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Volume 9, Issue 9

## Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

## Helping Your Child with Autism Thrive

THERE ARE MANY THINGS YOU CAN DO TO HELP A CHILD WITH AUTISM SPECTRUM DISORDER (ASD) OVERCOME THEIR CHALLENGES. THESE PARENTING TIPS, TREATMENTS, AND SERVICES CAN HELP.

#### A PARENT'S GUIDE TO AUTISM TREATMENT AND SUPPORT

If you've recently learned that your child has or might have autism spectrum disorder, you're probably wondering and worrying about what comes next. No parent is ever prepared to hear that a child is anything other than happy and healthy, and an ASD diagnosis can be particularly frightening. You may be unsure about how to best help your child, or confused by conflicting treatment advice. Or you may have been told that ASD is an incurable, lifelong condition, leaving you concerned that nothing you do will make a difference.



While it is true that ASD is not something a person simply "grows out of," there are many treatments that can help children acquire new skills and overcome a wide variety of developmental challenges. From free government services to in-home behavioral therapy and school-based programs, assistance is available to meet your child's special needs and help them learn, grow, and thrive in life.

When you're looking after a child with ASD, it's also important to take care of yourself. Being emotionally strong allows you to be the best parent you can be to your child in need. These parenting tips can help by making life with an autistic child easier.

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#### Don't wait for a diagnosis

As the parent of a child with ASD or related developmental delays, **the best thing you can do is to start treatment right away.** Seek help as soon as you suspect something's wrong. Don't wait to see if your child will catch up later or outgrow the problem. Don't even wait for an official diagnosis. The earlier children with <u>autism spectrum disorder</u> get help, the greater their chance of treatment success. Early intervention is the most effective way to speed up your child's development and reduce the symptoms of autism over the lifespan.

[Read: Does My Child Have Autism?]

### When your child has autism

**Learn about autism.** The more you know about autism spectrum disorder, the better equipped you'll be to make informed decisions for your child. Educate yourself about the treatment options, ask questions, and participate in all treatment decisions.

**Become an expert on your child.** Figure out what triggers your kid's challenging or disruptive behaviors and what elicits a positive response. What does your child find stressful or frightening? Calming? Uncomfortable? Enjoyable? If you understand what affects your child, you'll be better at troubleshooting problems and preventing or modifying situations that cause difficulties.

**Accept your child, quirks and all.** Rather than focusing on how your autistic child is different from other children and what he or she is "missing," practice acceptance. Enjoy your kid's special quirks, celebrate small successes, and stop comparing your child to others. Feeling unconditionally loved and accepted will help your child more than anything else.

**Don't give up.** It's impossible to predict the course of autism spectrum disorder. Don't jump to conclusions about what life is going to be like for your child. Like everyone else, people with autism have an entire lifetime to grow and develop their abilities.

## Helping your child with autism thrive tip 1: Provide structure and safety

Learning all you can about autism and getting involved in treatment will go a long way toward helping your child. Additionally, the following tips will make daily home life easier for both you and your child with ASD:

Be consistent. Children with ASD have a hard time applying what they've learned in one setting (such as the therapist's office or school) to others, including the home. For example, your child may use sign language at school to communicate, but never think to do so at home. Creating consistency in your child's environment is the best way to reinforce learning. Find out what your child's therapists are doing and continue their techniques at home. Explore the possibility of having therapy take place in more than one place in order to encourage your child to transfer what he or she has learned from one environment to another. It's also important to be consistent in the way you interact with your child and deal with challenging behaviors.

Continued on page 3.

**Stick to a schedule.** Children with ASD tend to do best when they have a highly-structured schedule or routine. Again, this goes back to the consistency they both need and crave. Set up a schedule for your child, with regular times for meals, therapy, school, and bedtime. Try to keep disruptions to this routine to a minimum. If there is an unavoidable schedule change, prepare your child for it in advance.

**Reward good behavior.** Positive reinforcement can go a long way with children with ASD, so make an effort to "catch them doing something good." Praise them when they act appropriately or learn a new skill, being very specific about what behavior they're being praised for. Also look for other ways to reward them for good behavior, such as giving them a sticker or letting them play with a favorite toy.

