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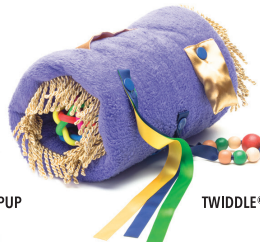
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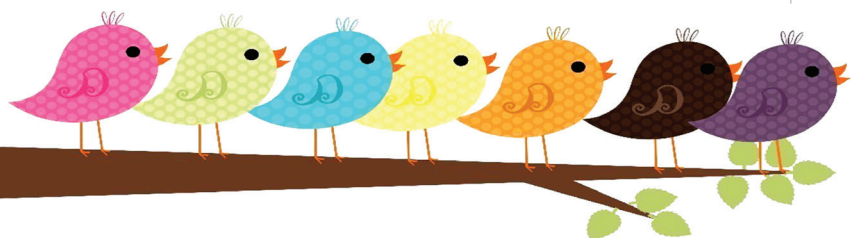
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Welcome to the Spring 2021 edition of Spectrum Life Magazine!

April may officially be Autism Acceptance Month, however it's something we practice every day. Until autistics of all ages, abilities and intersecting identities have the resources to be safe, healthy, enriched and empowered to live their best lives possible, we need to continue advocating for positive change. Come join us as an Ambassador for Autism Acceptance!

In this issue, we are centering and celebrating autistic voices in advocacy, education, poetry, podcasting, and entrepreneurial endeavors. We also show appreciation for family, friends and allies. Our cover story features the force of Disability EmpowHER Network Mentoring (page 10). Learn how Kimi, a teen from Washington state was matched with Victoria, a senior policy analyst in Washington, D.C.

In other advocacy news, the Oregon Commission on Autism Spectrum Disorder (page 7) is actively seeking self-advocates and allies to effect change. Ivanova Smith, an autistic and disability rights advocate shares the importance of how Mental Age Theory Hurts (page 12) and how every adult should have the right to grow up. Teaching Autistic People (page 32) reminds us we can all learn when supports are in place.

Valerie Gilpeer and Emily Grodin share a remarkable story of perseverance 25 years in the making in I Have Been Buried Under Years of Dust: A Memoir of Hope (page 16) and The Good Fight (page 18).

High school senior Sam Mitchell rocks out with celebrity interviews and autism advocacy in the Autism Rocks and Rolls Podcast (page 23). World traveler and popular EduTuber Willie Rates shares how KhAnubis (page 27) reached over 110,000 subscribers on YouTube by answering questions you didn't even know you had.

Shifting to more serious topics, we learn about Autistic Mate Crime (page 20), FERPA and HIPAA Privacy Laws (page 30), and Autism and Consequences (page 44). In health and wellness news, TriStar Family Chiropractic and Scoliosis Center (page 36), Virtual Personal Training (page 35) and Ask Spectrum Life (page 38) help us physically, mentally and emotionally.

Wherever you identify in your autism or autistic journey, we are here to meet you along the way with acceptance, enrichment, inspiration, and empowerment for the road ahead.

Karen

Karen Krejcha

Executive Director & Co-Founder: Autism Empowerment™
Editor: Spectrum Life Magazine™



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ON OUR COVER











Kimi Dyment is a 16-year old high school sophomore who gives excellent hugs, loves Star Wars, and is proudly autistic.

Disability EmpowHER Mentoring (page 10)

Photo courtesy of the Dyment family

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advocacy

EMPOWERING CHANGE WITHIN THE AUTISM COMMUNITY



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Oregon Commission on Autism Spectrum Disorder

Celebrating a Spectrum of Strength

By John Krejcha

Not too many people are aware that Oregon has a state-mandated commission that supports children, teens and adults on the autism spectrum along with their families. The Oregon Commission on Autism Spectrum Disorder has been around since 2009. They are looking for self-advocates, family members and allies to help improve the lives of those within autism communities in Oregon.

Spectrum Life Magazine recently connected with current Chairperson Joyce Bernheim to learn more about how the commission is making a difference in the lives of autistic individuals and their families all over Oregon. She also shares how you can get involved.

What is the purpose of the Oregon Commission on Autism Spectrum Disorder (OCASD)?

OCASD's ultimate goal is to help all autistic individuals in Oregon experience rich lives through physical and mental wellness, opportunities for authentic personal relationships, lifelong learning, self-determination, and meaningful work. This requires effective, efficient services and supports for autistic youth and adults and the families who are raising and caring for them.

Because of the biological, psychological, gender, and cultural/linguistic diversity of autism, a large part of our job is giving people the tools to better tailor their services to the unique characteristics of each autistic individual and their family.

What is the history behind the formation of the OCASD?

Family members both inside and outside of the legislature were the prime movers in creating the Commission. At the time (and still today), there were large gaps in awareness and understanding of autism, funding, insurance coverage, and public and private services to meet the everyday needs of autistic individuals and their families.

A legislative work group toured the state in 2008 to gather information from families and self-advocates. It also reviewed existing state services. This led to the governor establishing OCASD by executive order in 2009. But rather than simply creating an official forum for family members and self-advocates to express their needs, those who designed the Commission wanted to create a workspace where all the stakeholders could come together to solve problems and ensure they could and would be implemented.



Thus, our executive order created slots not only for family members and self-advocates, but also for a state senator, a state representative, a representative of the Oregon Department of Education, a representative from the Developmental Disability Services program, frontline educators, and frontline health care professionals. Most of our work gets done through collaborative work groups focused on specific issues or areas, such as the Screening, Identification, and Assessment Work Group.

What is your personal connection with autism?

I am the parent of a wonderful 26-year old son with autism and intellectual disability. After he was diagnosed, I quickly decided that I had to learn about the biology and psychology of social emotional interaction, because that is one of the big drivers of autism.

From the beginning, my husband and I were committed to giving him the same experiences and learning opportunities in the same settings as our typically developing daughter, in addition to services focused on social emotional development.

He is now largely independent, works about three-quarters time, has a girlfriend, plays piano, and is beloved by all who know him. When he was born, I was a lawyer helping health care organizations set up and improve their services. I eventually withdrew from my legal practice, both to support his development and to use my knowledge and skills to ensure that all autistic children had access to better services. I became involved in special education and autism policy and advocacy work at the local and state levels. Through these experiences, I have met many autistic individuals and their families, each of whom experiences autism in a different way.

There is often divisiveness in autism and autistic communities, particularly around therapy methods, language and including autistic people in meaningful leadership roles. How does the Commission work to bring autistic and non-autistic people together to learn from one another?

Continued on page 8



Photo courtesy of Joyce Bernheim

The divisions within the autism community are challenging for everyone and most of the Commission members have experienced them personally. We try to balance our membership to include diverse views and discuss issues from a range of perspectives, including recent science on autism and human behavior.

In the beginning, the Commission included a number of self-advocates. Over time, we lost our self-advocates due to a number of factors, including the demands of in-person meetings, term limits, and the nature of our work. Recruitment efforts by several of our chairs did not bear fruit.

When I became chair at the end of 2019, I knew this was a situation we needed to fix. The year 2020 was a wild year for everyone, but we have already addressed some of these issues and are working hard to address others. We are about to launch a major recruitment effort, and we would be delighted if self-advocates stepped up to become Commission members, work group chairs, or work group members. In addition, we will have roles for self-advocates as focus group members and survey respondents.

How does the Commission center autistic voices in its work and in identifying priorities for change?

As a Commission, we want to include autistic voices in as many ways as we can. Every current Commission member has devoted a significant part of their lives to autistic individuals, whether through their personal or family relationships, through their professions, or all three. Members are personally motivated to bring the variety of autistic voices they have heard into our discussions.

We need and want more self-advocates to feel welcome and enrich our work. We are creating regular avenues for autistic individuals to share their input even if they don't want to become Commission or work group members. Groups like AASPIRE (Academic Autism Spectrum Partnership in Research and Education) are trying to develop research tools that will help to gather the views of a broader range of autistic people. We applaud that work. We also know that there will always be some whose family members need to share their experiences with us.

With respect to identifying priorities, last year we created a Long-Term Vision and a three-year Strategic Plan as works in progress to identify significant needs as we understand them today. This was in preparation for a big recruitment effort we are undertaking this year.

The larger community will have multiple opportunities to become involved in issues they care about, so they can “vote with their feet.” But we will also be actively recruiting to fill work groups for projects that are essential to ensure better training for professionals and family members, better supports for families raising or caring for youth and adults, more effective and better coordinated services and supports for autistic individuals throughout the lifespan, and better social services and housing options for adults.

What are some of the accomplishments of the Commission?

One of our most impactful achievements is the recent adoption of new special education eligibility rules for autism. Previously, the definitions of autism and the evaluation process differed significantly between health care and education. This led to a lot of friction for families and inconsistencies in understanding and services. The new rules, which went into effect in 2019, incorporate the scientific definition of autism that is the basis for clinical practice as well as scientific research on autism.

There was initially a lot of resistance to this idea, but the Commission provided the means to address barriers, gain supporters from within education, and ultimately persuade the State Board of Education of the need for change. Commission members were able to improve other aspects of the rules and help train educators throughout the state.

We have anecdotal evidence that the quality of autism evaluations has significantly improved, meaning a better understanding of what autism is among school teams, fewer conflicts between school and medical teams, and better ability to coordinate care across the two. This is something that could not have happened without the Commission. You need to be able to convince people not only why something has to change, but also engage them in figuring out how to do it.

The Commission has also created a pathway for autism specialist endorsements on teacher licenses and a self-assessment tool and supporting materials to help school districts improve their programs. It developed and distributed service navigation maps for families of newly diagnosed youth. It developed and distributed detailed guidance on performing autism evaluations during the pandemic. Commission members and participants have also collaborated with other organizations who took the lead in creating and distributing autism awareness materials to pediatricians and child-oriented agencies throughout the state; developing eligibility rules for developmental disability services; developing a health care tool kit for autistic adults; and developing joint health care and education evaluation teams in nine communities throughout the state.

When and how often does the Commission meet?

We meet monthly on the 4th Friday of the month, except for August, November, and December. Most of our meetings are for two hours via Zoom. When the pandemic is over, we will

have two longer in-person meetings a year with the option to participate by Zoom.

What is the Commission currently working on?

The Commission is effectively relaunching itself to address head-on many of the hidden barriers that have stood in the way of effective, coordinated services and supports across the lifespan. Deep, systemic change is needed in some areas, which will take sustained effort over time.

We have long collaborated with other organizations, such as the Autism Society of Oregon and the Oregon Council on Developmental Disabilities, but we are also reaching out to new collaborators, such as the National Alliance on Mental Illness, so we can help inform work occurring in other organizations that affects autistic individuals and their families.

The Commission is looking to recruit people to assist in their efforts. Would you talk about this?

We will soon have an area of our website, www.orcommissionasd.org devoted to this effort. It will include our Long-Term Vision and Strategic Plan, a list of participation opportunities with a description of what each involves, and other materials. We are developing a plan to get this information out to as many people in as many venues as we can think of, including communities of color and other ethnic communities. We want as many people in the autism community as possible to give us feedback and participate in our activities.

What would make for a good candidate?

People who have a commitment to improving the lives of autistic individuals and their families; are willing to learn from and with others, including some with whom they disagree; are willing to speak up for their truth; and are willing to participate in more meetings than they at first thought would be necessary. Lasting change comes from changing people's minds, and that can sometimes take a long time.

Oregon is spread out geographically. How does the Commission ensure diverse voices and support throughout the state of Oregon?

We have long used video conferencing platforms and will continue to do so even after the pandemic. This has allowed us to get participation from throughout the state. We have in the past and will continue in the future to conduct surveys from folks all across the state, most recently on parents' back-to-school experiences, to which we got responses from 21 of 36 counties. We will also try to set up focus groups so we can get regular input from a variety of communities. Finally, when pandemic restrictions are over, several Commission members plan to travel around the state to talk with folks personally.

