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Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

The benefits of special interests in autism

Researchers are studying how the intense passions of autistic people shape the brain, improve well-being and enhance learning.

BY EMILY LABER-WARREN 12 MAY 2021

The first time Autumn Van Kirk noticed a computer was in her kindergarten classroom — it was an Apple 2, and she could not keep her hands off it. “I was playing with it one day. I was, like, ‘Hey, check this out. There’s little knobs and buttons and stuff. What do these do?’” The teacher ran over and said, “What are you doing? You can’t touch that!” Van Kirk recalls. Her parents got a talking to as well. But it would have taken a lot more than that to discourage Van Kirk’s interest in technology. She built a computer from stray parts when she was 13 or 14, and in college, she programmed a website that she ran from a server in her closet. Today she is a team leader for a top global tech company in Houston, Texas.

Van Kirk, 38, has leveraged one of the hallmarks of autism, an intense and often narrow focus on a specific topic, into a career. She is not alone. Livestock industry consultant Temple Grandin and automobile restorer John Elder Robison are famous for turning their special interests into careers. And in response to a 2020 Twitter post by autistic blogger Pete Wharmby — “Anyone #autistic managed to make a living from a special interest?” — dozens of people responded that their passions had led to jobs as diverse as librarian, TV producer, tattoo artist, train conductor and paleontologist.

But it’s only in the past decade or so that autism professionals have begun to recognize the value of these intense interests that emerge in early childhood. Clinicians have historically called them circumscribed interests, and they belong to the category of diagnostic criteria for autism called “restricted, repetitive patterns of behavior, interests or activities,” which also includes movements such as hand-flapping and an insistence on rigid routines. A distinguishing aspect of special interests is their intensity: They can be so absorbing that they are the only thing the person wants to do or talk about.

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THE BENEFITS OF SPECIAL INTERESTS IN AUTISM CONTINUED....

These interests are extremely common among people with autism: 75 to 95 percent have them. An interest may involve collecting items such as postcards or dolls, listening to or playing music in a repetitive way, or focusing intensely on a narrow topic, such as insects fighting. Special-interest topics may be commonplace — things such as trains, gardening or animals — but people on the spectrum sometimes gravitate toward more quirky fascinations such as toilet brushes, tsunamis or office supplies.

Whatever the subject, interests may hijack family life, and children may throw tantrums when parents try to redirect them. The sister of one autistic man complained in a 2000 study that his interest in maps “swallow[s] up everything, all the time. We can’t talk about anything else.” Teachers and therapists frequently discourage interests out of a belief that they distract from schoolwork and make it harder to fit in with peers.

But research conducted over the past 15 years is revealing what many people with autism have long known — namely, that special interests are valuable to people on the spectrum. In addition to occasionally launching a career, they reliably build self-confidence and help people cope with emotions. Studies also suggest they can help autistic children gain social skills and learn.

“The real paradigm shift is thinking about special interests as more positive.” Rachel Grove

This research is also changing the scientific understanding of what special interests are. Experts used to consider them an avoidance activity, something autistic people did to manage negative emotions such as anxiety. But increasingly, studies reveal that these interests are intrinsically rewarding. “There’s been a lot of negative language used around special interests, things like ‘inflexible’ and ‘obsessions,’” says psychologist Rachel Grove, a research fellow at the University of Technology Sydney in Australia. “The real paradigm shift is thinking about special interests as more positive.”

Instead of trying to erase or squelch special interests, teachers and clinicians are starting to leverage them. Educators are working them into the curriculum. Psychologists are finding ways to mitigate the problematic behaviors associated with interests without discouraging the interests themselves. And neuroscientists are beginning to probe how the brain processes special interests, to better understand the neural circuitry involved.



Special interests can dramatically improve children’s life skills, as journalist Ron Suskind revealed in his 2016 documentary, “Life, Animated,” about how his son Owen’s passion for Disney movies helped him learn to speak. Experts hope that the research on interests will help many more children who can be otherwise hard to reach. “Sometimes you hear this phrase, ‘To meet the child where the child is,’” says neuroscientist John Gabrieli of the Massachusetts Institute of Technology. “If this is their natural motivating capacity, then rather than try to suppress it, it might be more helpful to the child to build on it.”

Its own reward:

The Autistic Self Advocacy Network describes special interests as “narrow but deep.” The drive to engage with them is powerful. For example, in a 1996 study that used various rewards to discourage disruptive behaviors, young children with autism preferred access to their special interest over favorite foods. And in a 2014 study of 76 adults with Asperger syndrome, people reported spending an average of 26 hours per week on their interests. “There is nothing typical about this involvement,” says psychologist Mary Ann Winter-Messiers of Bushnell University in Eugene, Oregon. “A lot of people who have never seen it, they’ll say, ‘Well, all kids have hobbies.’ No, this is not a hobby; this is completely different.”

