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Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

Learning when to treat repetitive behaviors in autism

by [Clare Harrop](#), [Connie Kasari](#) / 10 November 2015

Autism spectrum disorder involves two core deficits: problems with social communication and restricted and [repetitive behaviors](#). Although therapies for improving critical social communication skills have advanced rapidly, researchers are less clear on whether and when to intervene for restricted and repetitive behaviors.

This conundrum arises from a considerable lack of understanding about why these restricted and repetitive behaviors (RRBs) develop, the mechanisms underlying them and how to manage them. Some of the behaviors may have hidden benefits for people with autism. For example, hand flapping can help children with autism cope in new or anxious situations or better communicate when they are frustrated.

As a result, uninformed attempts to halt these behaviors may not be successful or welcomed by individuals with autism. Instead, we should work with families to find a happy medium between acceptance and change. This approach is likely to include thinking about alternative ways to fulfill the need that prompted the original behavior.

RRBs are present in various neurodevelopmental disorders but are considered a hallmark feature of autism. The term defines a wide range of idiosyncratic actions, including stereotyped movements, repetitive self-injury, compulsive or ritualistic behaviors, insistence on sameness, repetitive language, and unusual or intense preoccupations.

These behaviors fall into two categories. So-called 'lower-order' RRBs typically include repeated motor actions such as hand flapping and sensory manipulation of objects such as peering at objects from different angles. 'Higher-order' RRBs are more cognitive in nature and include routines, rituals, insistence on sameness, and narrow and intense interests.

Continued on page 2.

REPETITIVE BEHAVIORS CONTINUED...

POOR PROGRESS:

These behaviors occur early in individuals with autism and are often red flags for clinicians and researchers¹. Studying the emergence of RRBs in children with autism can be difficult, however, given that some of the behaviors are similar to those present in typical early development. Repeating certain actions with toys and uttering the same sounds or words over and over again is a normal part of infancy and toddlerhood and considered vital for developmental progress. Although these early behaviors look similar in children with autism and typical children, in those with autism they do not decline as quickly and interfere much more.

Determining how to deal with these behaviors in autism is crucial because they can impede learning and restrict social opportunities. Studies have found that an increased rate and severity of RRBs can track with poor outcome in a wide array of skills, such as language and play development².

RRBs can create social problems as well. Intense interests often interfere with a child's ability to socialize, because other children cannot relate to them, leading to further isolation.

Motor RRBs can be even more concerning to parents and caregivers from a social perspective than defined social deficits are, as these unusual actions can be obvious and off-putting to others. A boy who talks insistently about road signs may be viewed as quirky and a girl who does not make eye contact considered shy. But a child who is flapping his or her hands or rocking back and forth may really stick out as odd, and caregivers feel the stigma associated with these behaviors.

What's more, caregivers are often at a loss for how to deal with these behaviors in the moment. Attempts to redirect the child can make the situation worse, as children can become agitated or aggressive and occasionally hurt themselves or others.

Caregivers report feeling stressed by these behaviors and unsure how best to respond to them. Unfortunately, clinicians cannot confidently prescribe an intervention, as there are few established ones for these behaviors^{3,4}. Common strategies include blocking, redirecting and teaching alternative behaviors. These techniques can be successful in the short term but can also have negative repercussions, such as self-injury, and are not proven long-term solutions.

ANXIETY RELIEF:

People with autism often feel differently from those who care for them, however. At the [2015 International Meeting for Autism Research](#) in Salt Lake City, Utah, [Robyn Steward](#), a visiting research associate at The Centre for Research in Autism and Education in London and a person on the spectrum, presented her research on why adults with autism 'stim,' or engage in self-stimulating motor RRBs such as twirling, hand flapping or rocking.



According to Steward, adults with autism may stim to calm themselves down and relieve anxiety. When such behaviors involve self-injury, she said, intervention is often necessary. But in other cases, rather than try to stop this behavior, the best strategy is to find other ways for that individual to relieve stress, she says.

