Behavioral & Educational Strategies

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<u>Outline</u>

1. General behavior management strategies for children with special needs.

2. Educational strategies for children with special needs.

3. Educational law and advocacy (time permitting)

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The following slides provide general suggestions to manage behavioral or educational concerns that may occur in children with one of the forms of Batten Disease. However, they are not a substitute for individualized services and care. They are also not "Batten-specific". We recommend that you consult with behavior / education specialists who know your child, before making changes to your child's behavioral or school plan.

General Behavior Management for Children with Special Needs

1. Defiance / Non-compliance
2. Tantrum vs. "Storm"
3. Aggression
4. Anxiety / Depression
5. Repetitive Thoughts / Behaviors

Some Goals of Behavior Management

A) Prevent (if possible) behaviors that cause problems for the child and/or others.

- Identify & modify or manage situations / people / settings that increase likelihood of negative behaviors.

- Provide child with skills (to extent possible) to engage in positive rather than negative behaviors.

B) Manage negative behaviors when they occur.

- Reduce severity, frequency

- Minimize negative outcomes to child & others

- Learn from the experience (child and/or others!)

Defiance / Non – compliance

Description / Examples...

- Refusing to follow parent / teacher requests

- Ignoring requests or 'testing' parent/teacher limits

- Rule – breaking behavior

- Back-talking, 'sassing'

"I'm not gonna, and you CAN'T MAKE ME"

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Defiance / Non – compliance

Strategies

"Look before you leap, and help the child look too…"

Assess the situation (what is going on in the child's environment?)

Give child <u>time</u> to make transition – provide a series of warnings (10, 5, 1 minute…)

Use "when...then" statements:
"When you finish this video, then it is time to set the table"

Defiance / Non – compliance

Strategies

"k.i.s.s."
(keep it simple & short)

Simple & short:
  "Please turn off the TV."

Not simple & short:
  "Please turn off the TV, come get these plates, and help your brother set the table, because we're eating dinner soon."

K.I.S.S.S. – "Keep it Simple, Short, and in Steps"

- Allow child to finish one step **before** giving next step of request:

  1. "*Please turn off the TV.*"

  2. *"Next, please come into the kitchen to help me."*

  3. *"Now put these plates on the table."*

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Defiance / Non – compliance

Strategies

"Time Out"

Time out is … time away from people / places / things that allow or encourage child to continue a negative behavior.

1 minute per age **_or developmental level_** of child, whichever is younger.

Choose quiet, non-distracting location.

Defiance / Non – compliance

Strategies

"Distraction"

Distraction = steer child to more appropriate or positive behavior, rather than get into discussion or limit setting about the negative behavior.

Example: Allie resists going to her room at bedtime.

Limit setting: *"If you're not in bed by the count of 3…[some consequence]*

Distraction: "*Oh, I remember that your favorite stuffed animal is waiting for you upstairs. Let's see if we can find it together."*

IMPORTANT: make sure that you offer a distraction that the child can continue doing if s/he wants (e.g., don't offer a video game at bedtime!)

Defiance / Non – compliance

Strategies

"Choice"

Provide Choice:

Examples:
> "It's time to get dressed. Do you want the yellow shirt or the black shirt?"

> "It's time to get in the car. Do you want your music or your game-boy for the drive?"

Note: Some children find "choice" overwhelming and may do better if you do not offer a choice:

Example:
> "It's time to get in the car. Here is your music player".

Defiance / Non – compliance

Strategies

"Pick your battles"

Pick your battles… Sometimes, you have to lose a battle in order to win the war…

Is the child's defiance going to get worse / last longer if I intervene or set a limit, versus letting it run its course?

…and pace yourself*: Do I have the time or energy to confront this particular behavior, at this particular time?*

What is the worst that will happen if I let it slide this time?

Defiance / Non – compliance

Strategies

"Read between the lines"

Read between the lines: Does "no" mean "No, I won't do it", or does it mean:

"(No), I'm not ready to shift gears yet."

"(No), this is too difficult for me to do."

"(No), I'm too tired/hungry/thirsty, etc."

"(No), I don't understand what you are asking me to do"

Try to respond to what the child might be feeling inside, rather than what s/he is simply saying. Communication problems may make it easier to say "no" than to express what is really happening.

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Defiant Behavior in the Classroom

- Behavioral treatment in school setting similar to the approach used in home with parents.

- <u>Specific school accommodations</u>
    - Provide structure and predictable routines (this will also help at home, extracurriculars, etc).

    - Use consequences and rewards, tied to specific behaviors.