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THE BENEFITS OF SPECIAL INTERESTS IN AUTISM CONTINUED....

In autistic children with intellectual disability, special interests may take the form of repetitive behaviors such as lining up objects, whereas for those without intellectual disability, these interests can become areas of precocious competency. Some special interests are transient, others lifelong. Bill Davies, professor of acoustics at the University of Salford in England, who is autistic, says he was always interested in sound. “As a kid, I was very into patterns of words, rhymes, bits of tunes. I liked repeating them,” he says. “When I found out you could do a whole degree in acoustics, I didn’t want to study anything else. I still don’t.”

A 2020 study of nearly 2,000 children on the spectrum showed that they had, on average, eight special interests at a time. Van Kirk estimates she has had about 100 so far. “They often interweave with one another,” she says.

“This is not a hobby; this is completely different.” Mary Ann Winter-Messiers

She and others say they often sacrifice sleep, forget to shower, and lose track of important tasks in pursuit of their interests. “It can potentially be distressing, because it’s like I literally cannot stop thinking about the first three years of the French and Indian War [or] whatever that thing happens to be,” Van Kirk says. “It’s this thing that gives us a lot, but it can eat up a lot of our spare cycles, if you will, our compute cycles.”

Nevertheless, studies increasingly suggest that the majority of autistic people feel enriched, not controlled, by their interests. One of the first researchers to explore the potential benefits of special interests was Winter-Messiers. Instead of relying solely on the observations of parents, teachers or clinicians, as most investigators previously had, she wanted to learn about special interests from autistic people themselves. In a 2007 study, her team conducted in-depth interviews with 23 children and adolescents with Asperger syndrome, during which the researchers made careful notes on body language, self-stimulating behaviors, facial expressions and tone of voice.

Winter-Messiers and her colleagues found that talking about special interests reduced other autism traits. For example, children who spoke at first with flat affect became enthusiastic when discussing their special interest. They fidgeted less, made more eye contact, and their speech shifted from vague comments such as “Uh, I don’t think so, I just, whatever,” to complex, vocabulary-rich statements. Many of the young people were also better able to initiate conversation and organize their thoughts. “We found it across every single major area of deficit,” Winter-Messiers says. “It was incredible.”

“
I strongly recommend that students with autism get involved in special interest clubs in some of the areas they naturally excel at. Being with people who share your interests makes socializing easier. ~Temple Grandin

Subsequent research indicates other benefits to special interests. For instance, in a 2017 study of 80 adults with autism, 65 described their special interests as positive, 74 considered them calming, and 77 felt strongly that children’s special interests should be encouraged. They used words such as “lifeline” to describe the role their interests played in their lives. And in a 2018 study, Grove and her colleagues found that special interests are tied to improved subjective well-being in adults with autism and increased satisfaction with social contacts and leisure time. “Our special interests are the air that we breathe,” Van Kirk says. “When we’re engaged in special interests, we’re living our best lives.”

A 2015 study by Grove’s team points to a potential basis for this positive effect. She and her colleagues developed a survey to understand what motivates autistic people to engage with their interests. The questions measured both intrinsic motivation — an inner drive or curiosity — and extrinsic motivation, a desire for recognition or tangible rewards. The team asked 610 people, 158 of whom were autistic, to rate statements such as “I like the feeling of being totally immersed in my special interest” and “When I do well at my special interest, I feel important.” The autistic people were more intrinsically motivated than the non-autistic people, the researchers found. The autistic people also more often reported feeling a sense of ‘flow.’ For them, engaging in an interest was its own reward.

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THE BENEFITS OF SPECIAL INTERESTS IN AUTISM CONTINUED....

That is the experience of Mariana De Niz, 33, an autistic microscopist at the University of Lisbon in Portugal. De Niz became fascinated by pathogens while growing up in Mexico City, Mexico. When she was a little girl, officials launched a public information campaign to eradicate cholera. “I found it super interesting,” she recalls, “I became sort of obsessed.” In her current research, De Niz studies *Trypanosoma brucei*, the sleeping-sickness parasite. She is known for making compelling images that require a degree of patience some of her colleagues say they could never muster. She often spends hours following a single *T. brucei* and capturing its most ephemeral movements. She gets so absorbed in the experience that she often forgets to eat, and her ophthalmologist says she is wearing out her eyes. “It’s this world that I go into,” she says. “I just feel that time doesn’t pass.”

Taking up real estate:

The drive that people with autism bring to special interests is akin to a non-autistic person’s focus on personal relationships, says neuroscientist Kevin Pelphrey of the University of Virginia Brain Institute. “Looking at other people, looking at their faces, reading emotions — that’s something that for the vast majority of typically developing people, they’re born with it, and then they develop a high level of expertise and never stop adding to it throughout development,” Pelphrey says. This consuming focus on other people could conceivably fit the definition of a special interest, Pelphrey says, except that it’s “not very special because it’s one that everybody does.”

