to another even if data collected at different times

Sample Behavior Data Collection Sheet

Name:

Please record the frequency of the targeted behaviors listed below.



Sample Data Sheet

Monday 8:30-2:00	<u> </u>	6/5.5 hours= 1.1 per hour
Tuesday 8:30-10:30		2/2 hours= 1 per hour
Wednesday 8:30-2:00		5/5.5 hours= 0.9 per hour

ABC Data Sheet

Date	Antecedent	Behavior	Consequence
1/2/03	Lining up for recess	Tantrum, 6 min	Delay to going outside
1/4/03	Walking down hall to bus	Hitting and tantrum, 12 min	Delay getting on bus

Functional Analysis

Manipulate environmental variables to demonstrate their effects on the behavior

Analog sessions to demonstrate function

Functional Analysis

Conditions

• Escape Attention • Tangible Alone • Toy Play • Any other potential function



The association between the environment and problem behaviors in CdLS does not differ from that seen in the broader population of intellectual disability (Sloneem, Arron, Hall, & Oliver, 2009).

Individuals with CdLS are not more or less likely to have behaviors associated with the environment than those without the syndrome

If the hypothesis is self-stimulation:

- Does the individual do this when s/he is bored?
- Does the behavior occur when alone?
- Does the behavior seem to be for pleasure?
- Does the behavior occur even in the presence of toys

If the hypothesis is to gain access to attention:

- Does the behavior get a response from someone?
- Does the individual try to use the behavior to get attention?
- Do people reprimand the individual?
- Does the individual engage in the behavior so you will come over to him/her?
- Does the behavior occur when you are already attending to others?

If the hypothesis is to gain access to a preferred item:

- Does the behavior happen when you remove an item from the individual?
- Does the behavior happen when someone else has a toy that the individual wants?
- Does the behavior happen when the inidividual wants you to get him/her something?

If the hypothesis is negative social reinforcement:

- Does the behavior happen when the individual is asked to do something?
- Does the behavior happen when the individual is asked to go somewhere s/he doesn't want to?
- Does the individual seem to be indicating that s/ he wants to be alone?

What is the cycle of problem behavior?

Cycle of Sensory Reinforcement

Self injury

Sensory Stimulation

Increase likelihood of self injury

Reinforcement

Cycle of Social Reinforcement

Problem Behavior

Attention is given (Positive Reinforcement)

Increase likelihood of self injury

Cycle of Negative Reinforcement

Task is presented

Problem Behavior

Increase Likelihood of problem behavior

Escape from task (Negative Reinforcement)

Now that we know the function, what do we do next?

Treatment Options

- Protective equipment
- Behavior Treatments
- Medication trials
- A combination of the above treatment options

Medication Trials

No single medication has been identified to target SIB or SIB in individuals with CdLS

Consult a psychiatrist with experience in CdLS or who is willing to consult with one

Behavioral Treatments

- Treatment strategies will depend on the function of behavior
- Start with one component at a time
- Add new components once behaviors have stabilized
- Change strategy if the treatment had no or little effect

Treatment Goals

Increase appropriate behavior

- Reinforce (strengthen) absence of behavior
- Teach and reinforce appropriate "replacement behavior"
- Increase availability of reinforcers in environment
- Improve academic compliance

Preference Assessment

To identify potential reinforcers for appropriate behaviors

Reinforcer = increases behavior

 Needed to assess preferences and potential "rewards" to include in treatment protocol



Proactive Treatment Options

Structured Schedule

- Leisure activities
- Teach pre-academic/Academic activities
- Teach/practice Activities of Daily Living
- Teach/practice play skills
- Social Stories
- Coping Skills
 - Deep breathing, relaxation training, squeeze balls, listening to music

Proactive Treatment Options: Redirection

Without commenting on the problem behavior, suggest something else to do

Praise the individual as soon as the engage in the other behavior

Proactive Treatment Options: Scheduled attention

- Differential Reinforcement of Alternative Behaviors
- Differential Reinforcement of Incompatible Behaviors
- Differential Reinforcement of Other Behaviors
- Non-Contingent Reinforcement (NCR): provide access to items or attention on a fixed schedule that is not based on behavior, i.e. every 10 minutes; NCA (noncontingent attention)