Where can people see what the Commission is doing?

In addition to the materials that we will be putting up on our recruitment page, we hold open meetings that anyone who is interested in can attend. Our agendas include time for public testimony. Our minutes and meeting materials are all accessible from our website: www.orcommissionasd.org

Follow us on Facebook at:

Oregon Commission on Autism Spectrum Disorders

What else would you like Spectrum Life Magazine readers to know?

The Commission provides a unique venue to effect change by working together and speaking directly with allies in the legislature and state agencies. The more people who help and give us input, the more we can accomplish. **Our power comes from stories, facts, persuasion, unity, and persistence.**



John Krejcha is co-founder of Autism Empowerment and serves as Programs Director. He serves on the Editorial Advisory Board of Spectrum Life Magazine and is a guest host for the Autism Empowerment podcast. John is married to co-founder Karen Krejcha and is the father of two amazing children and their feisty cat, Zula. While John is the only one in the family who is not on the autism spectrum, he identifies as a neurodiverse and loving ally.

CELEBRATING A SPECTRUM OF STRENGTH

Disability EmpowHER Network Mentoring

The force is strong with Kimi



By Karen Krejcha

Kimi Dymant is a 16-year old high school sophomore who gives excellent hugs, loves Star Wars, and is proudly autistic. Her family actively encourages her to pursue her passions and build independence. Recently Kimi's mom learned about a national nonprofit called Disability EmpowHer Network that connects girls with disabilities together with successful disabled women for mentorship and support.

Spectrum Life Magazine recently connected with Kimi's mom to learn more about Kimi's experience with the Letter from A Role Model program and to find out how other girls and women can get involved.

Hi Brandi. Please tell our readers a little about your family and family dynamics.

The Dymant family is just your not-so-average family of four: two parents, two kids, and a whole lot of stimmy goodness. While the rest of us claim to be neurotypical, with Kimi being our neurodivergent individual, we all have our "things."

Dad is what we call a "tinkerer." He always finds cars, grills, and things in the garage and backyard to tinker around with. Sumi is a reading machine. We can't seem to find enough books to keep her occupied. Mom is the planner; you will never find her without a checklist, calendar, or phone, making sure everyone is where they are supposed to be, when they are supposed to be there, and with everything they need while they are there.

Kimi is the routine keeper. She makes sure our calendar and activities line up. If Mom tries to spring something on the family that is not in the approved calendar, Kimi is the one to call her on it. She also makes sure the menu has your typical Spaghetti Monday, Taco Tuesday, etc. We all do our parts to make up the whole of the Dymant family. We strive to be respectful of one another and work together to keep our family a working unit. Mostly we love to have fun, laugh, and just enjoy whatever life brings.

What are some of Kimi's favorite things to do?

Kimi's favorite thing on the planet is the television show *Masked Singer*. She loves the costumes and guessing the celebrity behind the mask. She has been a volunteer with the Autism Serves Kids Care Club for many years. Kimi will tell you her biggest strength is doing puzzles and putting together LEGOs. She also has a great wolf whistle. Also, the first thing she always tells people about

herself is she has autism. It's a part of her identity and who she is. She is very proud to be an autistic young lady.

How has COVID-19 affected your family in the past year?

COVID has affected our family personally as each of us got Covid in the month of December 2020. Symptoms ranged from mild to severe. Thankfully we have all fully recovered and will be getting our vaccines in March 2021.

How did you learn about the Disability EmpowHER Network?

We learned about the Disability EmpowHer Network from an email from Darla Helt at PEACE. I'm always interested in programs that deal with women with disabilities. There aren't many resources dealing with females on the spectrum, so finding a program that covered all women/girls with disabilities was exciting.

Tell us about the Letter from a Role Model program.

When looking into the organization, I saw they focus on two main programs. One is to pair disabled girls with disabled women with similar disabilities for letter writing. The other program involves an EmpowHer Camp in which young disabled women discover basic survival skills, further develop their life skills, practice leadership, increase their independence, and become more confident. There is no cost to participate in the letter writing program other than a stamp. Girls do a little fundraising to participate in the camp. Kimi already has a mentor and we have also applied for her to attend camp.

How long did it take for Kimi to be matched with a role model?

I applied online through their website and the next day, one of their team members, Stephanie called me. She interviewed me about Kimi and started working on matching someone with Kimi right away. We worked through some accommodations. The mentor program is typically letter writing, which is not Kimi's strongest way to communicate. We came up with the idea that a video chat would work better for Kimi and Stephanie teamed Kimi up with someone who would be willing to make the accommodation.

Who was she matched with?

She was matched with Victoria Rodríguez-Roldán, a

Continued on next page

proud Autistic woman and a senior policy analyst in Washington, D.C. Victoria holds a B.A. in Psychology with honors from the University of Puerto Rico, and a J.D. from the University of Maine School of Law.

What has been Kimi's interaction with Victoria?

Victoria sent Kimi a 5-minute video talking about autism and encouraging Kimi to be authentically herself. She even referred to Autism as having "the force". Kimi being a Star Wars fanatic loved this idea. Victoria said that at the beginning, many people didn't understand those who had the force and who were perceived as weird or unusual, but in the end, it was their superpower. Kimi loves the idea that she has the force. Kimi immediately sent Victoria a message back and awaits another video from her mentor.

As a mom, how do you think it helps Kimi to have autistic women role models?

I think Kimi seeing other autistic women in the community really helps her see herself in the future. She doesn't always see people like herself represented.

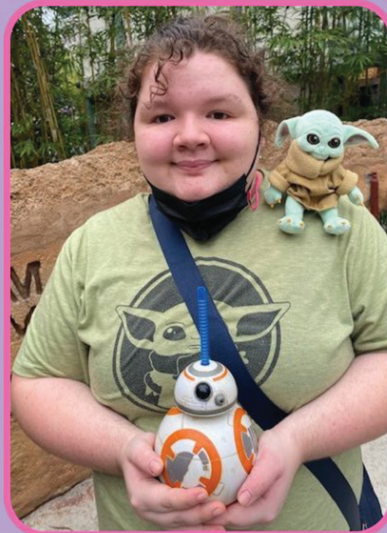
What would you say to other parents who might want to have their daughters participate in the Letter from a Role Model program?

I would recommend anyone to explore their website and follow them on social media on Facebook, Twitter or Instagram. It is really about empowering women.

What else is important for Spectrum Life Magazine readers to know?

One of the things Stephanie encouraged me to do was to continue exploring independence with Kimi. This includes letting her make mistakes, letting her be around other disabled teens, and really not trying to make her "fit in". She shared her experience as a disabled girl and how she wished some things had been different. It really impacted me listening to a self-advocate talk about their younger years and how it impacted them as adults.

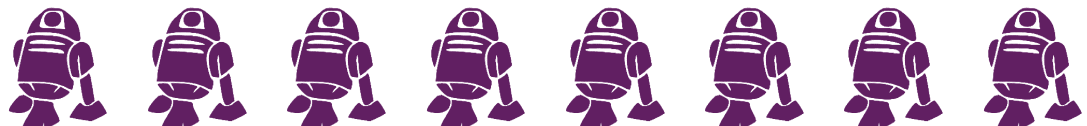
Letter from a Role Model



Kimi, 16
Animal Lover
Loves Star Wars



Victoria
Rodríguez-Roldán
Kimi's Role Model



To learn more about receiving a mentor or becoming a role model, please visit www.disabilityempowhernetwork.org.

Karen Krejcha is the co-founder of Autism Empowerment, where she serves as Executive Director. She is the Editor of Spectrum Life Magazine and host of the Autism Empowerment podcast. Karen was diagnosed on the autism spectrum in her 40s, after the diagnosis of her two children. She has been married to John for over 28 years and is devoted to promoting a culture of acceptance and empowerment within autism communities and worldwide.



Mental Age Theory Hurts

Every Adult has the Right to Grow Up

by Ivanova Smith

Have you ever heard the phrase, “That person has the mind of a five-year-old in an adult body?” We often hear the term “mental age of” when medical professionals or news media describe adults with intellectual and developmental disabilities (IDD). It is something very harmful that many adults with intellectual disabilities have to deal with.

It has been three years since I last wrote on the topic of mental age theory. A lot has happened since then. I was 28 then. Now I am 32, and I have definitely grown more and gained more life experience, which aging is all about. Mental age theory doesn’t recognize how time gives people life experience and different things happen in different years.

Since then, I had my daughter Alexandra and now have my second daughter Hildegard who is a newborn. Alexandra now is a happy, energetic three-year-old and Hildegard is a happy one-month-old.

I learned more things and have done lots more advocacy, including chairing Self Advocates in Leadership (SAIL) which is a coalition of Self Advocate Leaders working on Legislative policies that support the civil rights of people with intellectual and developmental disabilities.

We have been able to do lots of work to end discriminatory practices like ending subminimum wage, preventing the building of new institutions, and making sure self-advocates are represented in workgroups and committees that decide policy that affects the everyday life of people with disabilities.

Many of the policies that discriminate against people with intellectual disabilities use mental age theory to justify these awful policies. There are even times when I testify at public hearings about subminimum wage and legislators would call IDD workers “kids” and say that we are not deserving of minimum wage because we do not understand money. My thoughts on that are just because a person may not be aware they are being exploited for their work, doesn’t mean it is ok to exploit them. People also used mental age theory to justify institutions and not allow people with IDD to be parents.

It allows adults with IDD to be part of settings that restrict their adult rights. It is why it is important we educate lawmakers and the medical community about the harm of using mental age theory.

My experience working with the medical community is that I learned there are still areas of medical clinics that use mental age theory to explain intellectual disabilities



to parents of newly diagnosed kids. This hurts both the parents and the child. It says to parents your child will never not be a child and that is very harmful.

We need to encourage other more inclusive ways to explain intellectual and developmental disabilities that don’t take away the rights for children with disabilities to grow up! Having intellectual or developmental disabilities doesn’t mean a person is stuck as a child and never gets to do adult things like getting married or having their own children or living independently of their parents.

It is actually healthier for parents to support their young adults going into the community and getting the same rites of passage as non-disabled offspring, even if those rites of passage have to be modified to accommodate the person’s support needs. It is still important that we have the right to grow up! And parents should not be discouraged by medical professionals to not allow people with IDD be seen as able to grow as adults. In doing my work against mental age theory, some people thought I was supporting taking things of a person’s childhood away and promoting people only doing “age-appropriate” activities, which I am not supportive of that idea!

That is called normalization theory which says the only way to allow people with IDD to be adults is to not allow them to do activities associated with childhood. That is not helpful either. I know lots of non-disabled adults that enjoy things from their childhood and the same should be for adults with disabilities. It’s why it’s important people get to live the life they want to live and get

support to grow the way they want to grow!

That is my passion and that is how I do my advocacy. It is very personal to me. I am now 32 years old and have been blessed with a loving supportive husband and two beautiful children of my own.

I remember the fear my adoptive family had to go through thinking that I would not be able to get married and have children. I am glad they pushed me to keep trying to be more independent and allow me to explore adult things when I was an adult. They supported dignity of risk and that is something I encourage for all families with youth with IDD. Like when I hit puberty, my parents gave me education on sex and marriage and someday starting my own family. They didn't assume I would not be able to do it and did not need the information.

I was grossed out when I first heard about it, and I remember my mother saying, "You need to know this is important! I want grandkids someday!" She was right. I was able to know how to keep myself safe and not be misled by media and bad sources for that type of information that so many youth with IDD fall into.

Many schools don't allow students with IDD in segregated classes or "self-contained classes" information about their bodies and changes that happen in youth and what sex is. This hurts the community and sets people up for abuse and making bad decisions. This is just one of the ways mental

age theory still harms our youth by not giving them tools to safely transition to adulthood. That needs to stop and that is why I am passionate about making sure we end mental age theory and give every person with IDD the #righttogrowup!