The parallel between ordinary sociality and autistic fascination may have a biological basis, Pelphrey says. Multiple areas of the human brain evolved to manage social cues and relationships. “That’s a lot of real estate,” he says. A new hypothesis suggests that if an autistic child is born without the pull toward people, those brain areas adapt to focus on objects or concepts instead. Scientists know that the brain can divert unused structures to other purposes. For example, in blind people, the area usually dedicated to sight can rewire to manage a tactile activity: deciphering Braille.



Preliminary research hints that the brain’s reward system in people with autism may be calibrated to respond more to interests than to the interpersonal experiences that most non-autistic people find gratifying. In a 2018 experiment, 39 autistic and 22 non-autistic children played a game inside a magnetic resonance imaging machine. When a child scored, she received either a social reward — a video of a smiling actor giving a thumbs up — or a video showing her personal interest. The two sets of children were equally good at the game, but the non-autistic children had stronger brain responses for the thumbs up than the autistic children did, and less brain activation for their own interest. “It was what we call a double dissociation,” says the study’s lead investigator Benjamin Yerys, a child psychologist at the Children’s Hospital of Philadelphia in Pennsylvania, “where one group is really high with one kind of stimulus, and the other group is very high on the other one.”

Further evidence suggests that social brain regions are dedicated to special interests. In a 2016 study, researchers scanned 21 autistic and 23 non-autistic boys while they viewed images of their own or others’ special interests or hobbies. They found that a part of the brain called the fusiform face area that is typically responsive to faces seems in autistic children to be oriented instead toward special interests. In the study, this brain region was slightly more active in the brains of autistic than non-autistic people, says study investigator Jennifer Foss-Feig, a psychologist at the Icahn School of Medicine at Mount Sinai in New York City — only it was responding to Lego Bionicles, dirt bikes and other special interests, rather than faces. The finding is in line with the idea that the fusiform face area’s role is broader than face recognition, that it governs recognition of any object about which a viewer has expertise.

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THE BENEFITS OF SPECIAL INTERESTS IN AUTISM CONTINUED....

In the same experiment, Foss-Feig's team found a clue to why special interests may be so all-consuming. Both groups of children showed a heightened response to their own interest, compared with others' interests, in brain regions governing emotion, which likely underlies the interests' rewarding qualities. But the brain's 'salience network,' which directs attention, became much more active in the children with autism in response to images of their interests. "The degree to which [special interests] suck the attention away is higher, which may be one reason why these interests may be more interfering," Foss-Feig says. Indeed, the researchers found that the children whose salience network engaged the most were the ones whose parents reported that the special interest posed the most intense difficulties for day-to-day living.

A deeper neuroscience question remains: Do special interests fill an absence, engaging social brain areas that might otherwise be idle, as one hypothesis suggests? Or are autistic people simply born more oriented toward certain objects or ideas, and because of that orientation are less inclined toward the social world? "It's sort of like a chicken-and-an-egg question," Foss-Feig says. The next step for this research, she says, is to design studies that follow autistic children from infancy, scanning the brain at intervals to learn how it responds to social and nonsocial stimuli over time.

Teaching tool:

Whereas neuroscientists are just beginning to explore the biology of special interests, educators have been experimenting with them for more than 30 years. In a 2016 study, researchers examined 20 studies, dating as far back as 1990, in which teachers used students' special interests in the classroom. In some of the studies, teachers used special interests as a reward for good behavior, and in others, they incorporated special interests directly into the curriculum. The researchers found that all of the tactics were successful, but that students fared best when their interest was integrated into learning.



In one case, a second-grade teacher gave a student books on Thomas the Tank Engine, her special interest, and in a couple of months, the child's reading comprehension had improved from a first- to a mid-second-grade level. In another instance, teachers used a child's interest in the Titanic to teach social skills, using the phrase "Iceberg right ahead!" to reinforce the importance of keeping one's distance. The tactic helped this boy remember not to stand too close to classmates.

Preliminary results from an ongoing brain-imaging study by Gabrieli's team support the potential utility of special interests as an educational tool. The team has been brain-scanning children with and without autism while they listen to stories written by the study team that are about either their specific interest — soccer, dragons and the like — or nature. So far, the researchers have tested 20 children. For the autistic children, listening to a story about their special interest activated key language regions in the brain much more strongly than hearing a nature tale. Because much of the learning that takes place at school is auditory, Gabrieli says, the results suggest that working a special interest into a lesson could be a way to engage children with autism.