Another Treatment Goal

Decrease problem behavior

Extinction: Not providing the desired consequence

- Do the OPPOSITE of what the child wants through their behavior
 - Example 1. Child wants to get a reaction from you ⇒ ignore, or block and ignore the behavior

■ Example 2. Child wants to get out of doing something ⇒ ignore the behavior and keep going with the schedule ■ Example 3. Child wants something they can't have ⇒ tell them "no" calmly, ignore the behavior, and get them busy with something else

■ Example 4. Child seems to be doing it to get some kind of self-stimulation (that is causing tissue damage) ⇒ keep them busy and try to block the behavior; look for alternative way to gain that stimulation without causing injury Behavior maintained by physiological consequences

 Address physical problems: GI, sensory neuropathy, hyperactivity
 Includes self-stimulation, relief from discomfort

Behavior maintained by physiological consequences

 Provide alternative sources of stimulation: increase specific sensory reinforcement OR increase the general level of sensory reinforcement

Block and ignore behavior
 Teach toy play skills if absent

Behavior maintained by physiological consequences

Sensory Extinction: not allow the behavior to provide the sensory input; typically this involves using helmets and padding to cover the targeted area

Attention-maintained behavior

Teach child to request attention

- Functional Communication Training
- Picture Exchange Communication Systems
- Offer praise in the absence of problem behaviors (Differential Reinforcement of Other behaviors)
- Offer attention to specific positive behaviors (Differential Reinforcement of Alternative behaviors)

Attention-maintained behavior

- Ignore (look away, make no comments, walk away)
- Block and ignore (prevent behavior from occurring, but make no comment or eye contact)
- Time-out (remove child to isolated area, but provide no comment, eye contact, or other attention)

Behavior maintained by access to items

- State "no" once and continue with activity
- Provide no comment or other attention
- Teach child to request specific item or "more"
- Use a picture schedule to show when an item is available
- Use item as a reinforcer for other behaviors

Escape-maintained behavior Prompt through task despite behavior provide no comment or other attention Stop if necessary, but return to task once calm Teach child to request break or help Allow child to earn breaks Allow child to earn other powerful reinforcers Break task into smaller steps

Response Reduction Procedures

Brief, time-limited consequences added when initial interventions insufficient

Fade over time

Evaluate for quick effectiveness

School and Behavior Issues

Many children display problem behaviors in more than one setting

It is not atypical for a child to have more problem behaviors in one setting than in another

Schools need to play a role in developing a behavior plan

Behavior Plans in Schools

 If the child's problem behavior is impacting his/ her ability to make progress in the school setting, the school should complete a FUNCTIONAL BEHAVIOR ASSESSMENT

Usually completed by a behavior resource staff member, teacher or psychologist

 Once complete, the team uses the FBA to develop a BEHAVIOR INTERVENTION PLAN (BIP) FBA and BIP should be reviewed annually and modified if the plan is not producing a change in the behavior

BIP should state the behaviors that are to be increased as well as those to be decreased

Must include measurable data collection system

Evaluate routinely for effectiveness

PARENTS AND TEACHERS SHOULD WORK COLLABORATIVELY ON THE FBA AND BIP

STRATEGIES THAT WORK IN SCHOOL, MAY ALSO WORK IN THE HOME

CONSISTENCY ACROSS SETTINGS CAN BE VITAL

Conclusion

- Monitor individuals with CdLS for the development of problem behaviors
- Monitor the antecedents and consequences of the problem behaviors
- If any tissue damage (redness, swelling, etc), seek professional guidance
- Develop a communication system for the individual

Conclusion

- Identify the why the behavior is happening (FUNCTION)
- Record behavior data
- Implement the behavior plan consistently across people and settings
- Be persistent
- IT IS POSSIBLE TO DECREASE PROBLEM BEHAVIORS IN INDIVIDUALS WITH CdLS