I hope someday I will be able to go speak at big medical universities and help medical students see the harm of this theory and not spread this misinformation, but instead direct families to adult mentors with IDD who can help them see what adulthood with their child's condition is really like!

To learn the history behind Mental Age Theory and the harm it causes, see *Conversations with Ivanova: Mental Age Theory on YouTube*: bit.ly/mentalagetheory

Ivanova Smith is a passionate autistic and disability civil rights activist who was born prematurely in Soviet-occupied Latvia. Ivanova lived in an institutional orphanage until being adopted at age five and brought to live in the United States. Ivanova is an Activist Advocate with AtWork!, Chair of Self Advocates in Leadership (SAIL), a self-advocacy faculty member for UW LEND, and hosts Conversations with Ivanova at YouTube.
Email: ivanovas@atworkwa.org.



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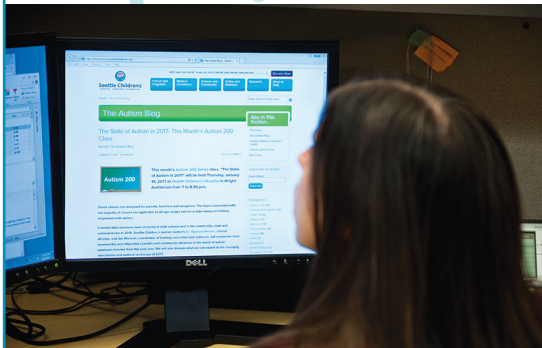
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3 Free Resources...

for Parents and Caregivers of Children with Autism from Seattle Children's Autism Center

The world of autism spectrum disorders is constantly changing and we at Seattle Children's Autism Center are eager to share with parents and caregivers the latest therapies, research, news and tips for families.



1. The Autism Blog

theautismblog.seattlechildrens.org

We provide information that may be helpful for raising a child with autism. Posts are written by staff including physicians, nurses, and psychologists who are knowledgeable about the diagnosis and latest in treatments and therapies. Parents and guardians also offer their perspective and share stories as guest contributors. Topics range from young adult transition to sibling support to new research findings to our perspective on the latest news and information about autism.

2. Autism 101

Available in-person at Seattle Children's or by live-streaming.

Autism 101 is a 90-minute presentation providing information and support for parents and families of children recently diagnosed with an autism spectrum disorder (ASD). Topics include up-to-date, evidence-based information about ASD, behaviors associated with autism, autism prevalence, treatments available and resources for families.



3. Autism 200 Series

Available in-person at Seattle Children's or by live-streaming. Watch past lectures on our website or YouTube®.

Autism 200 is a series of 90-minute classes for parents and caregivers of children with autism who wish to better understand autism spectrum disorder. Classes are taught by faculty from Seattle Children's and the University of Washington and other community providers. Topics include transition to adulthood, early intervention and school support. Each class includes time for questions.

Learn more or register at seattlechildrens.org/autism or by calling 206-987-8080.



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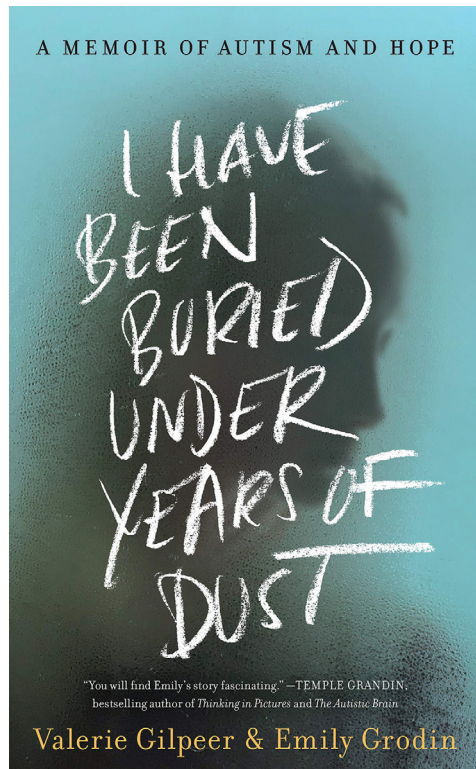
STORIES from the SPECTRUM

Autism from an Autistic perspective

I Have Been Buried Under Years of Dust

A Memoir of Autism and Hope

By Karen Krejcha



"I have been buried under years of dust and now I have so much to say."

Those 16 transformative words were 25 years in the making. Born with nonverbal autism, Emily Grodin's only means of communicating for a quarter of a century had been only one-word responses or physical gestures.

After a disastrous intercontinental flight from Ireland to Los Angeles when Emily was 25-years-old, a miraculous communication breakthrough came the following day. With the help of a trained specialist, a technique called Facilitated Communication, and an iPad, Emily's life trajectory changed forever.

On April 6th, 2021, Emily Grodin and her mom, Valerie Gilpeer published a remarkable memoir, *I Have Been Buried Under Years of Dust, A Memoir of Autism and Hope*. The story is about Emily's transformation from a nonverbal autistic woman to an amazing writer, straight-A student and passionate advocate for the voiceless.

We recently connected with Valerie and Emily to learn more about their exceptional journey.

Congratulations on your memoir! Please tell our readers a little about yourselves.

Emily is currently a college student majoring in Journalism. She is a 4.0 GPA student and truly loves to learn! She continues to write poetry and prose pretty much on a daily basis. There were lots of walks, hikes, and exercise, especially during the pandemic while we were pretty much in lockdown. Zooming became a way of life for her, as for everyone else.

Valerie is a retired attorney who spent 40 years practicing, the latter 20 of which were committed to civil and disability rights. She now volunteers with some nonprofits and consults privately with families.

How old was Emily when she was diagnosed on the autism spectrum?

Emily was 2 when she was diagnosed. It was a very challenging time. So much of our life had to change with the diagnosis as we were committed to doing everything we could to address her needs in the best way possible.

What methods of communication did you use in childhood through early adulthood to connect?

Valerie: Emily could give one or two words answers — and she did understand much of what was said to her — but not initially. Early on we could only try and sort things out based on her behavior. Even for most of her life, up through her breakthrough that remained our way.

Emily: I did not really have a system, we just fell into our own. I had a lot of one-word things I used and a lot of watching people when they talked to see their actions of the words. There were not any conversations that were two-way. I think my parents can get close to what I think from expressions. It's just intuitive between us, no method.

What is the significance of your book title?

"I have been buried under years of dust and now I have so much to say."

Those are the first words Emily typed out and we about fell over. That one sentence perfectly summed up 25 years of not being able to communicate. She hasn't stopped "talking" since.

Why are you publishing this memoir now?

The memoir was a way of shining a light on Emily. The story of our life is the back story to how she emerged as a writer. Mostly, I wanted to share her words with the world — her insights and observations, and experiences. There is so much that parents, educators, physicians, and the general public

can learn when this information comes from the person with autism, rather than filtered by professionals.

Tell us a little about Emily's journey with facilitated communication.

It's so hard to simplify in a few words a journey of 25 years in the making. It took 6 months of trying this form of alternative communication before she actually began to rely on it as a means of communication. Along the way, we were warned that it is a long and hard road to achieve any level of competency. But when she was ready, she had the breakthrough.

Valerie, what did it feel like to communicate with Emily after 25 years?

Quite amazing, but even more to be validated that what we believed to be true – Emily was a truly intelligent person. Her inability to share herself with the world verbally masked what was in her. Now, everyone can understand who she is and what is possible for those who are nonverbal or minimally speaking.

Did your husband Tom have a similar reaction?

Yes, we were both thrilled, astonished and grateful.

Emily, what did it feel like to communicate with your parents after 25 years?

It was a little frightening and exhilarating at the same time. It was something that is hard to explain because we were just used to the way it was. And actually, we were communicating, just not through typing. But it was a lot of explaining my feelings at first.

Valerie, what parenting advice would you give to parents of children who are either nonspeaking or mostly nonverbal?

If your child is not speaking by the time they are 6, get them an iPad and some support. Seek alternative forms of communication for your child and expose your child to as much of the world as you can. They are taking it in. Trust your instincts. If you feel a particular therapy is not working, step away from it.

Emily, what advice would you share for youth or adults who may not yet be able to communicate verbally?

First I will just say that communication comes in many forms. Verbal communication does not have to be the goal if something else works better.

But I will also say this. I did not know how typing would change my life. Don't let yourself fall into being content being silent. Find whatever it is that works best for you.

That is great advice. Where can readers connect with you and find your book?

The book is available through most bookstores for pre-order or order. Check out our website at www.valeriegilpeer.com or www.emilygrodin.com

Please follow Emily on Instagram @emilyfaithgrodin and Facebook: Emily Faith Grodin



Photo credit: Kelli Hayden, Kelli Bee Photography

Also see Emily's poem, *The Good Fight* in this issue on page 18.

I wish we had more space to continue this conversation. Would you be open to being interviewed on our Autism Empowerment Podcast?

Of course! Thank you.

(Editor's note: Listen to our follow-up podcast interview with Valerie in late April/May 2021.)

What else is important for Spectrum Life Magazine readers to know?

Being an Autism parent is not an easy journey, nor is it one that has a finish line. All you can do is your best. To the best of your ability, don't give up the fight!

Karen Krejcha is the co-founder of Autism Empowerment, where she serves as Executive Director. She is the Editor of Spectrum Life Magazine and host of the Autism Empowerment podcast. Karen was diagnosed on the autism spectrum in her 40s, after the diagnosis of her two children. She has been married to John for over 28 years and is devoted to promoting a culture of acceptance and empowerment within autism communities and worldwide.



The Good Fight

By Emily Faith Grodin

If you were to ask
all the ways in which
I have felt the need
to scratch at
and fight with
and challenge
I could write a novel
speak for hours on end
on those ways
because I still fight
every day
to live life the way
I want to.
The world does not bend for me.
Instead,
I bend to fit the world.
When there is no place for me
that I am able to see
I make one,
for all deserve the chance to be.
I will still fight
if I have to
still scream
if need be.
If life won't be what I need
I'll fight to make it right for me.

Emily Grodin is a college student studying journalism, psychology, and creative writing and has been recognized for her academic achievement. She recently co-authored "I Have Been Buried Under Years of Dust: An Memoir of Autism and Hope" with her mother, Valerie Gilpeer. Emily is an advocate for herself and members of her community in an effort to dispel the misconceptions and nonacceptance of those with autism. Visit www.emilygrodin.com

Photo credit: Kelli Hayden, Kelli Bee Photography





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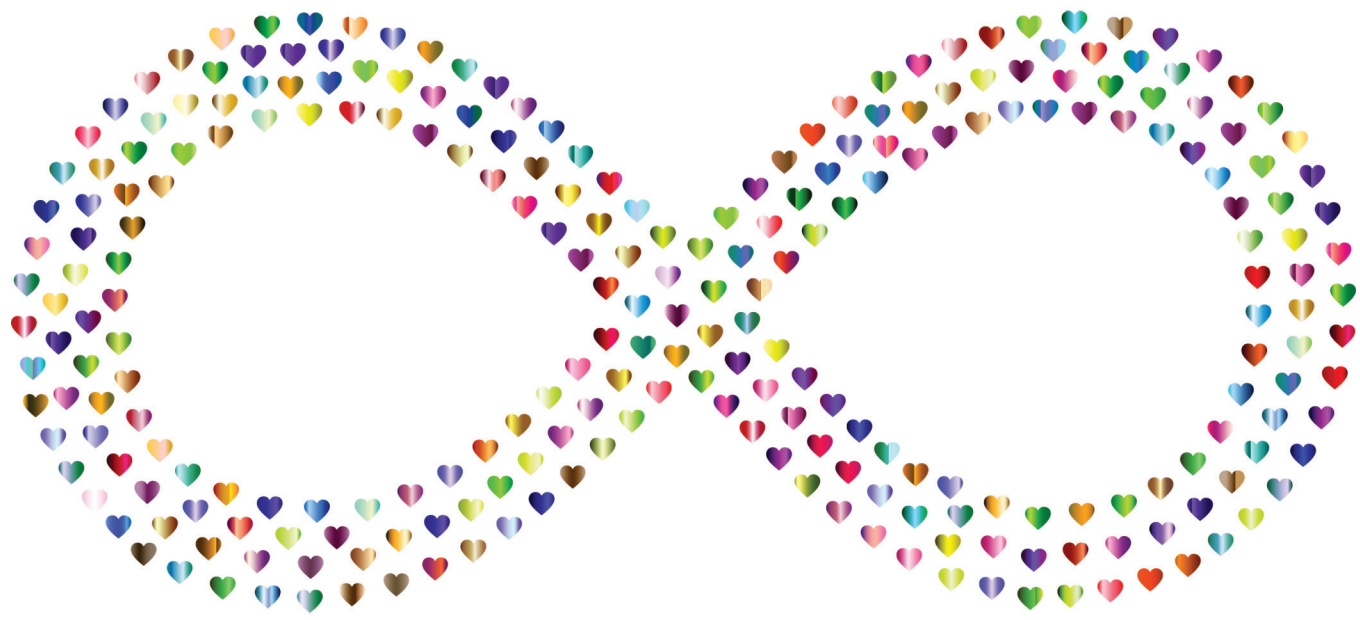



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WHY FIT IN WHEN YOU WERE BORN TO STAND OUT?