    - Support child's use of classroom 'survival' skills (asking for help, taking appropriate breaks).

    - Physical environment (sound level, layout of room, etc.)

Aggressive Behavior

SAFETY FIRST !!!! (the child <u>and</u> others)

Different goals, different strategies:

1. <u>preventing aggressive behavior</u>
   - Try using strategies in prior slides (distraction, pick battles, etc.), if this will help the child remain calm, non-aggressive
   - Engage child to use appropriate management strategies
   - Plan ahead for situations, tasks, environments, people who may provoke the child.

2. <u>containing / managing aggressive behavior</u>

Aggressive Behavior

2. <u>containing / managing aggressive behavior</u>

- Establish a safety plan ahead of time – does child need to be removed from setting & if so, to what location?; who should interact with child? Does talking or touching the child make the situation better or worse?

- Principal goal is to contain the situation and prevent injury/harm to all concerned. All other goals (e.g., teaching a lesson about not hitting, getting child to apologize, discussing the situation, completing an activity) should be set aside until aggressive episode is over.

2. <u>Temper Tantrum vs. "Storm"?</u>

"A 'Tantrum' is purposeful. The object is to get someone to do something…

...a **'Storm'** is not future oriented or manipulated'*

<u>Storms may be...</u>
…kept under control (prevented) for long periods of time
…made worse by stress, fatigue, overstimulation
…caused by working hard to "keep it together" for too long

Sources: *L. Packer (2000); Sheryl J. Pruitt: "Teaching the Tiger"

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Before the Storm...

Rumbling Stage:

- child "seems stuck"

- verbal defiance, cursing may increase

- may become very upset or frustrated by small things

- may be "overly sensitive to environment"

- "demands or needs immediate gratification" (can't wait until till later, feels it is impossible to wait)

Sources: *L. Packer (2000); Sheryl J. Pruitt: "Teaching the Tiger"

"The straw that breaks the camel's back..."

A child might be pushed closer to the "storm" itself if…

- S/he feels trapped or unable to move freely to an "escape route", preferred quiet space, etc.

- S/he is moved from a space physically (is pushed, shoved, carried, guided by arm, etc).

- S/he feels stressed, frustrated, anxious.

- Other people raise their voice to regain control over situation.

Sources: *L. Packer (2000); Sheryl J. Pruitt: "Teaching the Tiger"

"The straw that breaks the camel's back..."

A child might be pushed closer to the "storm" itself if…

- Child is asked to 'shift gears' (physically or cognitively) more quickly than he or she is able.

- Physically uncomfortable (medication side effects, fatigue, hunger, too hot or cold, recent seizures, etc).

- Unexpected changes in routine.

- Student lacks skills to handle a situation (e.g., socialize w/peers, interact w/teachers, express his or her feelings, communicate verbally or otherwise.)

Sources: *L. Packer (2000); Sheryl J. Pruitt: "Teaching the Tiger"

During the Storm...

Child may be...

- "Disinhibited, impulsive, emotional...explosive"

Behaviors...

- "screaming, biting, hitting, kicking, destroying property or hurting self. Unable to verbalize or react in a rational manner"

- May be unable to listen to reason

Sources: *L. Packer (2000); Sheryl J. Pruitt: "Teaching the Tiger"

After the Storm...

- "Child may feel sleepy, feel remorse, and have only fragmented memories of the episode".

- "Don't push...the child...to learn or resume activities. Let them engage in a highly motivating task".

    The goal is to have the child re-engage appropriately – make it more likely that s/he will do so by providing a positive/fun activity. After s/he has done so, you can gradually introduce a new learning activity, or resume the activity that was in progress before the storm.

Sources: *L. Packer (2000); Sheryl J. Pruitt: "Teaching the Tiger"

Managing "Storms"

- Collaborate with family, friends, school, etc. to identify potential triggers.

- Modify environment / interactions, in order to reduce triggers.

- Give child leeway when making transitions.

Managing "Storms"

- Provide accommodations to students to reduce likelihood of outbursts:

  - quiet place to work.

  - extra time to switch classes; fewer class changes.

  - Avoid crowded / busy hallways (if this is a trigger)

  - rest period on tired days.

  - Flexible behavior / education plan: fewer / easier demands on days when child seems at higher risk for storms.

Managing "Storms"

- If child is capable, help her to discuss and take responsibility for 'storm', *after* it is over and child has had time to regroup.

- Be empathic. Recognize the child is doing the best he can, and may truly be "stuck".

- During rage attack, avoid further 'stimulus overload', such as attempting to reason with the child, asking him to make choices, etc.

