# CdLS Foundation
# HOW TO ADDRESS CHALLENGING BEHAVIORS
# MAY 9, 2019

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

# OVERVIEW

- Behaviors common in CdLS
- What to do about problem behaviors
  - Assessment
  - Treatment

# IMPORTANT POINTS

- Challenging behaviors are not like diseases with one clear treatment path
- Causes vary widely
- 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

# BEHAVIORS IN CdLS

Behavioral problems such as:

- Self-injury
- Compulsive
- Repetitive
- Autistic-like behaviors
- Anxiety
- Obsessive Compulsive Disorder
- Attention Deficit Disorder with or without Hyperactivity

# Examples of SIB in CdLS



Head banging

Head hitting

Self biting: fingers

Hair pulling

Eye poking

Self scratching

Skin picking

Ear poking

Face poking

# Development of Self-Injury

- 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 mild-moderate intellectual disability.

# Prevalence in CdLS

- Prevalence rate of 55.6% for significant self-injury in people with CdLS (Oliver, Sloneem, Hall, & Arron, 2009)
- 32% had physical aggression
- 41% had destruction of property
- Prevalence did not increase with age

# 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

# ASSESSMENT OF BEHAVIORS

# FIRST STEP

Rule out medical/physiological problems first

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

# Use Applied Behavior Analysis

- Empirically based assessment and treatment
- Uses behavior principles
- Uses reinforcement and consequences to change behavior
- Can be used for communication, academic skills, social skills, challenging behaviors
- Across various diagnoses, ages, topographies, settings

# KEY ELEMENTS

- Consistency
- Objectivity
- Systematic evaluation
- Documentation of progress
- Use os well-researched techniques
- Adaptable to individual learners

# FUNCTIONAL BEHAVIORAL ASSESSMENT

- Indirect – interviews, questionnaires
- Direct Observation – ABC data
- Functional Analysis – manipulate environmental variables to demonstrate their effects on the behavior

# 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

# WHERE TO START:
# Data Collection

- Define the behavior – clear concise, observable
- Measure – take data

# Conduct a FUNCTIONAL ASSESSMENT

- To identify the variables maintaining the behavior
- Develops hypothesis of function of problem behavior
- Must know the function to develop an effective treatment

# COMMON FUNCTIONS

- ACCESS TO ATTENTION
- ACCESS TO TANGIBLE ITEMS
- ESCAPE FROM DEMANDS
- ESCAPE FROM NON PREFERRED ACTIVITIES
- AUTOMATIC

# FUNCTION OF BEHAVIOR AND CdLS

- 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

# QUESTIONS?
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# TREATMENT

# TREATMENT OPTIONS

- Medication Trials
- Protective Equipment
- Behavior Treatments
- Combination of the above

# 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

# GOALS OF TREATMENT

- Increase appropriate behavior
- Reinforce the absence of challenging behaviors
- Increase the availability of reinforcers in the environment
- Improve academic performance
- Reduce challenging behaviors