Steward says motor RRBs can also serve to communicate excitement or frustration. In those cases, any attempt to diminish these behaviors should be accompanied by alternative ways to communicate those same emotions.

In some instances, certain higher-order RRBs, such as an intense interest in Japanese anime or the video game Minecraft, can facilitate social interaction instead of hindering it, allowing a child with autism to find common ground with her peers. In some cases, narrow interests have helped people with autism develop social communication skills and even find employment opportunities.

Continued on page 3.

REPETITIVE BEHAVIORS CONTINUED....

COACHING CAREGIVERS:

With young children, teaching caregivers to implement an intervention shows the most promise, particularly for addressing social-communication behaviors. So far, only a few small studies have taught caregivers to address RRBs in their children^{5,6}. In a study we conducted this year, we sought to establish a baseline for interventions by determining how caregivers respond to RRBs naturally, without any training⁷.

We looked at the ways in which caregivers react to their child's RRBs while they play together. We found that caregivers naturally ignore about half of these behaviors but try to curtail others that seem to affect their interaction with their child.

In particular, caregivers do not acknowledge some of the most obvious motor or verbal repetitive behaviors, such as repeating words or hand flapping. Yet they frequently redirect a child when she is engaged in visual self-stimulatory behaviors such as the close inspection of objects or repetitive play with an object — for example, pressing buttons over and over. Knowing how caregivers instinctively respond gave us an excellent starting point for thinking about the best ways to train parents to help their children.

Earlier this year, researchers from Newcastle University in the U.K. tested a short-term 16-hour caregiver training program they call Managing Repetitive Behaviors⁵. The researchers taught 25 caregivers how to identify triggers for RRBs and when and how to intervene. Another 20 caregivers received the intervention at a later date and were the comparison group. The researchers delivered the training in a group setting, allowing for opportunities for support and sharing of experiences and strategies between caregivers. Caregivers identified target RRBs to work on and videotaped the behavior at home.

Following the training, caregivers rated how confident they felt in dealing with these behaviors, and researchers examined how well the caregivers were able to redirect and potentially reduce their child's RRBs.

In this small sample, the researchers reported that the trained caregivers were more confident than the untrained ones about their ability to redirect RRBs effectively at the right time. The participants also rated the training as useful and practical. The caregivers reported that their child's behaviors improved, but the researchers did not see as much of an effect. That may be because of a placebo effect or because caregivers consider many more situations across the child's life than researchers have access to.

To know when and how to intervene with RRBs, we need to better understand why these behaviors occur as well as how they may change over time. We need large controlled studies to evaluate how well evidence-based interventions for autism generally affect the behaviors. Those that focus on social skills and communication rarely include measures of potential change in RRBs.

Sometimes, RRBs subside on their own. Others, however, are more entrenched and require targeted intervention. Some persist throughout adulthood despite attempts to ameliorate them at a younger age. In the end, Steward may be right that it's best to leave them alone until we can provide definitive answers and proven interventions.

Connie Kasari is professor of human development and psychiatry at the University of California, Los Angeles. Clare Harrop is a postdoctoral fellow at the University of North Carolina at Chapel Hill.

<https://spectrumnews.org/opinion/viewpoint/learning-when-to-treat-repetitive-behaviors-in-autism/>



Sweeping study underscores autism's overlap with obsessions

by [Ann Griswold](#) / 3 December 2015

The largest study of people with autism and obsessive-compulsive disorder (OCD) to date adds to mounting evidence that the two conditions share genetic roots¹.

Compared with their typical peers, people with autism are twice as likely to receive a diagnosis of OCD and people with OCD are four times as likely to also have autism, according to a Danish study of more than 850,000 people. The findings were published 11 November in *PLOS ONE*.

The disorders don't just intersect in individuals: When OCD runs in a family, autism does too.