**Create a home safety zone.** Carve out a private space in your home where your child can relax, feel secure, and be safe. This will involve organizing and setting boundaries in ways your child can understand. Visual cues can be helpful (colored tape marking areas that are off limits, labeling items in the house with pictures). You may also need to safety proof the house, particularly if your child is prone to tantrums or other self-injurious behaviors.

### Tip 2: Find nonverbal ways to connect

Connecting with a child with ASD can be challenging, but you don't need to talk—or even touch—in order to communicate and bond. You communicate by the way you look at your child, by the tone of your voice, your body language – and possibly the way you touch your child. Your child is also communicating with you, even if he or she never speaks. You just need to learn the language.

Look for nonverbal cues. If you are observant and aware, you can learn to pick up on the nonverbal cues that children with ASD use to communicate. Pay attention to the kinds of sounds they make, their facial expressions, and the gestures they use when they're tired, hungry, or want something.

**Figure out the motivation behind the tantrum.** It's only natural to feel upset when you are misunderstood or ignored, and it's no different for children with ASD. When children with ASD act out, it's often because you're not picking up on their nonverbal cues. Throwing a tantrum is their way of communicating their frustration and getting your attention.

[Read: Autism Behavior Problems]

**Make time for fun.** A child coping with ASD is still a child. For both children with ASD and their parents, there needs to be more to life than therapy. Schedule playtime when your child is most alert and awake. Figure out ways to have fun together by thinking about the things that make your child smile, laugh, and come out of her/his shell. Your child is likely to enjoy these activities most if they don't seem therapeutic or educational. There are tremendous benefits that result from your enjoyment of your child's company and from your child's enjoyment of spending unpressured time with you. Play is an essential part of learning for all children and shouldn't feel like work.

Pay attention to your child's sensory sensitivities. Many children with ASD are hypersensitive to light, sound, touch, taste, and smell. Some children with autism are "under-sensitive" to sensory stimuli. Figure out what sights, sounds, smells, movements, and tactile sensations trigger your kid's "bad" or disruptive behaviors and what elicits a positive response. What does your child find stressful? Calming? Uncomfortable? Enjoyable? If you understand what affects your child, you'll be better at troubleshooting problems, preventing situations that cause difficulties, and creating successful experiences.

Continued on page 4.

## Tip 3: Create a personalized autism treatment plan

With so many different treatments available, it can be tough to figure out which approach is right for your child. Making things more complicated, you may hear different or even conflicting recommendations from parents, teachers, and doctors. When putting together a treatment plan for your child, keep in mind that there is no single treatment that works for everyone. Each person on the autism spectrum is unique, with different strengths and weaknesses.

## A good treatment plan will:

Build on your child's interests.

Offer a predictable schedule.

Teach tasks as a series of simple steps.

Actively engage your child's attention in highly structured activities.

Provide regular reinforcement of behavior.

Involve the parents.

Source: National Institute of Mental Health

Your child's treatment should be tailored according to their individual needs. You know your child best, so it's up to you to make sure those needs are being met. You can do that by asking yourself the following questions:

What are my child's strengths – and their weaknesses?

What behaviors are causing the most problems? What important skills is my child lacking?

**How does my child learn best** – through seeing, listening, or doing?

**What does my child enjoy** – and how can those activities be used in treatment and to bolster learning?

Finally, keep in mind that no matter what treatment plan is chosen, your involvement is vital to success. You can help your child get the most out of treatment by working hand-in-hand with the treatment team and following through with the therapy at home. (This is why your well-being is essential!)

### Choosing autism treatments

When it comes to autism treatment, there are a dizzying variety of therapies and approaches. Some autism therapies focus on reducing problematic behaviors and building communication and social skills, while others deal with sensory integration problems, motor skills, emotional issues, and food sensitivities.

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With so many choices, it is extremely important to do your research, talk to autism treatment experts, and ask questions. But keep in mind that you don't have to choose just one type of therapy. The goal of autism treatment should be to treat your child's unique array of symptoms and needs. This often requires a combined treatment approach that incorporates several different types of therapy.