Using special interests in the classroom is not yet standard. But at P.S. 32 in Brooklyn, New York, where autistic and non-autistic children learn together, teachers routinely incorporate special interests, and they see both academic and behavioral benefits. For example, a 6-year-old girl whose interest was outer space had trouble stopping what she was doing to move to the next activity. Her teachers turned the girl's folder into a rocket ship, cutting off the corners and drawing bolsters, a cabin and flames. "I would say, 'Okay, I'm opening the hatch; the work needs to go inside and board the rocket ship, blast-off in 10,'" says teacher Jenny Licata. "Transitions are not a problem anymore, because that's fun."

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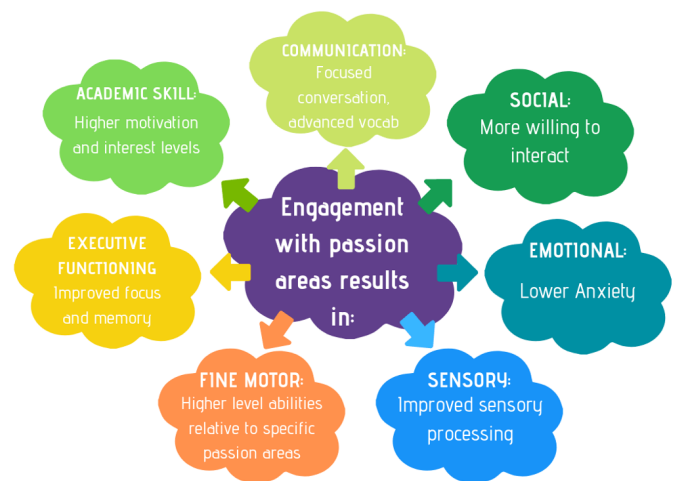
THE BENEFITS OF SPECIAL INTERESTS IN AUTISM CONTINUED....

“If this is their natural motivating capacity, then rather than try to suppress it, it might be more helpful to the child to build on it.” John Gabrieli

Teachers say special interests help children connect more with peers, and some evidence supports this observation. In a 2012 study, researchers designed school lunch clubs around the interests of three children with autism (movies, comics and card games) and advertised them to classmates through announcements and flyers. The children with autism had been socially isolated, but when they met with these clubs, they interacted with peers 85 to 100 percent of the time.

Some teachers balk at encouraging special interests, out of concern children will become distracted, says Shari Boylan, a special-education master teacher at P.S. 32. That notion does not make sense, she says, because these interests are often on a child’s mind anyway. “You can’t withhold a child’s special interest when their special interest is in their brain,” she says. And discouraging a special interest can cause distress. In a 2000 study, a boy who was fascinated with the calendar described how he felt when his interest was devalued. “I was so much knocked down, in the sense that my passion with time was just a waste of time,” he said.

In 2019, psychologist Alan Smerbeck of the Rochester Institute of Technology in New York developed a survey designed to untangle the positive and negative aspects of special interests. The 68-item questionnaire can flag difficult behaviors surrounding an interest — such as pursuing it at the expense of other important tasks, or not valuing other people’s interests — so that these can be addressed without discouraging the interest itself. The answers to the survey might suggest, for example, that a child needs to learn to talk less with peers about her interest, to avoid being teased or bullied and build stronger relationships. “Rather than making the goal to reduce the interest, we can make the goal to reduce the problem,” Smerbeck says.



Special interests may offer long-term practical benefits, says Kristie Patten, associate professor of occupational therapy at New York University. In a 2017 survey her team conducted, 62 percent of respondents said their interests had helped them succeed in life, and 86 percent reported that they are working in a job or studying in a program that incorporates the interest. “We have pathologized some of these things with autism that really, if we flip them and view them as strengths, the outcomes are going to be so much better,” she says.

In a professional context, the accumulation of specific, eclectic knowledge can be invaluable. Van Kirk once solved a catastrophic security problem for one of her company’s corporate clients by noticing a tiny anomaly in reams of code. “I remember those weird, obscure little things that you only see three or four times in a career,” she says. “And people come to me for those skills.”

Research shows that beyond such practical benefits, a special interest often has deeper value. “It reduces stress. It helps the person to calm down when they’re upset,” Smerbeck says. The top-rated item on his survey? “These interests seem to make my child genuinely happy.”

<https://www.spectrumnews.org/features/deep-dive/the-benefits-of-special-interests-in-autism/>

THE POWER CARD STRATEGY

The Power Card Strategy: Behavior Management and Social Skills Development for Children on the Autism Spectrum

Adapted from article on www.myaspergers.com

The Power Card Strategy is an effective way to teach behavior management and social skills to young children on the upper end of the autism spectrum.

Kids on the autism spectrum tend to have highly developed special interests, so this strategy capitalizes on those interests as a motivational force toward positive behavioral changes.