Functional Behavioral Assessment

- Functional Behavioral Assessments (FBA) are useful for addressing defiance, storms, and aggression. They can be provided by school.

- FBA will identify any triggers and perpetuating factors for undesired behaviors (may be same or different).

- FBA will develop an individualized plan to manage or modify triggers & perpetuating factors, and provide a specific response plan when negative behaviors occur.

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Anxiety & Depression

If symptoms are...

- persistent
- severe
- interfere with child's functioning
- cause distress for child
- cause distress for family

- Work with your child's treating physician to obtain a thorough evaluation & treatment as needed.

Anxiety and Depression

- Anxiety / Anxious Mood:
  - *Worries , fears that go beyond what is reasonable for the situation and/or interfere with everyday functioning*
    - Also can include: irritability, nervous energy, sleep problems (difficulty falling asleep b/c of worries), loss of appetite, stomachaches, headaches, clingy-ness, problems paying attention (preoccupied w/worries)

- Depression / Depressed Mood
  - *Sadness, 'feeling blue'*
    - Also can include: irritability, fatigue, sleep problems (too much or too little), appetite changes (too much or too little), lack of interest in previously enjoyable activities, social withdrawal, slower processing speed

- It is not unusual for children & teens to seem more "irritable" or grouchy than sad or anxious.

Strategies for supporting a child with anxiety or depression

- Psychiatric (medical) evaluation to clarify diagnosis and determine any medical treatment (such as medication)

- Psychological (mental health) evaluation to clarify diagnosis and determine any psychological treatment (such as counseling, family support, social support, peer group, etc.)

- Individualized treatment plan as needed for child.

- Close monitoring, follow-up, relapse prevention planning

- Seek individual care – the suggestions that follow (next slides) are not specific treatment recommendations.
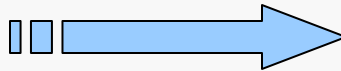
Strategies for supporting a child with anxiety or depression
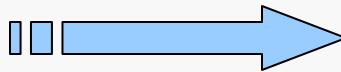
Slower processing speed

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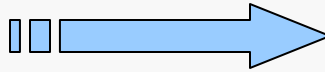
Provide extra time to complete tasks, give slower, shorter instructions.

May become easily overwhelmed

→

reduce demands, "be gentle"

May be reluctant to try new tasks / view tasks as "too hard"
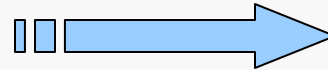
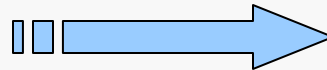→

support, encourage & praise; set step-by-step goals

Strategies for supporting a child with anxiety or depression

Memory Problems → Word banks, retrieval aids/cues, multiple choice tests & tasks
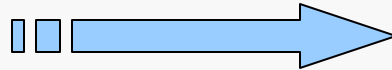
May "hang back" from interacting with peers → concrete, step-by-step guidance for interactions; peer 'buddy' or adult coach to facilitate interactions.
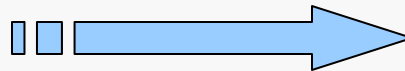
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Strategies for supporting a child w/anxiety or depression
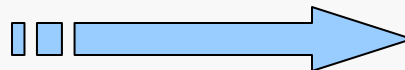
Low frustration tolerance $\longrightarrow$ empathic limit setting

Irritable / grouchy $\longrightarrow$ extra time for transitions, gentle but firm limit setting, don't insist child change her mood or attitude.

Fatigue (physical or mental) $\longrightarrow$ offer rest periods, break work into smaller chunks, adjust class schedule

Repetitive Thoughts / Behaviors

Strategies

"Take it slow & easy"

Slow & Easy:
Provide extra time to complete tasks or activities, but set overall time or production limit.

Allow child to return to a task later.

Provide ample warning for transitions.

Limit / control options to reduce overwhelming student with deciding among choices.

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Repetitive Thoughts / Behaviors

"Plan for success / Plan ahead"

Focus on child's strengths & tasks they find motivating / rewarding, but guard against inadvertently reinforcing repetitive thoughts/behaviors

Identify "triggers" to repetitive thoughts/behaviors, and remove triggers, as much as possible.

Be flexible & pick your 'battles'. For example, at school or in public settings, goal is to manage symptoms. It may not always be realistic to prevent or stop behaviors completely.

Repetitive Thoughts / Behaviors

"Be Creative!"

Be creative! If child has repetitive thought about something scary, work with child to 'banish' the scary thing (even if only temporarily).