Common autism treatments include behavior therapy, speech-language therapy, play-based therapy, physical therapy, occupational therapy, and nutritional therapy. But keep in mind that the routine is important and the program should be designed in a way that can be sustained. You should think about what skills and behaviors are most essential and treat those first. It may not be possible to tackle everything at once.

## Tip 4: Find help and support

Caring for a child with ASD can demand a lot of energy and time. There may be days when you feel overwhelmed, stressed, or discouraged. Parenting isn't ever easy, and raising a child with special needs is even more challenging. In order to be the best parent you can be, it's essential that you take care of yourself.

Don't try to do everything on your own. You don't have to! There are many places that families of children with ASD can turn to for advice, a helping hand, advocacy, and support:

**ADS support groups** – Joining an ASD support group is a great way to meet other families dealing with the same challenges you are. Parents can share information, get advice, and lean on each other for emotional support. Just being around others in the same boat and sharing their experience can go a long way toward reducing the isolation many parents feel after receiving a child's diagnosis.

**Respite care** – Every parent needs a break now and again. And for parents coping with the added stress of ASD, this is especially true. In respite care, another caregiver takes over temporarily, giving you a break for a few hours, days, or even weeks.

[Read: Respite Care]

**Individual, marital, or family counseling** – If stress, anxiety, or depression is getting to you, you may want to see a therapist of your own. Therapy is a safe place where you can talk honestly about everything you're feeling—the good, the bad, and the ugly. Marriage or family therapy can also help you work out problems that the challenges of life with an autistic child are causing in your spousal relationship or with other family members.

To read the last part of the article please go to : https://www.helpguide.org/articles/autism-learning-disabilities/helping-your-child-with-autism-thrive.htm



#### WHY AUTISM AWARENESS ALONE ISN'T ENOUGH

## Why Autism Awareness Alone Isn't Enough

Autism acceptance is the goal for the UCF Center for Autism and Related Disabilities and the 16,000 individuals with autism spectrum disorders they work to support.

BY TERRI DALY, DIRECTOR OF THE UCF CENTER FOR AUTISM AND RELATED DISABILITIES | APRIL 21, 2021

April has been known as Autism Awareness Month for more than 10 years. I remember the excitement when April 2 was established as World Autism Awareness Day by the United Nations General Assembly in 2007 — it was heralded as a victory for people on the autism spectrum.

Like many awareness movements, the autism awareness movement was initiated by parents and professionals with only the best of intentions. At the time, the prevalence of autism (now called autism spectrum disorder, or ASD) was about one in 90 individuals. In 2020, the Centers for Disease Control and Prevention estimated the prevalence to be about one in 54. Today we are likely to know someone who has a family member with autism or have a family member on the spectrum ourselves.

And while awareness was great in 2007, it's no longer good enough in 2021.

A meme I saw recently (reportedly created by someone on the spectrum) goes like this: Autism awareness means you know I'm here. Autism acceptance means you are happy to see me.

For the 16,000 individuals with autism spectrum disorders that my colleagues and I at the <u>UCF</u> <u>Center for Autism and Related Disabilities (CARD)</u> work to support, autism acceptance is the goal.

I say this as an outsider — an "allistic" or "neurotypical" to people on the spectrum. I am just a helper. I have no ASD diagnosis or direct experience to draw from, so I am sure there will be some who say I have no right to comment on this. But those of us who work with and for people with ASD every day agree we need more than awareness.

What that looks like depends on who you talk to. Autism occurs along a spectrum, with features that affect social communication, interests and behaviors, and sensory processing in different ways in different people. The community is diverse, even within itself.

Some individuals are proud and "out" and others are not willing to share their diagnosis for fear of stereotyping that may restrict their opportunities. Some wear blue to promote awareness, and others wear red for autistic pride. Some love the puzzle symbol, and others feel that it promotes a view that they are incomplete or missing something. Some prefer the person-first language that we as professional helpers have been taught to use for years — others prefer identity first.

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#### WHY AUTISM AWARENESS ALONE ISN'T ENOUGH CONTINUED...

We need to speak to many individuals with ASD to inform our actions toward acceptance, but here are some tips that should help.

#### 1. Let's talk about autism.

If we are to have acceptance, we must say the word.