The Power Card Strategy involves visual aids that incorporate the youngster's special interest to teach appropriate social skills, including behavioral expectations, routines, the meaning of language, and the "hidden curriculum" (refers to the set of routines, social rules, tasks, or actions that neurotypical kids readily understand, but people with ASD need to be explicitly taught).

In addition, the strategy can be used to aid in generalization, to clarify choices, to teach another's perspective, and to teach cause-and-effect between a specific behavior and its consequence.

The strategy consists of two basic parts:

1. A brief scenario or character sketch describing how a hero solves a problem
2. The "power card," which recaps how the youngster can use the same strategy to solve a similar problem.

In part one, a brief script of the special interest and the situation being addressed for the child created. The script is written at the child's comprehension level and includes relevant pictures or graphics. Initially, the script is read on a scheduled basis as the child learns to use the power card.

Darth Vader wants to play with other Jedi's at recess, but he does not know how to ask. He stands near a game but the Jedi playing do not know he wants to play. When Darth Vader does play a group game, he gets very angry when he is "out". He argues with other Jedi's and sometimes pouts and shouts.



RECESS
Yoda Wisdom

- Keep your hands to yourself.
- Say, "Can I play with you?"
- Do not use your finger as a gun or weapon.
- If you play a group game, make sure you know the rules before you play.
- If you are "out", then wait for a new game or inning.

In part two, the actual power card is created.

It is the size of a trading card and includes a small picture of the special interest and the solution to the problem situation broken into three to five steps. The card is created from the script and is carried by the child.

Below is an example of the use of the Power Card Strategy written for Michael, a 5-year-old boy with Asperger's who tends to act-out aggressively when he loses a game. This behavior was demonstrated in a variety of situations both at home and school. The following scenario was created featuring Teen Titans Go (Michael's special interest) with the three steps to success on the reverse side of the picture:

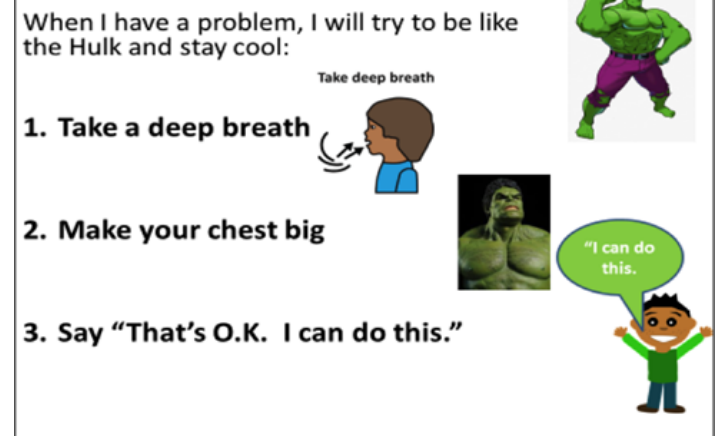
The Teen Titans love to play games. Sometimes they win, sometimes they don't. When they win, it makes them feel very happy. They smile, give each other a high five, and say "Hooray!" But, sometimes they lose games. When they lose, they may not feel very happy. But, they take a deep breath and say "good job" to their friends. The Teen Titans want everyone to have fun while playing games, whether they win or lose. The most important thing is to have fun. They want you to remember these three things when playing games the Teen Titan way:

1. Games should be fun for all kids.
2. If you win a game, you can smile, give a high five, or say, "Hooray!"
3. If you lose a game, you can take a deep breath and say "good job" to your friends.

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THE POWER CARD STRATEGY CONTINUED...

Here are some other examples:



In summary, when parents or teachers utilize the Power Card Strategy, they will need to (a) identify the unique or special interest of the child with ASD, (b) write a scenario describing how a hero solves the problem in question, and (c) create a power card to generalize the expected skill.

For more information, see the book, [The Power Card Strategy 2.0: Using Special Interests to Motivate Children and Youth with Autism Spectrum Disorder](#), or go to https://www.ocali.org/project/resource_gallery_of_interventions/page/power_cards for more examples, templates and resources.

SUMMER SUGGESTIONS

Online Summer Camps: <https://www.kidscamps.com/online-camps.html>

Design the Perfect playroom: <https://productdiggers.com/autism-playroom/>

Summer Activities for Individuals with Autism or Sensory Processing Disorders:

<https://www.easterseals.com/explore-resources/living-with-autism/summer-activities-for-kids-with-autism.html>

Museums, Zoos and Theme Parks with virtual visits:

<https://www.goodhousekeeping.com/life/travel/a31784720/best-virtual-tours/>

Virtual Field trips you can take from home:

<https://www.today.com/parents/try-these-virtual-field-trips-educational-fun-home-t176105>

Must Try Indoor Activities for kids at home:

<https://littlebinsforlittlehands.com/indoor-activities-for-kids/>

Parents Guide to teaching play skills:

<https://mission-cognition-share.com/wp-content/uploads/2018/04/A-Parents-Guide-Teaching-Play-Skills.pdf>

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SPECIAL INTERESTS

Special interests can potentially benefit individuals with autism

When he was in middle school, teachers would give Sam Curran a list of words to type in a computer to practice his vocabulary. But Sam, who has autism, was unable to stay focused on the task and required a significant amount of one-to-one direction from a teacher to complete his work. After his mother, Alicia, persuaded his teachers to allow Sam to change the colors of the words, he was able to complete work more independently and began making remarkable progress.