Image courtesy of: http://www.flickr.com/photos/mamayaga/94739014/

Maintenance/Relapse Prevention

Work together to identify/anticipate barriers to maintenance

- Any situations/settings when it would be hard to use a certain strategy?

- Strike a balance between consistency and flexibility.

- Strategies may need to change as the illness changes over time….

Summary

- Pick your battles! (…and safety first!)

- Plan ahead: *[what will we do if…?]*. Have some game plans in your toolkit, but let yourself be flexible / creative as situations change.

- Be realistic (teachers, parents, etc): Behavior management should match the child's developmental level. Strategies will shift from helping child self-manage him/herself to managing the environment (people, places, etc), as JNCL progresses.

- Use incentives to reinforce positive behavior (yes, it is okay to "pay" a child to be good (everyone appreciates rewards!)

- Be consistent, but also be creative. If a strategy no longer is working, why? Is the child just having a bad day? Or has the disease progressed?

- Practice forgiveness.

Some more strategies for classroom or home management

- Mix low-interest tasks in with high-interest tasks to maintain student's engagement.

- Brief activities to fit child's attention span.

- Teach child more challenging material when s/he is most alert during the day.

- Teach <u>functional</u> and "how to" skills as well as academics...

- ...and if you can, do so while child still has some vision and still has a good ability to learn and master new skills.

Educational strategies for children with special needs

1. Structuring the classroom
2. Inattention & vision loss in the classroom
3. Restlessness in the classroom
4. Technology in the classroom

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Structuring the Classroom

- Preferential seating near teacher.

- Physically enclosed classrooms with less noise visual distractions.

- Well organized, predictable classroom routine (tactile chart for vision impaired child).

- Well organized physical layout, to aid in navigation around the room (for vision impaired child).

- Aides and teachers should provide support as needed, but also permit child do to things independently if child is able to do so.

Batten Disease(s): Inattention & Vision Loss in the Classroom

- Cue child to attend to important information.

    "Michael, listen carefully. This part is important."

- Present info in short/concise format. Provide tactile or sound cues if child has low vision / is blind.

    "This is a story about a boy who wins a contest."

    "*The boy's name is Charlie."*

    "First Charlie finds a golden ticket in a chocolate bar."

    "Then he gets to visit the chocolate factory."

    "*The factory is owned by Willie Wonka."*

- Repetition of information, to allow for fluctuations in attention.

Inattention in the Classroom

- Stop periodically to summarize key points.

  "*So far, this is what we know. Charlie won a contest to visit Willie Wonka's chocolate factory. He saw many interesting things there. Let's see if we can remember what he saw there?*

- Keep Instructions/Information Short & Simple & in Steps.

- Remove clutter and distractions from desk / workspace.

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Restlessness in the Classroom

- Allow child to move about / stand while working, if it does not interfere with attention / learning.

- Permit student to leave classroom to release extra energy.

- Provide extra space for child to 'wiggle' without disrupting classmates.

- Assign active jobs to child:
  - erasing blackboard
  - handing out papers

Technology & Environment: Reducing Stimulus Overload

- Close the classroom door, control sound / noise in classroom.

- Relaxation exercises & techniques.

- Note – know the child's 'overload' modality/modalities before making accommodations.

Technology & Education Resources

Technical Assistance ALLIANCE for Parent Centers

http://www.taalliance.org

Council for Exceptional Children

http://www.cec.sped.org/index.html

National Federation for the Blind: Technology Center

http://www.nfb.org/nfb/Technology_Center.asp?SnID=124740260

3. Educational law and advocacy

- How to get help at school

- The Committee on Special Education (CSE)

How to Get Help at School

Options available include

- Specific arrangements with classroom teacher

- Accommodations offered by Section 504 of the 1973 Federal Rehabilitation Act

- Special education services through the Individuals with Disabilities Education Act (IDEA; 1997, 2004)
  - Individualized Education Plan (IEP)
  - Developed by the Committee on Special Education, or CSE

Surviving the 504 Plan or C.S.E. (Committee on Special Education) meeting:

Before the meeting:

- Know the state & federal education laws. A public librarian can help you find what you need.

- Organize your child's file. Request copies from cumulative file (at school) and central file. Place all relevant info on your child in 3-ring binder, in chronological order (results from doctor visits, school evaluations, outside evaluations, etc.)

- Find out about any local education advocates.

Surviving the 504 Plan or C.S.E. (Committee on Special Education) meeting:

During the meeting:

Keep your cool. Don't allow CSE/504 team the luxury of dismissing your concerns because you come across as an "emotional parent".

Bring a photograph of your adorable child to the meeting. Place in middle of table so everyone is aware of who your child is.