DR. SEUSS



Autistic Mate Crimes

What are they? What can we do about them?

By Dr. Anson L. Service



Geri is autistic and like most people, wanted to make a little money with a side hustle. She had an acquaintance who presented a short-term, low-cost business opportunity with big payouts. Geri's new business partner talked her into adding her name onto Geri's personal bank account because she was told it would be easier to make quick investment decisions to maximize profits.

Because they only agreed to a small amount of money as a total investment, Geri agreed. Over time, her new business partner withdrew money for small things that were somewhat related, but those withdrawals eventually were being used for personal reasons by her business partner. Over the course of the year, over \$5,000 was taken by her partner. She lamented her poor luck in business to another long-time friend, who informed her that she was likely being taken advantage of.

The police were notified. Geri's story ended up with a somewhat happy ending. She was able to get all of her money back with the help of a detective because Geri was considered vulnerable due to her autism diagnosis. However, Geri suffered serious emotional pain and now has difficulty trusting others.

An Autistic Mate Crime occurs when someone becomes a friend or acquaintance of an autistic individual and then purposely takes advantage of, or bullies them in some way.

Examples may include but are not limited to getting an autistic person to:

- commit a crime
- engage in risky drug or substance use behaviors
- engage in sexual behaviors
- lend or spend money on a person
- give away their things to other people that they really don't want to give away
- let others in their home to live or party
- give rides
- feel pressured in any way

One 2015 study¹ by the autism advocacy group, Autism Together, reported that 100% of autistic people between 16 and 25 years old have a hard time telling true friends from those who bully or abuse them. This shocking finding is in line with what I discover when interviewing autistic individuals.

Intellectually, they know the difference between a friend and a non-friend, but their spouses, partners, or parents often say that they have a long history of not knowing the difference in real-life situations. That is

when painful stories of friends taking advantage of them unfold. Autistic individuals who are in those crucial social years from mid-teens to mid-twenties are most vulnerable. This is when their social life is most important to them.

Why are autistic individuals more susceptible to being taken advantage of than neurotypical people?

Friendship Motivations: Many autistic individuals find it difficult to make and keep friends, a challenge they may have experienced since childhood. Friendship is not only important to most autistic people, but since it has been so hard to come by, they may be highly motivated to make or keep friends. It can be very lonely to be autistic, and others who recognize this may use it to take advantage of them.

Executive Functioning Challenges: Executive functioning has several components to it and is often problematic for those with Attention Deficit Hyperactivity Disorder (ADHD). I often see ADHD as a co-occurring diagnosis with autism.

An autistic individual with ADHD can have problems regulating their emotions and actions. They may feel their emotions so strongly that they have a hard time making sense of them in the moment, which can feel confusing and uncomfortable. They can also experience greater difficulty monitoring and controlling behaviors.

Many people are diagnosed with ADHD. However, when you add in the desire to make or keep friends, social challenges communicating true feelings and desires, fear of rejection, fear of not fitting in, anxiety, and other related issues, a person's vulnerability to be taken advantage of can be astronomical.

Genetics and Neurology: Some autistic people may also have a difference in the retinoic acid induced 1 (RAI1) gene which may be responsible for having greater trust in people and a diminished understanding of long-term consequences. When a friend asks them to do something, they feel wanted, useful, and good because of neuropeptides acting in their brain. They trust what they are being told is true and can be more willing to trade the consideration of long-term consequences for the short-term benefits of feeling good in the moment.

Shame and Embarrassment: Who wants to admit that they have been manipulated or taken advantage of? Who wants to be lectured or told they should have seen it coming? The embarrassment may be especially palpable if someone considers themselves smart and independent. Again, add ADHD to the difference in trust and long-term consequences, emotional and action challenges, difficulty "reading" people and not wanting to reach out for help because of embarrassment and shame, and you have a perfect storm in the forecast.

While we may have several reasons autistic individuals are more likely to be taken advantage of, the aftermath of this betrayal can lead victims to distrust those whom they really want to trust. They pull back from social situations that they are not sure about, and that can lead to depression, anxiety, and a host of other mental health issues.

Can you spot an autistic mate crime in process?

You might see changes in activities or friend groups, sudden changes toward unhealthy or risky interests, paying for other people's expenses, and defensiveness of new friends, to name a few.

If you are the victim of an autistic mate crime you can do something about it.

If you feel pressure in any way from anyone, it is okay to tell them you are feeling like you are being pressured. You don't owe anybody anything and you do not have to participate in any activity you are not comfortable with. You have permission to simply stop hanging out with them.

- Attend a support group for autistic people and you may find that others likely have had similar challenges and may have good insights and advice.
- If what someone is doing to you is illegal in any way, you can call the police and report it. They may be able to help.

Dr. Anson Service is a licensed mental health counselor, and part of a team that assesses individuals for autism, ADHD, and more at Adventure Psychological Services. Dr. Service has written for various magazines and authored several books and is happy to further educate others on autism and other areas of neurodiversity. He and his wife have raised three young men and are now raising their 1.5 pound puppy named Luna. To learn more, visit www.anson-service.com.

- Do not lend money to anyone without consulting with someone you trust whom you have known for a long time. A true friend will graciously accept "no" for an answer and will not pressure you to lend money. Never give money to someone approaching you in a parking lot asking for help with gas or money. Just say "no" and move along. If they start to bully you, say "NO" louder and then find someone who can help.
- Don't let people into your home unless you know them well and can trust them.
- Get a good therapist who knows autism well and can help you understand the intentions of others and how to deal with these issues.
- This last tip may seem obvious, but it is the most important. Do not hang out with anyone who mistreats you. Do not rush into any business with anyone. Avoid rushing into relationships, one-night stands, or other shenanigans.

The more I learn about autism, the more I realize that society really does not understand autism very well. It is difficult to help those who are autistic when we as a society cannot easily identify, let alone deal with autistic meltdowns, shutdowns, social differences, and traits that make the neurodivergent so vulnerable to this world that does not support them.

I think about the thousands of autistic people who have yet to be identified as being autistic and are suffering in a world that they feel is against them. I think about the many ways that autism presents in different people and it is clear that we have yet to even scratch the surface of understanding the neurodivergent.

Our city, state, country, and world must do better in helping identify autistic people as early as possible to help them navigate this wacky world we live in. **We must educate everyone about autism in a positive manner and see it as a difference, not a deficiency.** We must do better to protect those who have difficulty protecting themselves.

Those of us who have an understanding and a story to tell must make our voices heard by advocating to the government, the education system, and the medical community every chance we get. Most importantly, when you see an autistic person who needs some assistance, take time and gain the courage to help and protect them. Doing better starts with each of us in our everyday lives.

Reference:

1. *Mate Crime in Merseyside* (2015): www.autismtogether.co.uk/mate-crime



recreation

INCLUSIVE WAYS TO HAVE FUN



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Autism Rocks and Rolls Podcast..... 23

Autism Rocks and Rolls Podcast

Changing the World One Episode at a Time

By Karen Krejcha

Sam Mitchell is a motivational speaker, podcaster, and autistic advocate who strives to positively change the world for autistic youth and adults. Through his podcast Autism Rocks and Rolls, Sam combines his love for rock and roll music with autism advocacy, education, and human interest stories.

Spectrum Life Magazine recently connected with Sam and his mom Gina to learn about Sam's journey into podcasting, his favorite celebrity interviews, and the message he wants to share with the world.

Hello Sam and Gina! Please tell us a little about yourselves and your family.

Sam: I am Sam and I am a senior at my local high school. I love to write (creative writing), hang out with my dogs, and I LOVE WWE wrestling and can tell you anything about it.

Gina: I am Gina and Sam's #1 fan and his mom. I am an 8th-grade teacher of language arts at the same school Sam goes to. Sam is my life and helping him be successful is what I do. I also love to listen to audiobooks, other podcasts, and shop at thrift stores and flea markets. Sam's dad and my husband, Doug, is an electrician at GM and he is a huge supporter of Sam's podcast as well. We love dogs and have two Italian mastiffs, Lita and Phoenix.

Gina, how old was Sam when he was first diagnosed on the autism spectrum?

He was 4-years-old but he showed behaviors very early. He was a late talker, hated loud noises, had meltdowns if you moved his very organized toys, hated routine change, and we noticed he was a very out-of-the-box thinker at a very early age.

Sam, what inspired you to get into podcasting, and how old were you when you started?

I started with my high school media club when I was a sophomore in high school. I went to a Riley Dance Marathon at my school and saw the microphones and cameras. I asked what they were doing, I joined, fast forward, boom. Here I am. I started my own podcast and it has really taken off big time. I started Autism Rocks and Rolls as a hobby, but now, I am making money, getting sponsors, and love what I am doing. I started it to simply help people that have had struggles like me. I then saw a chance to monetize it while still helping people.

Gina Mitchell:
Mom/Manager/#1 Fan



Gina, what did you think when Sam told you he wanted to be a podcaster?

Honestly, I was not going to stop him, but I was concerned that it would not work. Little did I know that Dr. Temple Grandin would call me on my cell phone, Simon Majumdar would become a friend of ours and we would get to a point that we had a hard time keeping up with daily emails from people that listen to his podcast and request for him to be on other podcasts and featured in newspapers, magazines, etc.

It is overwhelming but such an amazing feeling that those around him believe in what he is doing. As a mom, I can sigh now. When you have a special needs child, you just don't know what their future holds. I now can see that his is very bright and he is going to be okay.

Why did you choose the name "Autism Rocks and Rolls" for your podcast?

I love rock music and we combined this with autism. We also looked at name availability. There wasn't another podcast called this.

What is the format of your podcast?

I have a home studio in my basement apartment. I have a soundboard and four mics. It is not live, it is only audio, and it is recorded so that I can edit it after recording. I publish every 13 days, so 2-3 times a month. My sponsors have gotten me other programs, such as Poddit and Podmatch, to help my business grow and other items that I appreciate so much.

How long have you been podcasting for and how many episodes have you completed?

Since October 2019 and 34 episodes. Almost 4,500 downloads so far.

Continued on page 24

How do you market your podcast?

My mom, my editor, and manager of everything behind the scenes uses all forms of social media (Facebook, Instagram, TikTok, Twitter, Snapchat, LinkedIn). She uses Google Analytics through my website, advertises sponsorships and handles all of the platforms where you can find my podcast (Podbean, ListenNotes, SoundCloud, YouTube, iTunes, Apple Podcasts, Stitcher).