Now 20 years old, Sam's mother continues to ensure his special interests are leveraged in an effort to continue to help him grow and develop. A new survey from the MU Thompson Center for Autism and Neurodevelopmental Disorders has found that similar strategies for children with disabilities can help reduce anxiety and improve mental health.

Kerri Nowell, a pediatric clinical psychologist at the MU Thompson Center, together with colleagues Stephen Kanne, Cynthia Brown and Courtney Jorgenson, developed the survey for caregivers of youth with autism to assess various special interests they may have and determine if those special interests were interfering with the child's development. After analyzing nearly 2,000 responses, in addition to possible reductions of anxiety and improvements of mental health, Nowell found that many caregivers also recognize the child's special interests as outlets that can potentially benefit them in social interactions or future employment and educational opportunities.



"I think there might be misconceptions out there about people with autism," said Nowell, who is also an assistant clinical professor in the MU School of Health Professions. "We know a lot of kids with autism get really focused on a particular thing, and while some may view a special interest as an oddity or cause for concern, the special interest can actually help reduce the child's anxiety and be used as a positive reinforcer or educational opportunity."

For example, Nowell suggests if a child is particularly fascinated with a specific television show, the parent or caregiver may consider using the show as a reward if the child completes a less desirable task like cleaning their room or finishing their homework. If a school assignment requires writing about a specific topic, the child can write about their special interest as a way to incorporate their passion into their schoolwork.

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SPECIAL INTERESTS CONTINUED.....

"Are there ways we can use this research to develop interventions where we can capitalize on their special interests and maybe modify them in a way that serves to their advantage? In middle school when students start learning about how to use the local library to conduct research, perhaps we can use that as an opportunity to incorporate their special interest in a way that supports their development and helps them become engaged members of society."

Kerri Nowell, Pediatric Clinical Psychologist, MU Thompson Center

Sam's mother, Alicia Curran, added that if parents, educators and health care providers can be creative and find a spark that motivates individuals with autism or neurodevelopmental disabilities, they may be surprised by what they can unlock.



"We as parents often make the mistake of thinking our children might not be capable of doing something," Curran said. "What I have learned is that you have to find the hook, something that ignites their motivation, and not only will they perform better, but you will find out that there is so much more potential that can be unlocked in the population of individuals on the autism spectrum. When Sam was able to change the colors to whatever he wanted--boom. He was suddenly able to complete the task with minimal oversight."

Since the autism spectrum is so wide, Nowell's research is also aimed at better evaluating and diagnosing kids with autism, which can potentially lead to defining specific subsets of autism down the road as researchers learn more about how the neurodevelopmental disorder presents itself in different populations.

"My over-arching goal is to try to get a really good, in-depth understanding of what it means to have autism and all the different ways it can look," Nowell said. "The research is geared toward better supporting those with autism so they can be as successful as possible as they get older."

Source: [University of Missouri-Columbia](#)

Journal reference:

Nowell, K.P., *et al.* (2020) Characterization of Special Interests in Autism Spectrum Disorder: A Brief Review and Pilot Study Using the Special Interests Survey. *Journal of Autism and Developmental Disorders*. doi.org/10.1007/s10803-020-04743-6.

<https://www.news-medical.net/news/20210115/Special-interests-can-potentially-benefit-individuals-with-autism.aspx>

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ALEXIS' STORY

Real Stories from People living with Autism Spectrum Disorder

Alexis' Story

Alexis Wineman is the first woman with autism spectrum disorder (ASD) to participate in the Miss America competition. Alexis was in middle school when officially diagnosed with PDD-NOS (Pervasive Developmental Disorder- Not Otherwise Specified), but felt “different” from an early age. As she got older, she struggled with some of the challenges that come with having ASD, such as a speech impediment, communication difficulties, and being sensitive to loud sounds, and other sensory-related issues. Alexis also had to deal with bullying that occurred because of her differences. Fortunately, her family has always been a source of strength and inspiration for her. We interviewed Alexis, her mother Kimberley, her older brother Nicholas, and her older sister Danielle, and her twin Amanda to hear more about the unique role that siblings play in families living with ASD.



Alexis' Perspective

Prior to being diagnosed with autism, neither I nor my family had an explanation for my meltdowns and other issues. After the diagnosis, it was incredible how my siblings reacted. They were superheroes. They took me everywhere and pushed me into activities. They helped me with homework. It was just amazing how they sprang into action after years of not knowing what was going on.