Recent trends toward using more generic terms like and "sensory-friendly" instead of using autism perpetuate the stigma that autism is something to be hidden. So let's say it proud and loud! It's fine that others benefit from the work the autism community has done to change opportunities for people on the spectrum, but let's not let autism get lost in the mix.

#### 2. Create opportunities for participation with acceptance.

Become part of the autism-friendly movement. What does that mean? Do a self-assessment to see what you have in place to welcome people with ASD into your life — be it in your business, neighborhood or among your family members — and then seek out consultation and training in best practices to support people with ASD.

#### 3. Show grace.

We see this when an autistic member of the faith congregation bellows out a few noises at top volume during the service, and the leader smiles and thanks him for his participation, or when a <u>Universal Studios employee comforts a child</u> having a meltdown because the Spider-Man ride broke down. Recognize the parent at a grocery store standing over a child who is covering his ears and screaming may be dealing with a difficult moment for a child with ASD. Instead of looking away or giving an unforgiving stare, ask if there is anything you can do to help, or even just give a reassuring smile.

#### 4. Teach your children well.

A child with ASD may not talk, but that does not mean they don't think or feel or communicate. Acceptance means celebrating their strengths instead of focusing on challenges. Make sure that classmates with ASD are included in birthday parties. Use books like *Crow Boy* by Taro Yashima to teach the value in unique abilities.

#### Acceptance

I don't want to "fix" my child.

I want him to thrive.

At its core,
there should be nothing
wrong with being autistic.

It just is.

Deciphering Morgan

Continued on page 8.

#### WHY AUTISM AWARENESS ALONE ISN'T ENOUGH CONTINUED...

#### 5. Hire people with ASD.

They may not ace that interview. They may have some quirky traits. But give them a chance to shine. They often have a keen eye for detail and excel at following routines. They are reliable and loyal. Over the past two years, we have helped connect over a dozen adults with employment in our communities. Some employers who were initially skeptical have become huge champions for hiring people with ASD. The current statistics of one in 54 children means one in 54 will grow up into our workforce, and they need jobs. Reach out to CARD if you are ready to hire — we just may have someone we know who meets your needs.

#### 6. Stop the stigma.

Autism is not a disease, and therefore it doesn't need to be cured or eliminated. While many parents and some people on the spectrum wish they could eliminate certain traits or tendencies, or quickly develop skills to help fit into the typical mold, trying to fit square pegs into round holes only damages the pegs. ASD is a complex, neurologically-based difference in how someone sees the world, and it can be stressful to the individual as well as those around him or her.

There are things that can be done to help a person with ASD thrive. At UCF CARD, we provide more than 500 parent education seminars, social groups, support groups and outings each year — and we have maintained them even through COVID-19. We collaborate with entertainment venues, employers, schools, after-school enrichment programs and sports leagues to foster community inclusion. We provide support that ranges from helping design potty training plans and providing sensitivity building sessions that prevent bullying and help children understand what ASD is, all the way to linking employers to adults with ASD seeking employment and promoting adulting skills.

Help us help our children and adults with ASD by demonstrating acceptance in every way you can.

Our community will be a better place for it.

https://www.ucf.edu/news/why-autism-awareness-alone-isnt-enough/?fbclid=lwAR2aqL0Vvw0I4q4i3fB67xMkFKH5koy5TPciHZp9EOg4m1ZSlkHYoFjBoj8



#### ST. CLAIR TEEN WITH AUTISM AND PHOTOGRAPHY

# St. Clair teen with autism finds creative outlet, satisfaction through photography

By Brian Wells Post Huron Times Herald

https://www.thetimesherald.com/story/news/2021/04/30/st-clair-teen-autism-photography-phillip-will/7323604002/



Phillip Will enjoys playing games on his computer and photographing things on his family's St. Clair farm. His favorite photo is one he took of a sunrise at the Blue Water Bridge.

Julie Will said learning photography has given her 14-year-old son with autism a growing independence and passion.

"We don't look at it as a disability at all. He's just different," she said. "You're just you."

Computers and photography came quick to Phillip. He started taking photos as part of a class project using only his cell phone. With art being his favorite school subject, he enjoyed the project, and has recently moved to a more advanced camera.