She also uses TONS of Facebook groups and manages all of my contacts. We also have sponsors, Wellspring Pain Solution, Commercial Service, Perfection AutoGlass, CPA Tax Service with Stephen Miller, Greene County General Hospital, Fowler's Farm, Little Blu Chocolates, Little Blue Tattoos, Lifepaths Counseling Services, and Bells Built Automotive. They have helped me tremendously to make things grow exponentially. My mom makes so many contacts and so many people contact her.

Considering your autistic neurology, what do you think are your biggest strengths and challenges and how do they tie in with your podcast?

Strengths: Ideas I come up with. They are totally out of the box, but this would fit into a podcast about autism. Also, many experts call what people on the spectrum do "obsess." I call it "success." If I want to talk about something, I know a lot about it. This type of knowledge, to my family and me, is a strength. This knowledge and behaviors of those on the spectrum can lead to lots of things after high school. Like Dr. Temple Grandin said, those on the spectrum need to tap into those abilities instead of being excluded, thinking we are disabled and can't be successful. We can be. That is my mission, to show that.

Challenges: Where do I go next? I get anxious about what my future holds. Do I keep podcasting or will this lead to something big, which I hope it does?

I get stressed too. I am a senior, and I am getting ready to go to college, start my real life, and run a business. My mom works full time and does this as a second job with no pay. She works hard and has no time for herself. But she does it for me. My dad works a lot of overtime so that I can have time to do what I do. I appreciate them so much.

We understand that you interviewed rock singer James Durbin from *American Idol*. Tell us about that experience.

It was a good experience. He was very cool. He was completely chill. He has autism and Tourette's. He is an example of success even though, like me, he has had challenges. He is a father, is married, and is a very talented musician. He called his autism a condition, not a disability. His abilities overshadow his autism really.

What have been some of your favorite interviews?

My very favorite interview was with Simon Majumdar, the Iron Chef from shows like *Cutthroat Kitchen*, *Iron Chef America*, and *Guy's Grocery Games*. He plays for autistic charities and when I reached out to him, he was glad to be on the show and help me out. He is an amazing person. He is very humble and my mom and I still talk to him. Dr. Temple Grandin was my second favorite interview. She is phenomenal and I look up to her so much. She is so blunt,



which is great. She commands respect and she deserves it. She has changed the autism world and perceptions for so many.

Who would you like to interview that you haven't had a chance to yet?

My ultimate guest is Mick Foley, the WWE wrestler. He has a son on the spectrum and he is my favorite wrestler. That would be a dream come true for me. Secondly would be Lt. Joe Kenda from *Homicide Hunter* and *American Detectives*. After he retired, he drove a special needs school bus which I admire so much. I am also interested in forensic science when I watch the show.

Lastly, Gordon Ramsey. He is on *Hell's Kitchen*, *Kitchen Nightmares*, and *Master Chef*. He is so blunt, but he has moments where he has a heart. My mom has a list too: Dan Akroyd (who is on the spectrum), and my mom would love for us to be on *The Ellen DeGeneres Show*, which would be the ultimate promotion for my podcast.

What goals do you have for your podcast?

I want to keep growing as much as I can. I want to learn all about media as much as I can. When I go to college, I think I want to major in media and entrepreneurship. I want to make this a business, which means I want to be a public speaker to tell my story, offer some podcast coaching and/or teaching, get more sponsors, sell merchandise, and be able to have this be my job.

What advice would you give to another autistic teen or adult out there who might like to start their own podcast?

Go for it. It is trial and error. If you run into walls, try something else. If it is working, keep going with it. Do. Not. Give. Up.

Where can readers connect with you and listen to Autism Rocks and Rolls?

Autismrocksandrolls.com, all of the social media platforms, Poddit, Podmatch, and I am on all podcasting platforms.

I wish we had more space to continue this conversation. Would you be open to being interviewed on our Autism Empowerment Podcast?

YES. (Editor's note: Look for Sam's interview on the Autism Empowerment Podcast in April or May 2021.)

What else is important for Spectrum Life Magazine readers to know?

I am not broken. The stigma on autism needs to go away. I do not need to be fixed. I am successful, with autism. I don't want to change. I embrace who I am. I have a lot of abilities because I have autism. This is what society needs to understand. Do not feel sorry for me. I am Sam first. I just happen to have autism.



SAM MITCHELL | AUTISM ROCKS AND ROLLS PODCAST

education

KNOWLEDGE TO EMPOWER FAMILIES AND INDIVIDUALS



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KhAnubis on YouTube

Answers to questions you didn't even know you had

By John Krejcha

Every other Sunday, my 14-year-old and I try to see who can be the first to watch the new video that KhAnubis will post to his YouTube channel as both of us love geography and learning about our world.

The KhAnubis YouTube channel is dedicated to teaching its viewers about the world and how everything works. It is education made fun. From facts about Luxembourg to important tips for going through immigration while traveling internationally, you can learn a wide variety of things. His video, "The Anthems You're Not Supposed to Sing - Behind the Anthem" recently reached over 1 million views.

I was excited (geeked out to be honest) to have the chance to interview Willie "KhAnubis" Rates and learn more about how this entrepreneurial autistic video maker and EduTuber is helping to make our world easier to understand.

Hi Willie. Please tell us a little about your background.

I'm originally from the Washington, DC area (born in nearby Silver Spring, Maryland), and moved to the Portland area when I was 8, where I currently live, at least whenever I'm not living in Berlin, Germany. I have one sibling, a younger brother named Jake, who is more severely impacted by autism and is nonverbal. I myself have Asperger's.

What is the history behind your KhAnubis YouTube channel?

I first started back in 2009 making stop-motion animation videos with my Playmobil toys. I have always enjoyed the idea of using film and video to tell stories and educate others, so I suppose it's no wonder YouTube drew me in so much.

I eventually figured out how to use iMovie to put together these short films, though at first, the only way I knew how to make them was by putting all the pictures together in this animation program called Scratch... and then recording the screen with a camera.

Around 2012 to 2013 though, I began to watch more educational YouTubers like Vsauce, CGP Grey, MinutePhysics, Crash Course, etc. and also enjoyed what they were doing. So I gradually phased out the Playmobil videos in favor of the more explainer-type videos I make today. I still used iMovie for the first couple of years, so I liked to joke that these videos were like "glorified slideshows" in terms of production quality. I finally started editing with Final Cut Pro in 2016, which is what I've been using ever since.

My channel barely grew at all during all that time, only reaching 1,000 subscribers by summer 2017. After joining



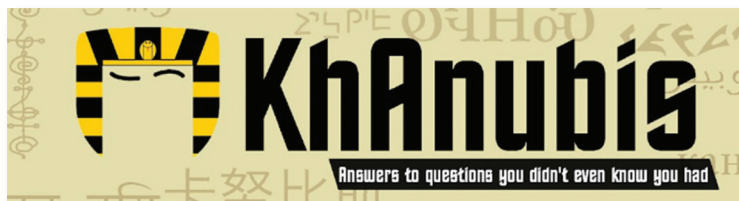
a community of fellow educational YouTubers (EduTubers) called WeCreateEdu, the channel started to grow more quickly, eventually exploding from 4,000 to more than 20,000 subscribers in November 2018 after posting a video titled "How the Soviet Anthem Became a Meme" (and presumably also having a large stockpile of other videos for new subscribers to watch).

What does KhAnubis mean? Is there a story or reason for this name?

Okay so this is kind of a nerdy, over-specific story, but when I was 9 and still deep in my Ancient Egypt phase, I saw the movie *Night at the Museum 2*. The main antagonist of the film was a fictional pharaoh named Kahmunrah, which I at the time thought was a portmanteau (a word blending the sounds and combining the meanings of two others) of 'ka' (which I also thought was spelled 'kha') and Amun Ra (chief of the Egyptian gods).

Nonetheless, I thought it would be a cool idea for a name but naturally, I didn't want to just copy off that name, so I thought of other Egyptian gods with names beginning with 'A', which meant Anubis, and thus... KhAnubis. I also capitalize the A to emphasize the connection to Anubis, though people don't always seem to get the message about that.

Continued on page 28



What draws you to Egyptian culture?

Something Asperger's means for me (especially as a kid) is that I have different phases in my life where I'm deeply fascinated and obsessed with a specific topic, but that topic may also frequently change, and this obsession with Egypt only really lasted for about a couple years when I was 9 and 10. I have no idea what first drew me in about it so much though. I must have just been fascinated because at that point, I never really learned about them in school.

We've heard you're quite the world traveler. Where are some of your favorite places to visit?

So far I've been to 21 countries across four continents. Of the cities, I would say my five favorites are Berlin, Germany; Hong Kong; Amsterdam, Netherlands; Istanbul, Turkey; and London, UK (though this is far from an exhaustive list).

How does your autistic neurology impact you when you travel?

I guess one plus (for me personally) is that I'm really good at memorizing maps — especially of metro systems — of different cities, so I kind of always have a kind of internal GPS in my head.

Whenever I start a trip and arrive in my first city though, I have found it best to immediately go to my hotel and spend the rest of the evening there, which I guess kind of gives my brain the chance to fully digest that we are not at home, which I've found lets me better enjoy my trip. I only really get sensory overload in extremely loud or overwhelming places though, so personally, I just try to avoid those places wherever I can.

We've got to ask about the hat. What is the story there?

I went as a pharaoh for Halloween one year and eventually got so attached to the hat that it just felt weird not wearing it. If I'm completely honest, a large part of me wants to retire it

(at least in everyday life) just so I can go around like a normal person again.

Where do you get your ideas for your explainer videos?

You know that moment when you're sitting around doing nothing or taking a shower or doing some other work? Yeah, that's when I'll usually get some of my best video ideas, and whenever I do, I have a Google Docs document full of different ideas, which I may come back to if I need a topic for a particular week.

How long does it usually take you to create, edit and publish a video?

Now that I make my videos on a two-week schedule, I usually spend about a week researching and writing (which for me is the same step, because writing the script is actually how I personally learn the subject matter best), and then probably 5-7 days editing. Then, if a video has a sponsor, I'll send it over to the sponsor about a week early so they can review it and make sure they're comfortable with how I present them in the ad at the end. Because of the sponsorships, I actually staggered my schedule by a week, which means whenever I release a new video, I've probably already finished the script for the next one.

You've now passed 110,000 subscribers on YouTube. That's awesome! How did you celebrate passing 100,000?

I hit 100k back in November 2020 and we didn't really do anything special on that day, but in the weeks after, I applied for YouTube to verify my channel (that little checkmark next to my channel's name, which I got within a few days). Then about a month later, I got my silver play button award, which is basically this big slab of silver with YouTube's logo embossed at the top, and with the text "Congratulations to KhAnubis for passing 100,000 subscribers" at the bottom. It was really exciting to receive that because I had made it a goal to get my play button sometime in 2020.

How long did it take you to monetize your channel?

I believe I first got monetized back in 2014 or 2015, but getting monetized back then was very different than how it is now. Nowadays you need a minimum of 1,000 subscribers and 4,000 watch hours on your videos (i.e. people have watched your videos for a cumulative total of 4,000 hours).

As far as how long it takes, everyone is different, some may reach that in a couple of months, while others might take a couple of years.

What advice do you have for autistic youth or adults who might want to start their own YouTube channel?

Well first, if you're asking about money, my greatest advice would probably be: don't do YouTube just for the money! Growing a YouTube channel is a labor of love and not something you should do purely for the money, because the truth is we don't always make that much (which is why we have to ask brands to sponsor our videos or our fans to support us somewhere like Patreon).

Continued on next page

In general, however, I'd say my greatest piece of advice for an up-and-coming YouTuber is to remember that growing a YouTube channel takes a really long time, so if you've had your channel for two years and still have 100 subscribers, that's completely normal! I would also say that, while making good videos is really the key to growing big on YouTube, if you're just starting out and you think your first videos are going to suck, let them suck! Even if you aren't proud of your first videos, making videos and putting them out is how you learn to make better and better videos!