# 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

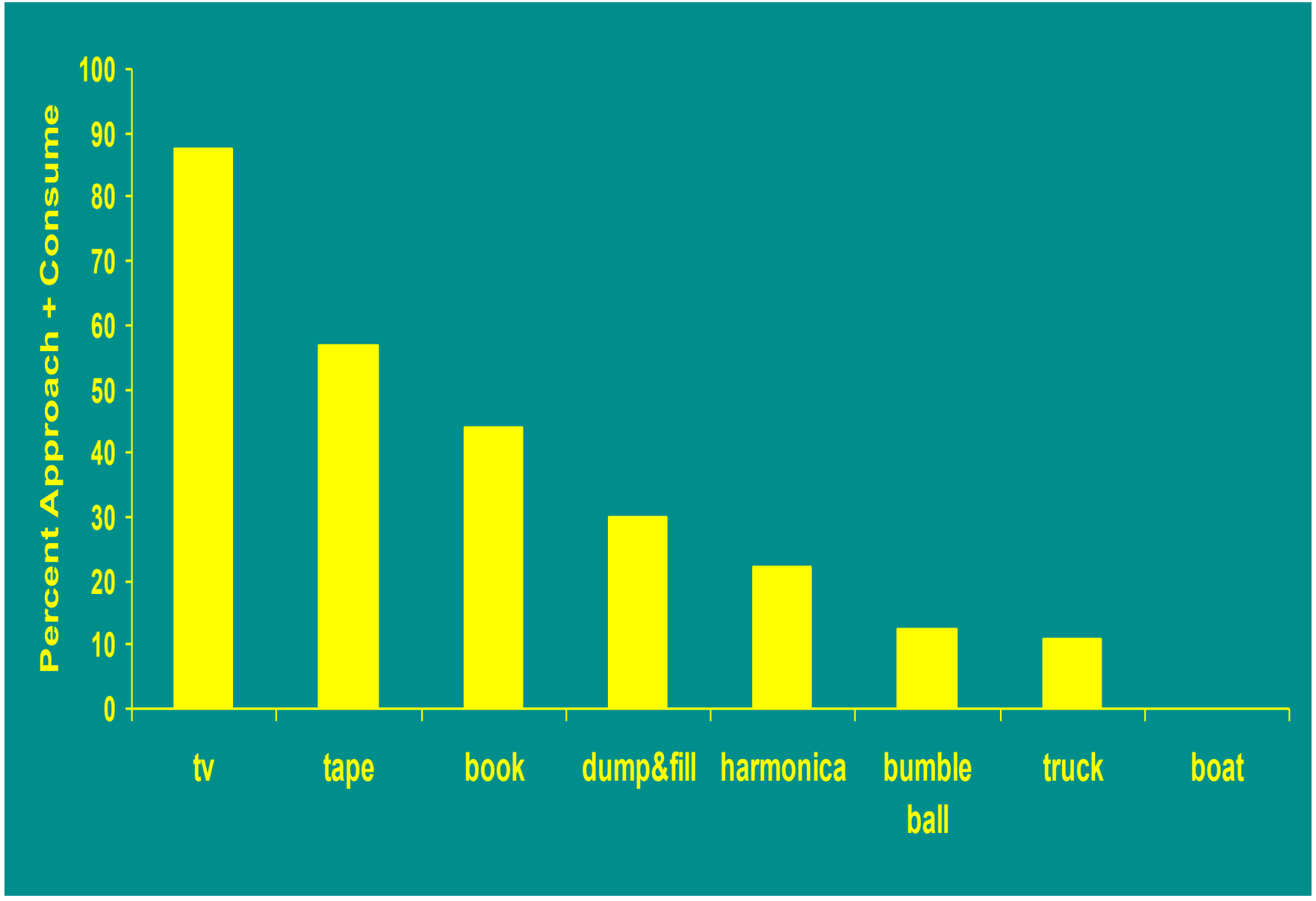
# New or Mild Problems

- 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

# PREFERENCE ASSESSMENT

- To identify potential reinforcers for appropriate behaviors
  - Reinforcer = increases behavior
  - Needed to assess preferences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truck
boat

# Proactive Treatment Options

- Structured Schedule
- 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)

# TEACH REPLACEMENT BEHAVIOR

- Functional Communication Training
- Leisure skills

# Prompting and Fading

- Prompt – ALWAYS FOLLOW THROUGH
- Reinforce
- Fade
- Monitor results

# Repeated Practice

Provide multiple opportunities to practice the skills in a variety of settings with a variety of people

# 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

- 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

- 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)

# 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

# Behaviors at School

- School is required to conduct a Functional Behavior Assessment (FBA) if the behavior is impacting progress in school
- Based on the results of the FBA, they would then 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

- Need to assess behaviors to determine the function
- Develop replacement behaviors
- Implement plan consistently
- Be persistent
- IT IS POSSIBBLE TO INCREASE APPROPRIATE SKILLS AND DECREASE CHALLENGING BEHAVIORS IN INDIVIDUALS WITH CdLS

# QUESTIONS?
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# THANK YOU