Besides the class project Phillip is self-taught, and has developed his skills through practice and by watching YouTube videos. When he first got his new camera, he took to the internet to learn how to use all of its different features and settings.

Phillip said it's rewarding to be able to share his photos and see them get attention on his Facebook page. His mother said he's become more creative and his photography has improved.

On a recent trip to Escanaba, Phillip kept asking his mother to pull over so he could take photos. A drive that would normally take two hours took almost four, she said.

"We must have stopped 50 times," Julie Will said, laughing.

In the coming months, Phillip plans to start doing photography with the school's yearbook program. Eventually, he hopes to do photography full time.



You can see more of Phillip's work on his Facebook page, Pj's photography.

#### 2021 SUMMER ACTIVITIES AND PROGRAMS ...

## 2021 Summer Camps for Kids with Autism and Special



Needs

The following camps target kids with special needs. Go to their websites or contact organizations directly for more detailed information, including their Covid safety measures. You can also contact your local Parks and Recreation Department or OSU's KidSpirit programs (<a href="http://kidspirit.oregonstate.edu/programs-0">http://kidspirit.oregonstate.edu/programs-0</a>) for information about camps available to the general population.

Camp & Location	Description	Website/Contact Info	Ages/Population	Session Dates/Times	Registration Deadline
Camp Odakoda Falls City, OR	Overnight	http://www.asdoregon. org/	Ages 10 – 18 High-functioning ASD or similar disorder	August 9-14	CLOSED Financial assistance
Camp Attitude Foster, OR	Overnight	http://www.campattitu de.com/	All ages/entire family. A "unique Christian camping experience."	Various week-long sessions	CLOSED
B'Nai B'Rith Camp Lincoln City, OR	Overnight/Day Camp	https://bbcamp.org/	Grades 2-10 Based in Jewish values, but all faiths and abilities welcome; have an inclusion coordinator	Sessions of various lengths – see website	OPEN Financial assistance
Autism Rocks Friends & Family Camp Florence, OR	Overnight (provides other events year- round)	https://kindtree.org/calendar/camp/	All ages/entire family People with autism, parents, caregivers	August 27-29 Saturday only option	OPEN Financial assistance
Easter Seals Lyons, OR And Neostu, OR	Overnight	http://www.easterseals. com/oregon/our- programs/camping- recreation/	Ages 10 and up All types of disabilities	July 11-15 (ages 18-59) June 20-24 (ages 10-25)	OPEN Limited scholarships K Plan
Camp Yakety-Yak Lake Oswego, OR	Day camp	http://www.campyaket yyak.org/	Ages 5 – 15 HF ASD or similar Siblings and peers Ages 16 – 21 Apprenticeship Program	10:00 AM-3:00 PM 4 week-long themed sessions July & August	OPEN Discounts and partial scholarships
Mt. Hood Kiwanis Mt. Hood, OR	Overnight	https://mhkc.org/summ er-camp/	Ages 12 and up All types of disabilities	Various sessions in various locations See website	OPEN Financial assistance
Blue Compass Camps Seattle, WA	Overnight	http://www.bluecompa sscamps.com/	Ages 10 – adult Asperger's and high- functioning autism	Various sessions in Washington See website	OPEN

#### 2021 SUMMER ACTIVITIES AND PROGRAMS CONTINUED...

## 2021 Summer Activities and Programs for Kids with Autism and Special Needs

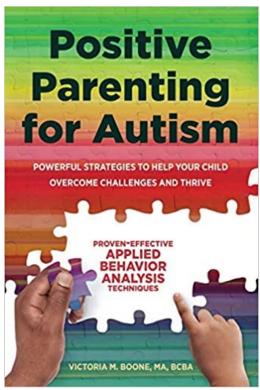
The following programs provide services all year round to children with specialized needs, but are well-suited for summer fun and learning. See websites for more information and Covid safety measures.