Do you have any plans for future expansion of KhAnubis?

Oh absolutely! In the near future I really want to take on someone to help me out with the art and/or animation, as well as maybe someone to help me with the scriptwriting and research, once I have enough money to be able to pay them of course. I've also been working on expanding to another channel called Celestium, which will be all about space, space exploration, and the future of humanity in space.

What else is important for Spectrum Life Magazine readers to know?

Talking especially to parents of children on the spectrum (or children in general really), the best thing you can do for your child is allow them to be who they are and follow whatever passion they want to pursue.

To watch and subscribe to KhAnubis on YouTube, visit: www.youtube.com/khanubis
Learn more about upcoming projects at www.KhAnubis.tv



John "King Tut" Krejcha is co-founder of Autism Empowerment and serves as Programs Director. He serves on the Editorial Advisory Board of Spectrum Life Magazine and is a guest host for the Autism Empowerment podcast. John is married to co-founder Karen Krejcha and is the father of two amazing children and their feisty cat, Zula. While John is the only one in the family who is not on the autism spectrum, he identifies as a neurodiverse and loving ally.



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How Do FERPA and HIPAA Affect Your Child in Special Education?

By Diane Wiscarson and Susana Ramírez



Laws that affect students receiving special education services can be daunting to parents, especially for issues that fall outside of the Individuals with Disabilities Education Act (IDEA). Parents often ask how other federal laws affect their child at school, such as the **Family Education Rights and Privacy Act (FERPA)** and the **Health Insurance Portability and Accountability Act (HIPAA)**.

Parents may not understand privacy rights and may have questions about protecting their child's personal information, such as who the school district can release records to, protecting a child's health information, or why the school won't give the name of the student who is bullying their child. These types of information are protected in different ways under both FERPA and HIPAA.

What are FERPA and HIPAA?

FERPA protects the privacy of a student's education records, limiting when information can be disclosed and to whom. Student's education records are everything the school maintains about the student – including attendance records, evaluations, Individualized Education Programs (IEPs), Behavior Support Plans (BSPs), behavioral records, medication administration, report cards, etc.

FERPA also gives parents the right to inspect, review, and request corrections to their child's education records. When a student turns 18 or attends a postsecondary educational institution, the student is considered an "eligible student" and those rights transfer from the parent to the student.

FERPA applies to educational institutions like schools, colleges, and universities that receive federal funds.

FERPA limits information a school can disclose and protects personal characteristics or other information that would make a student's identity easily traceable. Under FERPA, personal information includes, but is not limited to:

- a student's or parent's first and last name
- a home or other physical address (including street name and the name of the city or town)
- a telephone number
- a social security identification number
- a student's date of birth, place of birth, and their mother's maiden name.

HIPAA protects the privacy of health information, specifically an individual's identifiable patient information. HIPAA applies to covered entities, such as health care providers, health plans, and health care clearinghouses that maintain and transmit health information in electronic form. Schools are not generally subject to HIPAA because a student's health information is considered an education record under FERPA. Schools must follow FERPA, not HIPAA, when personally identifiable and health information is shared for Medicaid billing and parents sign consent under FERPA. However, HIPAA rules may apply in some situations, such as how to transmit health records.

In rare cases, if a school operates a medical clinic open to students, family members, and staff, then it is considered a HIPAA-covered entity. Under this scenario, the school could be subject to both HIPAA and FERPA. The records of non-student clinic patients would be subject to HIPAA requirements, while the student patient records might instead be subject to FERPA.

Differences between FERPA and HIPAA

FERPA protects education records, while HIPAA protects health records. The real difference comes down to who maintains the record, not who created the record. Records that are maintained by a school district usually fall under the definition of "education records." If a record is considered an education record, it is protected by FERPA and not by HIPAA. A student record covered by FERPA cannot also be covered by HIPAA.

For example, if you sign consent for your child's pediatrician to send records to the school, the transmission of the records from the doctor to the school is covered by HIPAA. But if you sign consent for the school to send records to your child's pediatrician, the transmission of those records is instead covered by FERPA.

Parent Rights under FERPA

Under FERPA, parents (or eligible students) have the right to access, inspect, and review their child's education records. Parents also have the right to copy education records. Parents can try to amend or delete a record that is misleading, inaccurate, or violates their privacy. FERPA also addresses the destruction of records and grants parents the right to file a complaint if a violation occurs. Schools must notify parents and eligible students of their rights under FERPA annually.

A school generally needs a parent to give written consent, including the date and purpose of the release, in order for records to be shared with a third party. This includes sharing education records with your child's doctors, private counselors, or other providers.

When can my child's records be accessed without my consent?

A school district does not always need a parent's consent to share a child's education records. Student data can be shared by a district without consent if it is shared with someone that has a legitimate educational interest in the student. This includes sharing student records with teachers, principals, assistants, or volunteers, as long as the individual needs the student's information to fulfill their duties.

Student data can also be shared without consent when a student transfers to another school, for purposes of an audit, financial aid, to comply with a judicial order, or if there is a health or safety emergency. Schools must make a determination on a case-by-case basis whether a situation qualifies as a health and safety emergency but it must be related to an imminent emergency to protect the student or others from a significant threat.

Directory information can also be disclosed by schools unless the parent has been given a reasonable amount of time to request that the school not disclose directory information. Directory information is defined by information in a student's education records that is not considered harmful or an invasion of privacy if disclosed. Directory information may include, among other things, a student's name, address, telephone number, e-mail address, photograph, date and place of birth, grade level, dates of attendance, awards received, and most recent school attended. Directory information never includes a student's social security number.

Consent may also not be required in situations where schools contract with outside professionals for services or functions, such as conducting evaluations or threat assessments.

How do FERPA and HIPAA affect my child in Special Education?

While FERPA, and sometimes HIPAA, apply to all students in public schools, it seems issues come up more frequently with special education students, given the nature of the special education process. Special education students tend to have additional records in their educational files, such as

evaluations, IEPs, progress data tracking, medical diagnoses, and other information not likely found in the file of a student who solely participates in general education at a school.

FERPA issues also come up when parents request information about what is going on with their child at school. When this involves interactions with peers, school districts are bound by FERPA rules and cannot give information to a parent about another student. For example, a child may come home and tell parents they are being bullied at school. A parent naturally will ask the school for more information and want to know who the other student is, and whether the other student is going to be disciplined. The school cannot, and should not, give the parent any personal information about the other student. If a district shares the name of other students involved in an altercation, it may be a FERPA violation.

Conclusion

FERPA and HIPAA are extensive bodies of law which can be quite confusing. Generally, records maintained by elementary, middle, and high schools are generally covered by FERPA, and not HIPAA. Even medical information, such as immunization records or treatment notes from a school nurse that are created or maintained by the school, are considered education records and therefore fall under FERPA and not HIPAA.

FERPA is the law parents need to be familiar with in order to protect their children's confidentiality and right to privacy at school. If you believe your child's information has been disclosed by a school district in violation of FERPA violation, you can file a complaint with the Department of Education.



Diane Wiscarson is the founding attorney of Wiscarson Law, the only firm in Oregon with a primary practice area of special education law for families, and has represented thousands of families of special education students in Oregon and Washington. **Susana Ramirez** is a special education advocate who previously served 18 years at Disability Rights Oregon, as a citizen member on President Obama's Committee for People with Intellectual Disabilities, and as founder of *Padres en Acción/Parents in Action*, a nonprofit organization that supports and mentors Spanish speaking parents about their rights, and their children's rights, to become valued members of their communities living a self-determined life.

Teaching Autistic People

We can all learn when supports are in place

By Judy Endow, MSW, LCSW



conscious attention and effort must be brought to regulate whatever systems need regulation. For most autistics I work with, the sensory system is so dysregulated that it masks emotional and movement dysregulation.

External Regulation

(interactive visual schedule) – It really helps to know what is going to happen when – the schedule of events. Most students have a neurology that can pick up this sort of information without being instructed. They can sort out the spoken words of the teacher. Students with

Just like people of all ages can learn, so is it that autistic people of all ages can learn. It is an utterly sad state of affairs that this even needs to be said, but unfortunately, it needs to be said. Too often, I see autistic children being babysat rather than being taught at school. When I ask about the academic curriculum being used, I am told, “Oh, he has autism,” as if this is an answer to my question.

In my work as an autism consultant, I am called on to go to public schools to see autistic students who are thought to be failing what the system has to offer. Most of the time, students I see have behaviors that don’t work well in a school setting. For all students I am called in on, I use the stabilization techniques below, which are also the first steps I use when teaching autistic students if the student is not stabilized.

This is why I can say that even when your student has autism, including when behaviors are present, he can learn just like any other student can learn. Autistic people are just as deserving of an education as other human beings. That being said, specific supports must be in place to ensure access to that education. After all, nobody can do math (or any subject) when they are literally bouncing off the wall (a sign of extreme sensory dysregulation).

Stabilization

Internal Regulation (sensory diet) – Autistics have a neurology that means many systems (sensory, emotions, movement) in their body do not automatically regulate. This means

autism typically have weak auditory processing abilities. Their neurology may not allow them to take in verbal words, sort out which words are relevant and process those words to understand what will happen next. This means every transition from one activity to another can hit them as a huge surprise, causing further dysregulation.

When typical students are distracted and miss the teacher’s verbal instruction of “get out your math books now,” they usually become aware that the other students are getting math books out of their desk so they know they are meant to get out their math books too. Autistic students do not pick up these external cues as readily.

Even when they see other students getting out math books, autistic students do not necessarily take that to mean they should also get out their math book. This has nothing to do with cognitive ability. It has to do with weak connections between areas of the brain – several areas of the brain working together to synthesize environmental, social, emotional, and other kinds of information to inform them “I need to get out my math book.”

Visual schedules support this issue for most autistic students. It is often helpful for the schedule to be interactive – meaning the student needs to do something with the schedule before each transition.

Relationship – Most students I have been called on to consult for have experienced much angst along the way. They know

they are not like other kids. They may or may not know they have autism. **One thing I find is that students who are able to communicate are very aware they are different from other kids and they have made up a narrative to explain their differences to themselves.** I have been honored by a number of students sharing these stories about why they are different. I have yet to hear a positive story. They are typically stories about major character flaws, sometimes character traits they have heard others ascribe to them such as lazy, stubborn, willful, violent, refuses to share, refuses to co-operate, etc.

As I begin working with new students, I typically use a simple interactive schedule to show them “work” and “sensory break.” I ensure they are successful at following this schedule, even if it means we work for a few seconds and engage in sensory regulating activities for a much longer time. I am visually instructing how schedules work while getting the student’s sensory system regulated and doing that in the context of forming a positive relationship.

Most students I see have not experienced a lot of positive relationships. They have learned not to trust others around them. I am giving them an exact visual of the way our time works. They can count on it, become part of it, and will always succeed. Over time strong relationships develop. Once a relationship is solid, we know what sensory activities are needed (along with how long and how often) and the student has mastered his interactive visual schedule, I know he is now stabilized. Once stabilized, we are ready for more formalized instruction.

Instruction

Identify and Teach Needed Skills – Besides academic instruction, students with autism often have particular skills for which they need to receive direct instruction. This can be anything from how to open a milk carton to waiting for the teacher to call on you when your hand is raised before contributing. It is helpful to identify a few of the skills that are deal-breakers to your student getting along in the classroom. Learning and using these skills can be intertwined with academic content and other parts of the day.

Ensure Success by Decreasing Task Demands – Differentiated instruction is one way to reduce educational task demands to match the needs of an individual student while ensuring them the opportunity to learn along with their peers even though they may not have the same personal resources to bring to the task.