"We also see that at the familial level, when you have at least one parent with OCD, their offspring have a higher risk of autism," says lead investigator [Sandra Meier](#), assistant professor of business economics in the NCRR-National Centre for Register-based Research at Aarhus University in Denmark.

The disproportionate number of autism diagnoses among the children of people with OCD supports the idea that the two conditions share a genetic predisposition, says [Evdokia Anagnostou](#), associate professor of pediatrics at the University of Toronto. These results suggest that clinicians should look carefully for signs of autism in individuals who have OCD and vice versa — information that could inform treatment choices.

Symptom similarities:

To make their discovery, Meier and her colleagues mined the [Danish Psychiatric Central Research Register](#), a database of records from every Danish resident who received psychiatric care through the nation's public healthcare system dating back to 1969. The registry contains medical details of roughly 855,000 people and their 3.9 million outpatient and inpatient visits.

"There's almost 100 percent coverage" of the Danish population, says [Per Hove Thomsen](#), clinical professor of psychiatry at the Psychiatric Hospital for Children and Adolescents at Aarhus University. Thomsen published related findings on children with OCD earlier this year but was not involved with Meier's study².

The researchers identified 18,184 people with autism, 11,209 with OCD and 739 with both. Of the individuals with both conditions, 253 were diagnosed with autism first, 281 were diagnosed with OCD first and 205 received both diagnoses at the same time.

The fact that nearly one-third of children who have both conditions received the OCD diagnosis first is surprising because OCD symptoms typically emerge after puberty. Autism, by contrast, usually surfaces before age 5. This reverse diagnostic sequence suggests that children with OCD typically have subtle autism symptoms that are recognized only later in life, perhaps after traditional OCD treatments fail.

Earlier this year, Thomsen's group reported that up to 17 percent of Danish children with OCD display mild symptoms of autism.

Children with OCD are less likely to have severe autism with cognitive impairment — not because this combination is incompatible, but because of how OCD is diagnosed. "We cannot make the diagnosis in people who cannot tell us what they're thinking," Anagnostou says. Clinicians typically make an OCD diagnosis after people recognize and articulate thoughts as being obsessive.



OBSESSIONS CONTINUED.....

Behavior therapies:

The overlap between the two disorders suggests their common symptoms have genetic underpinnings. Children with both conditions rely on [repetitive behaviors](#) to calm their anxiety, for example. Increasing evidence suggests the two conditions stem from the same genetic variants, including one for JMJD2C, an enzyme involved in stripping chemical tags off DNA³.

However, in many ways, autism and OCD are distinct conditions. People who have autism struggle with social communication, whereas those with OCD have no such difficulties: They tend to engage in compulsive behaviors to ward off obsessive thoughts, rather than to relieve social angst.

Still, if the two disorders share a common biology, treatments for one might be useful for the other. A meta-analysis published in June found that modified forms of cognitive behavioral therapy — an effective treatment for OCD — alleviate anxiety and repetitive behaviors in people with autism⁴.

Some researchers [discourage interventions](#) intended to curtail repetitive behaviors in people with autism, because those behaviors may relieve the individuals' anxiety or offer other benefits. But rituals such as hand washing are not necessarily calming, and when they start to hinder a child's development and social functioning, strategies to ease them may be warranted, Meier says.

"If you treat these behaviors, the child could probably spend less time with the ritual," Meier says. "This might increase their social ability so they could spend more time trying to talk to people."

<https://spectrumnews.org/news/sweeping-study-underscores-autisms-overlap-with-obsessions/>



LBL ESD AUTISM RESOURCES

Did you know that LBL ESD has amazing autism resources?