Program & Location	Description	Website/Contact Info	Ages/Population
Hand in Hand Farm Lebanon, OR	Faith-based organization providing caring mentors and farm- based activities	http://www.handinhandfarm.org/	All ages and needs
Bright Horizons Therapeutic Riding Center Siletz, OR	Therapeutic mounted horseback riding adapted to fit the needs of the rider	http://www.brighthorizonsriding.org/ therapeutic-horseback-riding.htm	All ages and needs
OSU IMPACT (Individualized Movement and Physical Activity for Children Today) Corvallis, OR	Various physical activity opportunities (swimming, dancing, climbing, etc.) 9:30-11:00 Friday	http://health.oregonstate.edu/impact	6 months – 21 years
The ARC Benton County	Various recreational activities and classes (art/crafts, bowling, Legos, dinner & movie, etc.).	https://www.arcbenton.org/enrichme nt	Teens and adults with intellectual and developmental disabilities
Special Olympics Oregon Virtual Summer Games	Athletics Golf Fitness Soccer	http://www.soor.org/Sub- Page.aspx?Name=Linn- County&PID=107	Ages 8 through adult



The LBL ESD Autism Agenda Newsletter is a compilation of national and regional resources designed to support families and school teams. Every effort is made to provide accurate and complete information in the LBL ESD Autism Agenda Newsletter; however, LBL ESD cannot guarantee that there will be no errors. For example, some of the content within curated resources from across the nation may not apply to Oregon. LBL ESD does not assume any legal liability for any direct, indirect or any other loss or damage of any kind for the accuracy, completeness, or usefulness of any information, product, or process disclosed herein, and do not represent that use of such information, product, or process would not infringe on privately owned rights.

#### **BOOK SUGGESTIONS**



Positive Parenting for Autism: Powerful Strategies to Help

#### **Your Child Overcome Challenges and Thrive**

by Victoria Boone MA BCBA

Help your child with autism build essential social and life skills

It can be a challenge to manage life as a special needs parent and feel like you are doing all you can to support your child's growth and development. *Positive Parenting for Autism* offers proven techniques for helping your child with autism develop the foundational skills they need to thrive and live a fulfilling life.

Using scientifically supported strategies based in applied behavior analysis (ABA), this practical guide provides concrete tools for developing personalized behavior change plans aimed at both increasing your child's positive behaviors and decreasing unwanted or problem behaviors associated with autism spectrum disorders. Take a deep dive into topics like punishment alternatives, the power of reinforcement, communication and cooperation, and teaching complex behaviors in straightforward ways.

# A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence

By. Chantal Sicile-Kira & Jeremy Sicile-Kira

A guide for helping our children lead meaningful and independent lives as they reach adulthood

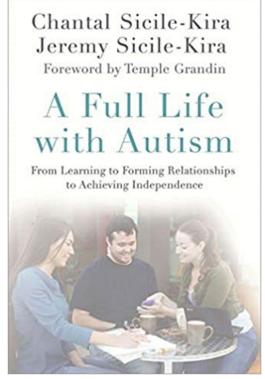
In the next five years, hundreds of thousands of children with autism spectrum disorder will reach adulthood. And while diagnosis and treatment for children has improved in recent years, parents want to know: What happens to my child when I am no longer able to care for or assist him? Autism expert Chantal Sicile-Kira and her son Jeremy offer real solutions to a host of difficult questions, including how young adults of different abilities and their parents can:

\*navigate this new economy where adult service resources are scarce

\*cope with the difficulties of living apart from the nuclear family

\*find, and keep a job that provides meaning, stability and an income

\*create and sustain fulfilling relationships





#### **VISUALS**

#### This is an Example of a Core Communication Board

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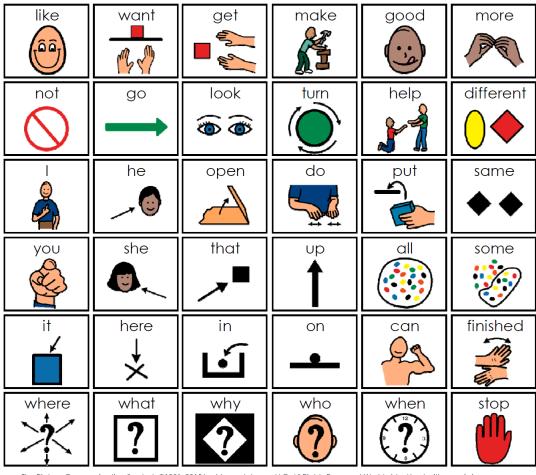
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