My advice for other individuals with autism would be to have patience for your siblings just like they have patience for you. It's good to try and figure out what's going on from their perspective rather than focusing on yourself.

Kimberley's Perspective

Once Alexis was diagnosed and we knew what we are dealing with, her siblings took control. They shoved her into things and got her involved. They wouldn't let her use autism as a crutch or excuse for not being involved. Her brother got her into cross-country and her sisters got her into cheerleading. All three siblings got her into speech and drama. Had she not been involved in those activities, she wouldn't have been able to accomplish all that she has accomplished. Alexis was able to find activities where she was accepted, and she wouldn't have found those on her own.

Her siblings also became very protective and helped with the teasing and bullying. Siblings can be such a positive force for combatting bullying. They can educate the peer group. That's something a sibling can be much more effective at than a parent.

My advice for someone who has a sibling with autism would be to engage them and help them find their niche.

Continued on page 12.

ALEXIS' STORY CONTINUED....

Nicholas' Perspective

Before Alexis was diagnosed, we just didn't understand why she was acting out. It was very confusing and frustrating. After the diagnosis, things made a lot more sense. Being able to help and take preventive measures, it was a whole new world. It has made us all better people. We learned patience.

It was a common occurrence that we would get into fights, but being able to make up and process what happened was different for Alexis compared to the rest of us. With Alexis, when the fight was over, the board was erased clean. In other words, five minutes later everything was completely back to normal. It seemed like she was doing it to annoy you, but she wasn't. Not understanding why it was so easy for her to get over a fight was hard. Going through experiences like this makes you have to be more understanding. You learn that people handle things differently.

My advice for someone who has a sibling with autism would be to practice empathy. I consider myself to be empathetic and living with Alexis was a huge part of that.

Danielle's Perspective

My brother and I had to do some growing up fast. You have to take on a parenting role when you're trying to understand what's going on. From the time she was diagnosed, it opened our eyes to understanding people with disabilities. We have openness to people with differences and are able to maintain that empathy. We've grown up having to deal with all levels of ups and downs.

I played a second mom when Alexis was younger. If she didn't listen to mom, I'd go in and say the same thing. Sometimes it's easier to have someone on her level explain things or give her the opportunity to vent.

My advice for someone who has a sibling with autism is that you have to become a solid shadow for your sibling. They might not fully understand how much you are putting in to be there for them. At the end of the day, each success, no matter how small, is part of you. You deserve to celebrate too. When you're diagnosed with autism, it's a diagnosis for the entire family and not just that person. It's really a test of family.

Amanda's Perspective

Having a twin is how we figured out there was a problem. There was a direct comparison to a neuro-typical child, and they could see that Alexis wasn't meeting milestones the way I was. When I was little, whenever I came home from school, I tried to teach her to do things that I had learned so that she could keep up with me.



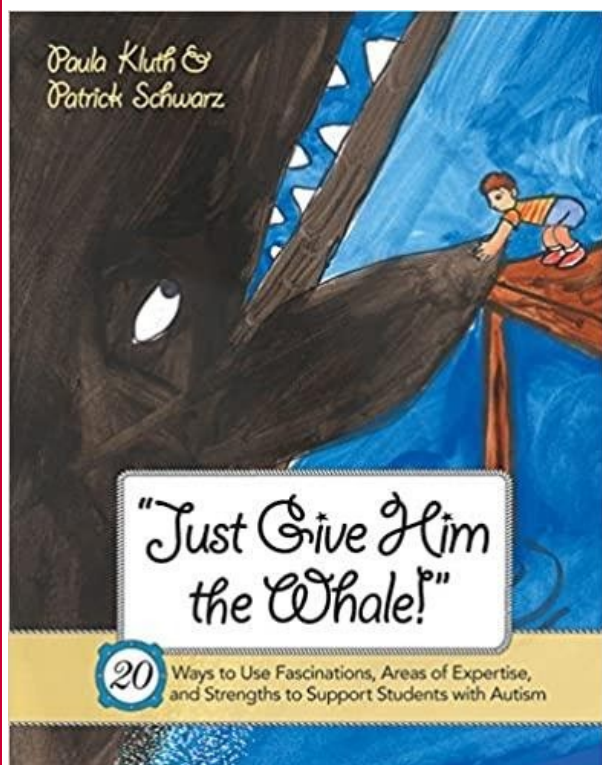
We are now roommates in college. But I still have to wake her up and help keep her on a schedule. It's been interesting to see how people in college react to our interactions. They don't understand that I'm acting in a couple of different roles—sometimes as a sibling and sometimes more as a mother.