If you go to the LBL ESD website and click on the Cascade Regional Autism section you will find resources available in your community. A short cut link to the Autism page is <https://www.lblesd.k12.or.us/cascade-regional-program/autism-program/>

On the Cascade Regional Autism page there is a brief description of what LBL ESD Cascade Regional Autism program offers and a resource section. In our resource section we have four tabs: Teacher & Parent Resources, Professional Development, Local Resources & Services and Autism Agenda Newsletter. Each section is full of a variety of resources and supports to help individuals, families and communities. If you come across a resource or service we do not have on our website please let us know so that we can add it to our list. In addition, if you have an area of need that we do not have resources, please let us know and we will add it. We love your suggestions to improve the website!



CHALLENGING BEHAVIORS TOOL KIT

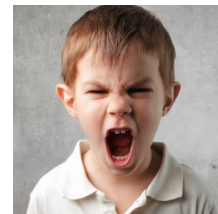
Snap Shot of the Autism Speaks “Challenging Behaviors Tool Kit” Purpose and Scope of this Tool Kit

Challenging behaviors represent some of the most concerning and stressful features of autism. These behaviors can often cause harm or damage, family and staff stress, isolation, and caregiver burnout. Parents may feel guilty or responsible, but it is important to know that you should not blame yourself for behaviors that you find difficult.

Sometimes, the extraordinary steps parents go through for their children with complex needs might not be enough, and additional supports and resources might be necessary. It is important not to think of your child, or these behaviors, as ‘bad,’ but to learn how to better understand and respond to challenging situations to make them more manageable for everyone. Hopefully this kit will help provide you with strategies and resources, and lead you to professionals within your community.

For the purposes of this tool kit, we classify challenging behaviors as behaviors that:

- are harmful (to the individual or others)
- are destructive
- prevent access to learning and full participation in all aspects of community life
- cause others to label or isolate the individual for being odd or different



Challenging behaviors can occur throughout the lifespan of an individual with autism. The core and associated symptoms of autism can adjust over time and as a result, many individuals with autism experience changes at various stages of life that might result in new behaviors. An individual's behavior can often vary considerably even minute by minute in response to internal (such as stomach pain) or external (people, places, noises, activity levels, etc.) issues. In addition, many individuals with autism experience other associated concerns and co-occurring (co-morbid) conditions that can layer on additional concerns, such as those described here and here.

As time passes, families and caregivers adapt to meet the needs and demands of their loved ones. At times their responses and expectations can drift into a place that becomes difficult for everyone. These feelings often increase stress levels and may even limit access to their own friends and community.

Sometimes as children age and become stronger, challenging behaviors can reach crisis levels. Many families who have previously managed the trials presented by autism might experience crisis situations when their child hits older childhood or the teenage years. This may be because the challenges have grown as the child becomes bigger and stronger, or because of new factors that accompany growing up or puberty. To address more significant concerns that might create risk to the child or others, later in the kit there is section to help with Managing a Crisis.

The guiding principle used in developing this kit is that each individual with autism and his family should feel safe and supported, and live a healthy life filled with purpose, dignity, choices, and happiness. With this in mind, positive approaches and suggestions are highlighted throughout the kit. The general framework and intervention principles included are relevant at any stage of life, and we have included basic background information, with links to further information and resources on a variety of topics.

“When James reached age 18, he was 6’2” and 210 pounds, and strong. He was learning that aggression was an effective way to avoid tasks that he didn’t like because it worked – I was afraid of him. Every morning when I asked James to make his bed, he would usually begin doing it correctly but would often make mistakes. When I told him that he had made a mistake, he would start biting himself and hitting me, so I would back away and leave the room. But this allowed James to escape the task of making his bed and taught him (and me) that his aggression worked! With a little help from a behavioral consultant, I decided that whenever James began to get upset while making his bed, I would prompt him to say, “Help me please.” It was explained to me that this behavior served the same purpose as his aggression and self-injury. When James asked for help, I’d give him some assistance, which made us both a lot less frustrated.”

– AG, mother

Please access the Toolkit at http://www.autismspeaks.org/sites/default/files/challenging_behaviors_tool_kit.pdf

What Are Repetitive Behaviors in Autism?