Take notes. It is okay to bring a friend with you to the meeting to be your note-taker (usually you just have to let the CSE/504 team know ahead of time). You might also be able to tape-record the meeting.

Consultants, docs, and other experts on your child who cannot physically attend the meeting, may be able to join in by phone (arrange it ahead of time with the CSE/504 team)

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Surviving the 504 Plan or C.S.E. (Committee on Special Education) meeting:

During the meeting:

Bring a copy of the education laws to the meeting. Place on table in front of you, so CSE/504 team knows you are aware of them.

You do not have to sign the I.E.P. (Individualized Education Plan) or 504 Plan in the meeting, unless you reviewed it before the meeting and already approve of it. You are entitled to review the draft I.E.P./504 Plan and make comments.

For IEP's, know what you are entitled to (Parts A through D of education law).

Write down the names / roles of the people attending the meeting, so you can follow up with them later if necessary.

Surviving the 504 Plan or C.S.E. (Committee on Special Education) meeting:

After the meeting:

Review notes. Follow up with CSE/504 Chairperson if you are unclear on anything.

Review I.E.P. /504 Plan carefully. Make sure goals are realistic (both short & long term goals).

Talk with someone about how the meeting went (blow off steam, share a success, etc.)

IDEA: 4 Parts (applies to IEPs)

Part A)   General provisions, definitions

Part B)   Assistance of Education of All Children with Disabilities (I.E.P., etc).

Part C)   Infants & Toddlers with Disabilities

Part D)   National Activities to Improve Education of Children with Disabilities (includes teacher training)

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IDEA: Six Principles

1) Free & Appropriate Education (FAPE)

2) Appropriate Evaluations

3) Individualized Education Plan: contains info on:

        -student's present level of ability

        -short & long term goals

        -special ed & related services for student

        -student participation with other students, regular ed, extracurriculars

        -dates of service

4) Least Restrictive Environment (LRE)

5) Due Process

6) Parent Participation

"504 Plan"

Rehabilitation Act of 1973, Section 504:

Civil rights law, to prevent discrimination of individuals with disabilities, including providing children with equal access to education.

Can provide access to accommodations, classroom modifications.

Does not require the school to provide an I.E.P. that is unique to the child's own needs.

Fewer legal / procedural protections under Section 504 vs. IDEA.

"IEP" (Individualized Education Plan)

A legal document – a contract between you and the school.

Lists what special education services your child will receive, and why these services are educationally necessary.

Can be implemented, changed, or discontinued at any time, based on the needs of the child.

IEP's are not "written in stone", but changes must be approved by school & parents. An IEP can be changed at any time, if a child's educational needs have changed. To revise or update an IEP, put your request in writing to the Committee on Special Education (CSE) which develops and monitors IEPs.

What goes into an IEP?

Will include

- Your child's educational classification (the category of need your child falls into. "Other Health Impairment" often used for child with a medical condition.
- What type of classroom placement & the teacher-to-student ratio
- Services (e.g., one-to-one aide, counseling, speech therapy, occupational therapy/physical therapy, etc.)
- Academic & behavioral goals, and how progress will be measured
- A behavior plan, if needed
- Transportation plan
- Any medical alerts
- Progress reports from educational team.
- Start and end date of services. IEPs must be reviewed and renewed on an annual basis.
- A comprehensive review must take place every three years "Triennial Review"

IDEIA: 2004 Amendments

(Individuals with Disabilities Education Improvement Act)

Understand what is the same (from 1997) and what has been changed / updated since 2004.

For example….

Since 2004, "discrepancy" or "difference" between IQ and achievement no longer required to classify a student with learning problems

Since 2004, much <u>greater</u> responsibility on parents to know the education law and be active in their child's education.

Schools may not always offer a service up-front, but may wait for parents to ask for it specifically.

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For more information about education law & advocacy:

"Understanding the Individualized Education Plan"
http://www.telability.org/handouts/TelAbilityHandoutIEP04.pdf

Wrightslaw website (clearinghouse of information on educational law & advocacy:
www.wrightslaw.com

Links to the various sections of education law (IDEA & IDE-IA)
http://www.wrightslaw.com/idea/law.htm

Links to state-based resources & State Departments of Education
http://www.yellowpagesforkids.com/help/seas.htm

References

1. Atkins, Pelham, 1992; 68-88;

2. Barkley RA & Cunningham CE, *Archives of General Psychiatry,* 1979 pp. 201-208

3. L. Packer (2000); Sheryl Pruitt: "Teaching the Tiger"

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6. Special education slides, adapted from K. Bjoraker.