My favorite person when it comes to differentiating instruction is Paula Kluth. Every student can do something. If you need ideas on how to use general education curriculum for students with autism who you think cannot do general education curriculum please look up Paula’s work. (paulakluth.com)

My favorite people when it comes to a discussion about decreasing task demands are Ruth Aspy and Barry Grossman of The Ziggurat Group. (www.texasautism.com) An example of decreasing task demands for a student who struggles with handwriting is to take handwriting off the table in all subjects except handwriting instruction. Perhaps a scribe is used to do the actual handwriting task or an app such as Dictation Dragon, which means he can now do creative writing through dictation. If the student is an efficient typist, perhaps that is the way to go,



which means the student can now do social studies assignments that involve answering questions with a paragraph.

Reinforcement – There is significant brain research that shows students with autism do not benefit from the same kind of social reinforcement that typical students do. For typical students, in general, the more social opportunities you can add into instruction and use for reinforcement, the more learning that takes place.

For students with autism, social reinforcement and adding social aspects to learning detract rather than enhance learning. Tangible reinforcement tied to learning has been shown to work better than social reinforcement. In fact, it has been the ticket to learning for many autistic students.

NOTE: I realize ABA therapy has had a history of using reinforcement in a punitive manner tied to repetitious drilling, often quite disrespectfully. This makes punishment, demeaning drilling, and disrespect wrong. It does not make reinforcement wrong. All human beings benefit from positive reinforcement.



Judy Endow, MSW, LCSW maintains a private practice in Madison, Wisconsin providing consultation for families, school districts, and other agencies. Besides having autism herself, she is the parent of three grown sons, one of whom is on the autism spectrum. Her newest book, *Autistically Thriving* can be purchased at www.judyendow.com.

health & wellness

DEVELOPING A SENSE OF WELL-BEING AND WHOLENESS



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C H E S S
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Virtual Personal Training

Specialty Guidance and Accountability

By Ryan Lockard, CSCS*D, CSPS*D



Imagine that you walk into a room and are instantly paralyzed by the bright lights. While standing there motionless, erratic and unpredictable sounds are so loud that you can't hear anyone speak, even though you see lips on the blurred faces moving everywhere as you observe the room. There is a weird aroma in the air, part Axe body spray, and part body odor. The aerosol from the body spray and other cleaning agents in the air quickly overwhelm you and make you feel that someone has a death grip around your throat. Welcome to the weight room.

Aside from feeling intimidated by all of the machines and not knowing what to do or where to start, the experience described above can also make visiting a fitness facility a nightmare for many. This is especially true for Specialty Athletic Training clients who experience sensory processing issues or who have been diagnosed with Sensory Processing Disorder (SPD).

Even with these challenges, exercise still needs to be a part of daily life for these individuals in order to decrease other comorbidities that may arise and live a prolonged and healthy life. Virtual training can be (and has been for many) a great alternative to visiting the gym.

People seek personal trainers for several reasons, but they usually are seeking guidance and accountability. Connecting with a trainer who provides a virtual training option can provide both benefits without the negative in-person gym experience.

At Specialty Athletic Training, our virtual training option has been our lifeline throughout the pandemic. With all of the regulations that have been placed on gyms over the past year, offering online training to the people we serve has allowed us to still be able to work with our clients in 1:1 and group settings. It has enabled us to keep our sense of community and our clients active. Both have played a crucial role in maintaining their mental health during such an anxiety-ridden time in our history.

It has also allowed others to have access to our services that they may not have received prior to COVID. Proximity to the locations we offer training has been a barrier to access in the past; however, virtual training has made it possible for us to work with clients worldwide and provide services to our clients while they are on vacation.

Although virtual training can be a great alternative for many, some need and crave our in-person instruction. The word "struggle" doesn't even begin to describe the experience that some of our clients have had with "distance learning" over the past year, let alone trying to receive workout instruction via a computer screen. We take pride in building relationships with our clients, which in turn leads to earning their trust. This can be difficult without the in-person experience.

Our approach is to make fitness fun and encourage self-esteem building and healthy lifestyle choices. We are passionate about the positive effects that exercise can have in the lives of our clients and their families.

We have worked with over 450 individuals with a wide range of disabilities and health care needs, including but not limited to Autism, ADHD, Cerebral palsy, diabetes, Down syndrome, Alzheimer's disease, Parkinson's disease, and Williams syndrome.

Virtual training can provide the guidance and accountability that one may need to stay on track to reach their health goals without stepping foot in the typical gym setting. It has allowed us to remain a part of our clients' lives, even though we haven't been able to see many in-person since March 15, 2020.

We look forward to the day when individuals will have the option of accessing our services physically at one of our Oregon or Southwest Washington locations or virtually worldwide, whichever best suits their needs.

If you are interested in virtual fitness and training options for yourself or a loved one, please visit www.SpecialtyAthleticTraining.com or call 503-863-0512.

Ryan Lockard is the Founder and CEO of **Specialty Athletic Training**, a personal training company located in the Portland Metro area and Central Oregon, that specializes in fitness programs for children and adults with special needs. He is a Certified Strength and Conditioning Specialist (NCSA), Certified Special Populations Specialist (NSCA), and currently serves on the board of directors for the Autism Society of America and the Central Oregon Disability Support Network. He can be reached at Ryan@SpecialtyAthleticTraining.com or www.SpecialtyAthleticTraining.com.



Photo courtesy of Lavinia Nitu - Ma.Ni. Photo Studio

TriStar Family Chiropractic and Scoliosis Center

Managing health from the inside out.

By John Krejcha

Serving the Vancouver, WA area for the past six years, TriStar Family Chiropractic and Scoliosis Center specializes in providing personalized inclusive chiropractic care for all family members. Their founder, Dr. G. is a true local champion for underserved populations and a national speaker.

Spectrum Life Magazine recently connected with founder Dr. Gloria Arroyo, DC, BA, BS to learn more about how their award-winning practice helps support families and teaches family members how to view and manage their health from the inside out.

Hi Dr. G.! Please tell us about TriStar Family Chiropractic.

On January 1, 2015, I woke up from a dream that I had opened my own specialized wellness center and I saw three angels holding a sign with the name “TriStar” and so I grabbed my phone and started a blog with that name on Facebook. In less than 30 days of sharing family wellness tips, specifically for families on the spectrum, survivors of childhood trauma, scoliosis reduction information, and concussion wellness, I had a great following. I am a mom of three kids and with three angels by my side, I was encouraged to follow my dreams!

TriStar Family Chiropractic and Scoliosis Center opened in August 2015. We specialize in pediatric mental health and have wellness programs for individuals with Autism, Asperger’s, developmental disabilities and dementia. We also offer scoliosis reduction and spinal/postural correction.

Do you have a personal connection to someone on the autism spectrum?

In 2001, I almost lost my son at birth and unfortunately, he was diagnosed with neurological delays due to oxygen deficiencies. We were told that he may have permanent neurological delays and required various years of assessments. After a few years of cognitive evaluations, he was diagnosed with Asperger’s.

At that time, I researched, studied and watched so many seminars and lectures about the spectrum since it was a fairly “newer topic” in healthcare. That is when I learned about alternative therapies that could help my son’s development including toxin-free nutrition, heavy metal detoxing, chiropractic care and acupuncture to name a few.

When my son was six, I was so enamored with wellness care and how it had helped my family’s health that I decided to go back to school and pay it forward by becoming a Chiropractic Physician.



In what ways can chiropractic care support youth and adults on the autism spectrum?

The simplest way I help all individuals on the spectrum is to “unkink” the full nerve flow from the brain to every organ, tissue and cell in the body. Your spinal cord is an extension of your brain and then branches out to your entire body wired with a complex system of nerve “highways”.

These “highways” are protected from the brain stem to tailbone with 23 moveable joints and bones called vertebrae. Your brain and spinal cord are the ONLY two organs in your body completely covered by bone. Therefore, I gently remove tension on the nerves that causes inflammation that over time causes increased behavioral episodes, gastrointestinal disturbances, focus issues, bedwetting, etc.

People on the autism spectrum may often have low muscle tone. How can chiropractic care help with this?

Some people on the spectrum have a very high pain threshold (insensitivity to pain), while others have very low pain thresholds due to moderate to severe loss of muscle tone, which can limit their gross and fine motor skills.

In the past nine years, I have co-managed with physical therapists, occupational therapists, and speech and language pathologists to help strengthen the areas of weakness. In my practice, I utilize neuromuscular re-education techniques with different modalities as well as gentle traction type of adjustments and manual therapy on low tone muscle groups, including face, neck, and postural muscles. Postural deficiencies and behavioral episode management are the two top reasons I see patients on the spectrum, with much success!

What type of approaches and services do you offer at TriStar Family Chiropractic?

We offer individualized care to our patients and not a one size fits all type of treatment. I have additional training in specialized neurological care practices such as Pettibon, Gonstead, Thompson, CLEAR scoliosis chiropractic, as well as being a trauma-informed specialist.

During my care visits, I incorporate the entire person holistically. We look at each individual’s nutrition. Also, each visit incorporates therapeutic exercise, muscle work, neuromuscular re-education, and chiropractic care as needed for the individual.



We all have spines, muscles and nerves but we are individual when it comes to treatment at my practice. We also have other practitioners in our building that offer medical massage, acupuncture, Chinese medicine, female health, and other complementary therapies all under one roof. My favorite part is that we all happen to be mothers.

What are some of the wellness topics you have spoken about?

I have been in healthcare for over 25 years and have spoken all over the United States on various topics including postural disturbances, scoliosis, wellness care for concussions, cancer, neurological disorders, autism spectrum, non-pharmacological pain care, opioid abuse, effects of trauma & DNA, office wellness/ergonomics, chronic disease prevention, dementia, and violence against immigrants.

What age range do you work with?

In my family wellness center, I see pregnant mamas, children and adults up to 100 years old thus far!

Would you share a story about an autistic client you have helped?

One of my favorite stories is a nine-year-old boy that had no pain but his parents were concerned with his bedwetting, behavioral outbursts and severe postural disturbances. He was on several medications for behavior and gastrointestinal deficiencies that led to needing ointments for skin disorders. After the first visit, his facial expressions and demeanor changed so significantly that his parents commented after the treatment.

I incorporated therapeutic exercises, nutrition counseling, muscle work, chiropractic care and neuromuscular re-education during his weekly treatments as well as co-managed with his primary physician and counselor. After less than six weeks of care, he was titrated off some of his meds and had no episodes of bedwetting. He grew about an inch and a half thus improving his posture, his grades improved and he had fewer behavioral outbursts. He is now in middle school and continues to be thriving, despite distance learning efforts at home.



How has COVID-19 changed the way that TriStar Family Chiropractic has provided its services?

As a volunteer for the Washington State Department of Health, we were able to re-open in May 2020 on a limited schedule to provide backup to the emergency rooms for urgent care musculoskeletal conditions and referrals.

I am also a mom of two girls in school, so I had to divide my time as a teacher and run the practice. Thanks to the best staff in the world, we have been able to remain open on a limited schedule. We have been an example for many health clinics in the area for policies and procedures of sanitation and PPE, involving safe patient care for our community.

We also have been successful in remaining sanitary by not using dangerous chemicals that interfere with our patient base. We are looking forward to opening full-time hours once allowed by the Department of Health. In the meantime, we continue to screen all patients before and during their visits, wear PPE, and follow all federal and state sanitation requirements.

Where are you located and how can people connect with your practice?

We are located at 8221 NE Hazel Dell Avenue, Suite 104, Vancouver, WA 98665. We have been at this location for almost five years and it was formerly Hagen Chiropractic for almost 30 years.

Our building is on Hazel Dell Avenue between Safeway and Target. We actually share a fence with Safeway and half of our building is technically Hazel Dell and the other half is Salmon Creek. We are in the process of expanding to the other side of the building.

How would somebody get started to determine what would be best for them?

A consultation is the best way to chat with me and see what your situation is. I give honest feedback on whether I can help or offer a referral, whatever is best for the individual. We are an all-inclusive and discrimination-free practice. We also speak Spanish, French, and American Sign Language in our office.