Repetitive Behaviors Are Part of Autism, But They're Not Always a Problem

By [Lisa Jo Rudy](#) | Reviewed by [Joel Forman, MD](#)

Updated February 14, 2018

Repetitive, purposeless behaviors are almost always a symptom of autism. In fact, many parents worry about autism when they see their child repetitively lining up toys, spinning objects, or opening and closing drawers or doors. Repetitive behaviors can also involve saying, thinking about, or asking about the same thing over and over again. In rare cases, repetitive behaviors can actually be dangerous; more often, though, they are a tool for self-calming.

They can become a problem, though, when they get in the way of ordinary activities or make it tough to get through school or work.

"Stereotyped" (Repetitive) Behaviors Are Part of Autism

Practitioners and researchers call repetitive, apparently purposeless behavior "stereotypy" or "perseveration," and such behaviors are actually described as symptoms of autism in the DSM-5 (the official diagnostic manual):

Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. *Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, [echolalia](#), idiosyncratic phrases).*
2. *Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).*
3. *Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).*



What Do Stereotyped Behaviors Look Like?

Repetitive behaviors in autism can vary radically from person to person.

For some people, it involves saying or talking about the same things over and over again (for example, listing all the Avengers and their powers, reciting scripts from TV, or asking the same question many times in a row). For others it involves physical actions such as repetitive rocking, flicking, or pacing. In more severe autism, stereotyped behaviors can be violent; head banging, for example, is a stereotyped behavior. Some people on the autism spectrum engage in repetitive behaviors constantly, while others only occasionally perseverate (get stuck in a behavioral routine) when they're stressed, anxious or upset.

Many people with autism feel very anxious when asked to change their routine or schedule. In some cases, a regular routine is nearly invisible to the casual observer. After all, most people have a morning and evening routine, and many follow a fairly inflexible schedule during the day. In other cases the routine is unusual in one way or another. When a person with autism is asked to change a routine, the response can be extreme anxiety or upset, even if the person is very high functioning.

Sometimes perseverative or stereotyped behaviors are obvious because they are so marked or unusual.

Often, however, particularly with high functioning autism, perseveration may not be obvious to the casual observer. A person with autism may, for example, ask "Do you like Marvel movies?" Upon hearing that the answer is "yes," the autistic person may then run through the same speech about *Iron Man* that he has run through ten times before, in exactly the same words, with exactly the same tone and gestures. As a parent, you might know the speech backwards and forwards, but as a new friend you might not even notice the repetition.

Continued on page 8.

LEARNING TO WRITE CONTINUED....

Are Repetitive Behaviors a Problem?

Of course, perseverative behaviors are not unique to people with autism.

Most people engage in some such behaviors. Nail biting, pacing, pencil or toe tapping, compulsive cleaning, or even a "need" to watch the same TV shows or sporting events without fail are all forms of perseveration.

For some people with autism, the problem of perseveration is really no problem at all, since it only arises at the same times as it would for other people (usually under stress) and the behaviors are fairly unobtrusive. Perseveration can even be a plus for people with autism, since it may relate to a passionate interest that can lead to friendships or even careers. An individual who is perseverative in his interest in computer games, for example, can join gaming clubs where she'll find others with a similar passion.

For many people with autism, though, perseveration or repetitive behavior is not only disturbing to others, but it's also a major roadblock to communication with others and engagement in the world. A person who compulsively flicks his hands to the exclusion of anything else is clearly unable to attend to the world around him or take part in real-world activities. And while there is nothing intrinsically wrong with talking about the same subject in the same way over and over again, such behavior can cause a variety of social and practical problems.