My advice for someone with a sibling with autism is to be patient. As stressful as the role you have to play is, it's also rewarding. If you try to be patient, you get to share in success. Alexis' America's Choice Award during the Miss America competition ranks as one of the highlights of my life because I got to share in that success. Never give up on trying to help.

<https://www.cdc.gov/ncbddd/autism/stories.html>

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BOOK SUGGESTIONS



Just Give Him the Whale!: 20 Ways to Use Fascinations, Areas of Expertise, and Strengths to Support Students with Autism

by Paula Kluth and Patrick Schwarz.

When learners with autism have deep, consuming fascinations—trains, triangles, basketballs, whales—teachers often wonder what to do. Written by top autism experts and nationally renowned speakers Paula Kluth and Patrick Schwarz, this guide is brimming with easy tips and strategies for folding students' special interests, strengths, and areas of expertise into classroom lessons and routines.

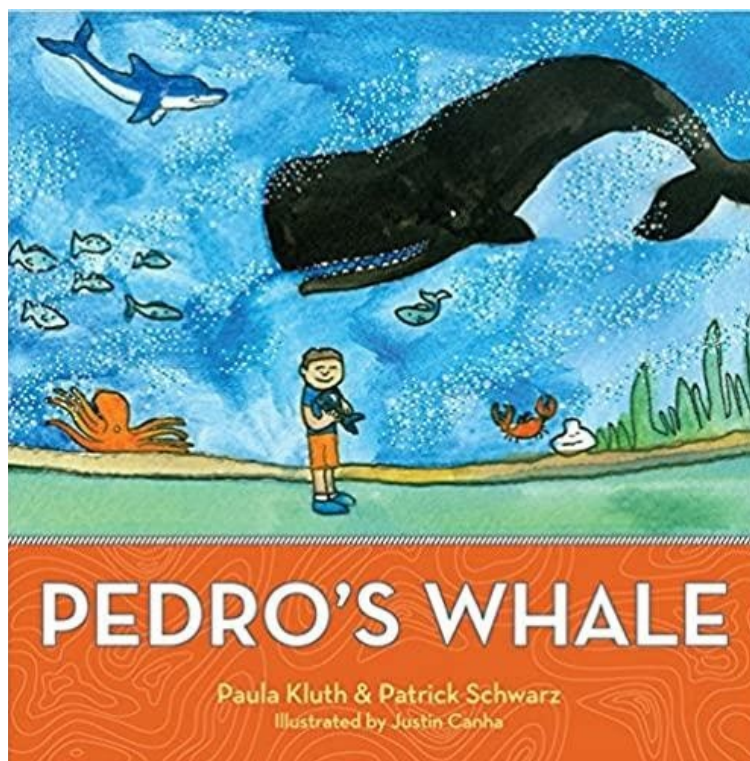
Just Give Him the Whale! is packed from start to finish with unforgettable stories based on the authors' experience, firsthand perspectives from people with autism themselves, research-based recommendations that are easy to use right away, and sample forms teachers can adapt for use in their own classrooms.

Pedro's Whale

by Paula Kluth and Patrick Schwarz

Based on the real-life event that inspired Paula Kluth and Patrick Schwarz's bestselling *Just Give Him the Whale*, this simple but powerful story introduces educators to one of the best, most effective inclusion strategies: using students' fascinations to help them learn.

Pedro, a young boy who loves whales more than anything, is heartbroken when he's told to put away his favorite toy whale on the first day of school. But then Pedro's teacher discovers the secret to helping him do his best work: not only giving him his whale, but also incorporating his special interest into the whole curriculum.



VISUALS

Everyone Looks Different



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| | |
|--|---|
| | Every person we see is different. |
| | Some people have short hair. |
| | Some people have long hair. |
| | Some people have a little hair. |
| | And some people have no hair. |
| | Some people have blue eyes. |
| | Some people have green eyes. |
| | Some people have brown eyes. |
| | Some people are tall, and some people are short. |
| | Some people have light skin. |
| | Some people have dark skin. |
| | Being different is what makes us all so special. |
| | Everyone is the same on the inside. All people are created equal. |

AuTalkz

Everyone responds differently to types of motivation. Some need a firm hand to guide them, while others respond to a gentle one. Folks with ASD tend to do better with the latter, since we're very sensitive people.



Back when I tried to hold a job, there were days when I had big trouble just gettin' in the car and goin'. On those days, I didn't know if I was more afraid of dad yell'n at me for not go'n, or my manager gettin' angry. In the end, I'd hide and stay home.



That sorta situation is where positive reinforcement can come in. Though it's easier to reward non-daily stuffs like appointments, be'n offered a reward for going in, even just ice cream, might have helped.



Not that there shouldn't be any punishment for bad behavior, of course! Everyone needs to learn that actions do have consequences. But with motivating someone on the spectrum, positive reinforcement goes a long way.



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