Causes of and Treatments for Repetitive Behaviors in Autism

No one really knows what causes perseveration in people with autism, though there are a variety of theories. Depending on the theory you espouse, you are likely to select a particular treatment (or no treatment at all). Of course, if a behavior is dangerous or risky it must be changed. Some treatments have been more fully researched than others, but all have had some success with some individuals and less success with others. For example:

- If you believe perseveration is a behavioral issue, you are likely to use [behavioral techniques \(rewards and, in some cases, consequences\)](#) to "extinguish" the behavior.
- If you believe repetitive behaviors are a self-calming technique used to block out too much sensory input, you are likely to use [sensory integration techniques](#) to help the individual self-calm and regain a sense of control.
- If you believe perseveration is a manifestation of real interests on the part of the person with autism, you are likely to use therapeutic techniques such as Floortime or SonRise to connect with the autistic individual and help him turn perseverative actions into meaningful activities. For example, a person who lines up toy engines can often turn his repetitive actions into symbolic play, and can even build on his perseverative interest to develop social skills.
- If you believe perseverative behavior is caused by anxiety or a chemical or neurological issue, you are likely to attempt to control the behaviors through the use of [pharmacotherapy](#).

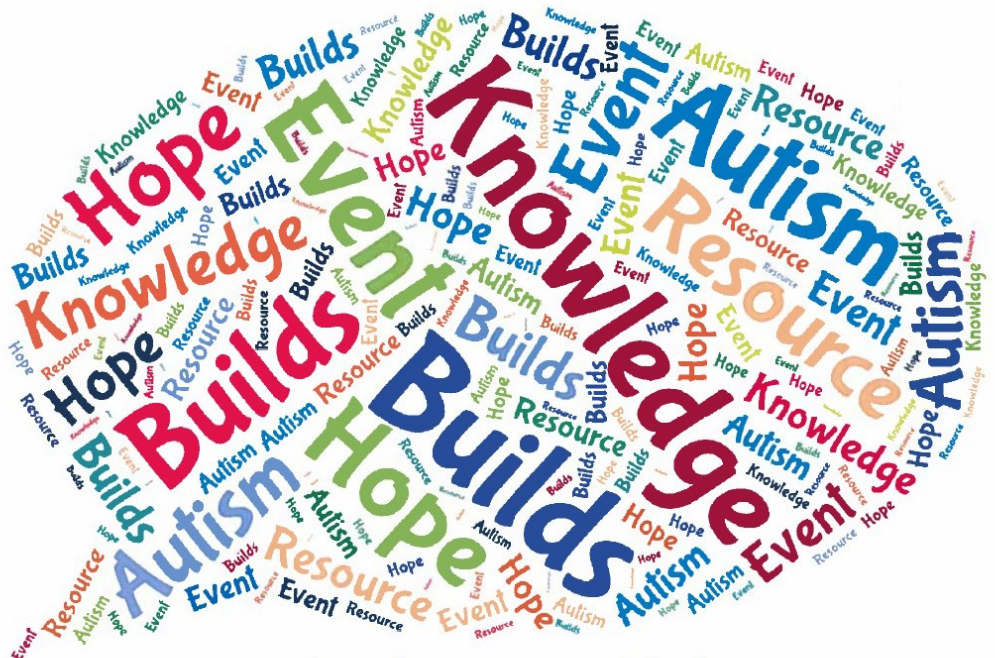
A Word from Verywell

As a parent, you may be embarrassed or put off by your child's repetitive behaviors. Before taking action to "extinguish" them, however, it's important to understand the purpose they serve. If they are really helping your child to stay calm, manage sensory challenges, or otherwise handle the demands of daily living, you'll need to support your child as he or she modifies or expands upon his routines. That may mean finding a therapist to work with your child, or modifying your child's environment to make it less challenging.

<https://www.verywell.com/repetitive-behaviors-in-autism-260582>



Linn Benton Lincoln Education Service District and the Cascade Regional Autism Staff
present our Third Annual Autism Resource Event



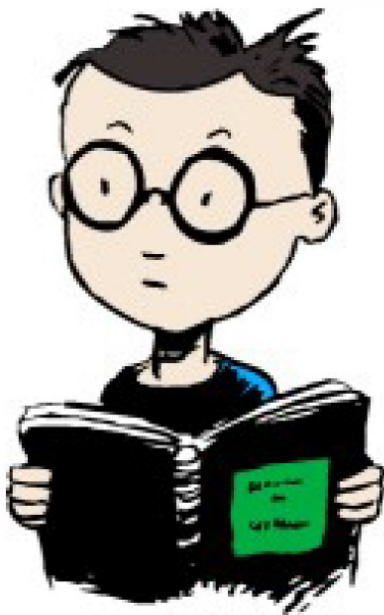
“Knowledge Builds Hope”

April 12, 2018

4:00-7:00PM

5pm Guest Speakers Dawn and Russ McUne
 “Autism - A Family Perspective”

Philomath Elementary School Gym
239 S. 16th Street
Philomath, OR 97370



This event will offer you an opportunity to see what community resources are available to support individuals with autism.

Here is a sample of who will be available to meet and visit with you:

- | | | |
|--------------------|----------------------------------|--------------------|
| * FACT | * Resource Connections of Oregon | * Support Groups |
| * Dental Hygienist | * Developmental Disabilities | * Social Groups |
| * OFSN | * Vocational Rehabilitation | * Physical Therapy |

If you have any questions, please contact: Michelle Neilson 541-812-2678 or michelle.neilson@lblestd.k12.or.us

BOOK REVIEWS

Plausible Answers to the Question: “Why Do They Do That?” For Parents and Teachers Who Need Solutions to Some Common and Not-So-Common Questions About Young Children’s Behavior

by Glenda Fuge, Paul Pitner, and Kirsten McBride

This is a hands-on reference for parents, caregivers, and teachers that takes a unique approach to the behaviors of children with ASD and other special needs that often dismay and puzzle adults. Using a practical and reader-friendly format, the book presents a behavior, such as crying, on a two-page spread with clear and easy-to-read sections such as: *Question*, *Plausible Answers* (does it stem from social, sensory, communication issues), *Basic Training* (suggestions for what to do), *Over and Above* (further ideas, who to consult in serious cases, etc.), *Red Flags* (first signs that the behavior needs attention), and *What’s Next* (possible follow-up). Applicable to children up to five years old.



“Just Give Him the Whale!”: Ways to Use Fascinations, Areas of Expertise and Strengths to Support Students with Autism

by Paula Kluth

When learners with autism have deep, consuming fascinations—trains, Minecraft, whales—teachers often wonder what to do. This concise, highly practical guidebook gives educators across grade levels a powerful new way to think about students' "obsessions" as positive teaching tools that calm, motivate, and improve learning. Teachers will discover how making the most of fascinations can help their students learn standards-based academic content, boost literacy learning and mathematics skills, develop social connections, expand communication skills, minimize anxiety, and much more. *Just Give Him the Whale!* is packed from start to finish with unforgettable stories based on the authors' experience, first-hand perspectives from people with autism themselves, research-based recommendations that are easy to use right away, and sample forms teachers can adapt for use in their own classrooms.





Linn Benton Lincoln ESD Cascade Regional Autism Program

905 4th Ave SE
Albany, Or. 97321

Tel: 541- 812-2600
Fax: 541 926-6047
E-mail: webmaster@lblesd.k12.or.us

Autism Consultants:

Skye McCloud- skye.mccloud@lblesd.k12.or.us
541-336-2012

Sue Taylor– sue.taylor@lincoln.k12.or.us
541-574-3744

Melissa Bermel– melissa.bermel@lblesd.k12.or.us
541-812-2773

Amanda Stenberg– amanda.stenberg@lblesd.k12.or.us
541-812-2676

Scott Bradley– scott.bradley@lblesd.k12.or.us
541-812-2677

Michelle Neilson– michelle.neilson@lblesd.k12.or.us
541-812-2678

SENTENCE STARTER VISUALS