Call us at (360) 258-1506 or email us at tristarfamlychiropractic@gmail.com. You can also reach us through our website at www.tristarchiro.com.

Follow us at Facebook at www.facebook.com/tristarchiro.

What else is important for Spectrum Life Magazine readers to know?

I am on a mission to offer any individual, family member, or parent with a loved one on the spectrum the best possible alternative care to help alleviate any associated behaviors, nutrition deficiencies, musculoskeletal conditions, etc with specialized wellness care. I don't cure anything; I just help allow the body to repair itself with the right techniques and lots of love and smiles!



Ask Spectrum Life

Autism Resources for our Community

Each issue, *Spectrum Life* Editor and content curator, **Karen Krejcha** answers frequently asked questions about autism-related resources across the lifespan for our community.

Dear Spectrum Life Readers,

In January 2021, Autism Empowerment created and launched the first episode of our new and improved Autism Empowerment Podcast. Since that time, we have produced 15 episodes and have received quite a few emails. In this edition of *Ask Spectrum Life*, we're going behind the scenes to answer the most frequently asked reader and listener questions.

We also published a feature article about the Autism Empowerment Podcast on pages 13-15 of the Winter 2020-21 issue for those who may not have seen it or want a refresher. bit.ly/aepodcastatlm

We'll share a little of the same content in this article, but for the most part, this is fresh information. Past topics included:

- History of Autism Empowerment Radio & Autism and Scouting Radio (our previous podcasts)
- Why is Autism Empowerment relaunching our podcast now?
- Who is our target audience? (also see below)
- How often will podcasts be produced?
- Connection with Spectrum Life Magazine (cross-promotion)
- What kind of topics will you be discussing?
- Will you re-air past podcast episodes on the new show?
- How can we find and support the podcast?

Who is the Autism Empowerment Podcast meant for?

Autistics? Parents? Family? Teachers? Professionals?
Yes. Yes. Yes. Yes. And YES!

Wherever you identify in your autism or autistic journey, Autism Empowerment is here to meet you along the way with acceptance, enrichment, inspiration, and empowerment for the road ahead.

Our goal is to provide interesting, informative, and inspirational content. We know that not every episode is going to resonate with every listener, and that's okay. We want people to know we "get" the ups and downs of an autism journey because it's something we experience ourselves.

We're all on a journey, and although the roads we take will be different for each person, we aim to meet people where they're at, providing help, support, and motivation along the way.

I have a great story to tell. Can I be on your show or in your magazine?

Maybe. Right now, we have a backlog of emails from people who have pitched us. Sadly, there just isn't enough time in the day for us to interview all the interesting people who have stories to share. But, that doesn't mean we don't want to hear from you.

Perhaps we can shine a light on your story in a blog post on the SpectrumLife.org website or if we have space, maybe tell your story in *Spectrum Life Magazine*. Part of Autism Empowerment's expansion focuses on increasing our content production and using that to crossover in a variety of media formats. Watch our AutismEmpowermentPodcast.org website by the end of April 2021 for our new submission guidelines page.

What does it cost to subscribe?

It's free! (Although donations are always appreciated and welcome!) Our show has listeners worldwide. We encourage you to subscribe to our show wherever you listen to your favorite podcasts. Even if you don't listen to every show, subscribing allows you to be aware of recent releases. Subscribing helps support Autism Empowerment as the more subscribers we have, the easier it becomes in search engines for people to find and listen to our show.

Where can I find you?

Apple Podcasts, Spotify, Google Podcasts, Amazon Music, Stitcher, iHeart Radio, Pocketcasts, Castbox, Podchaser, TuneIn, deezer, PodcastAddict, YouTube and more!

What episodes have you done so far?

Episode 1: Welcome to the Autism Empowerment Podcast — This episode is an introduction to Autism Empowerment and the Autism Empowerment podcast. You'll meet co-founders and hosts, Karen and John Krejcha, learn about Autism Empowerment's past, present, and where we're heading in the future.

As a passionate, proactive, and positive autistic and disability-led organization, we are deeply committed to including people of

Continued on page 40



Introduction to Autism Empowerment and the Autism Empowerment Podcast



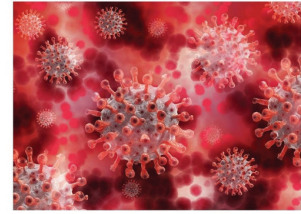
Episode 001



Spectrum Life Magazine Amplifying Autism Acceptance



Episode 002



My Journey with COVID-19 An Autistic Perspective from Karen Krejcha



Episode 003



Autism Support Groups: 9 Points to Ponder in the Journey for Connection



Episode 004



Autism Support Groups - Part 2 Priorities, Plans and Strategies for Success



Episode 005



When the Best Autism Therapy is Love A Letter to Autism Parents



Episode 006



Early Signs of Autism in Children Learn the Signs. Act Early.



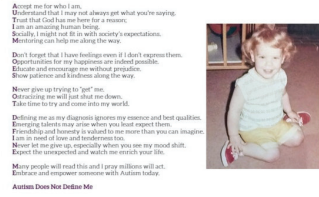
Episode 007



Signs of Autism in Adults Commonly Overlooked in Childhood



Episode 008



Autism Does Not Define Me by Karen Krejcha



Episode 009



Autism Diagnosis Disclosure (Part 1) Disclosing an Autism Diagnosis to a Child



Episode 010



Disclosing a Child's Autism Diagnosis to Family and others in the Community (Pt 2)



Episode 011



Autism Diagnosis Disclosure for Adults



Episode 012



Spring Ahead with Autism Empowerment Organization Updates for Spring 2021



Episode 013



Ways to Get Involved with Autism Empowerment



Episode 014



Autism Acceptance Month 2021 How can we each be better?



Episode 015



all ages, ability levels, and intersecting identities in the work we do. Whether you identify as a self-advocate, parent advocate, family member, ally or service provider, we learn from and value the lived experience of all community members.

Episode 2: Spectrum Life Magazine — This episode provides an introduction to *Spectrum Life Magazine*, a print and online publication written by and for autistic, autism, and disabilities communities. Learn about the magazine's history, where we are today, and our plans for expansion in the future.

Episode 3: My Journey with COVID-19 - An Autistic Perspective — In March 2020, Karen Krejcha, Autism Empowerment Podcast host, became seriously ill with COVID-19. She was sick for many months and is now considered a COVID long-hauler. In this episode, Karen discusses that experience and her subsequent journey back to health. Karen also wrote about these challenges in *Spectrum Life Magazine's* Winter 2020-21 issue as part of the Stories from The Spectrum, Autism from an Autistic Perspective series. bit.ly/autismandcovid19

Episode 4: Autism Support Groups: 9 Points to Ponder in the Journey for Connection (Part 1) — This episode kicks off a two-part series about Autism Support Groups and Forums. In this episode, we discuss the importance of autism-related support and support groups for autistic adults, youth, parents, and family members. Content from the article, *9 Points to Ponder in the Journey for Connection* is included: bit.ly/9pointstoponder

Whether you're searching for connections with others experiencing a particular challenge, seeking resources and referrals, or are hoping to develop new friendships and relationships, support groups and support forums can reduce isolation and provide great benefits.

Episode 5: Autism Support Groups and Forums: Priorities, Plans and Strategies for Success (Part 2) — Now that we've discussed *9 Points to Ponder in the Journey for Connection*, we expand into discussion about Autism Support Groups and Forums - Priorities, Plans, and Strategies for Success. We cover:

- Taking your priorities and turning that into a plan.
- Search tips to help you cut through the clutter.
- Benefits and pitfalls of different types of groups.
- Strategies to encourage a loved one to seek support.

Episode 6: When the Best Autism Therapy Is Love - A Letter to Autism Parents — This episode focuses on supporting parents who are new or early on in their child's autism journey. In the Summer 2018 issue of *Spectrum Life Magazine*, Jasmyn Jones wrote a letter to parents called *When the Best Therapy is Love*. As an autistic mother, Jasmyn shared advice and wisdom that resonates with parents new in their autism journey and is also encouraging for other spectrum travelers. We read that letter and discussing key takeaways. bit.ly/besttherapyislove

Episode 7: Early Signs of Autism in Children - Learn the Signs. Act Early. — In this episode, we talk about common early signs of autism in children from a parent perspective, professional perspective, and self-advocate perspective. We

discuss early sensory signs, speech signs, physical signs, emotional signs, and changes in routine. We talk about play, special interests and autism in girls.

Additionally, we discuss developmental screenings, the CDC's Learn the Signs, Act Early Program, the free CDC Milestone Checker app, and next steps to take if you are concerned about your child's development.

Episode 8: Signs of Autism in Adults Commonly Overlooked in Childhood — This episode focuses on commonly overlooked Signs of Autism in Adults and why so many people in their 30s to 60s and older don't get identified or diagnosed until later in adulthood. Discussion points we break down include: a brief history of autism, social signs, verbal and nonverbal communication, repetitive and ritualistic behaviors, sensory and physical signs, seeking a diagnosis, and finding support. It is estimated that over 2% of adults in the United States are on the autism spectrum. If you are asking yourself if you or an adult family member or friend may be autistic and what to do next, listen to this episode. (As of March 2021, this has been our most downloaded episode.)

Episode 9: Autism Does Not Define Me — In this hope-filled and inspirational episode, we share and discuss the poem, *Autism Does Not Define Me* written by Karen Krejcha, an autistic mom parenting two children on the autism spectrum. The poem has been translated into multiple languages and also appeared in the book *Chicken Soup for the Soul: Raising Kids on the Spectrum: 101 Inspirational Stories for Parents of Children with Autism and Asperger's*. We discuss the concept of Autism Acceptance and the deeper meaning behind the key lines in the poem.

Episode 10: Disclosing an Autism Diagnosis to A Child — This episode begins a three-part series on Autism Diagnosis Disclosure. Topics in this series include disclosure of the diagnosis from parents to their children, from parents to family, teachers and professional providers, from youth to peers, and from autistic adults to others.

Part 1 focuses on why and how to disclose an autism diagnosis to a child. Why is it important for children to have information to better understand themselves? What are common fears that parents have which may keep them from disclosing? What might happen if a child isn't told? We also give suggestions on when and how to share this vital information.

Episode 11: Disclosing a Child's Autism Diagnosis to Family and Others in the Community — In Part 2 of our series on Autism Diagnosis Disclosure, we discuss how and when to disclose a child's autism diagnosis to family members, friends, medical providers, schools and others in the community. We can't cover every family dynamic or personal situation, so what we're doing in this episode is giving an overview including why to tell, who to tell, common talking points, and examples that you can personalize to your own family's needs. We also cover Passive, Reactive, and Active disclosure in community settings.

In most cases, disclosure is about your autistic child being successful, respected and accepted in whatever environment they are in. When done in a positive and meaningful way,

disclosure helps to ensure that your child has their needs met by others. It also can facilitate a positive attitude toward autism and promote autism acceptance.

Episode 12: Autism Diagnosis Disclosure for Adults - When, Why and How to Disclose Your Autism Diagnosis – This episode wraps up our three-part series on Autism Diagnosis Disclosure. We focus on the pros and cons of Autism Disclosure for Adults: if and when to tell, why and how. As adults on the autism spectrum, we have likely been in situations where social quirks and behaviors related to our autistic neurology made others misunderstand, feel uncomfortable, or even judge us. We may not have even known we were autistic but we knew we were somehow different.

We'll look at this from an autistic lens in the context of health, education, employment and relationships.

- Questions to consider in the disclosure process
- Differences between Passive, Reactive and Active Disclosure
- Situations you may wish to disclose (relationships, employment, education)
- Suggestions and tips before disclosing.

Episode 13: Spring Ahead with Autism Empowerment (Program and Organization Updates for Spring 2021) – In this episode, we discuss recent programming changes to content production, support groups, social clubs and service activities at Autism Empowerment and *Spectrum Life Magazine*. We also introduce listeners to a Social Micro Grant opportunity we are fundraising for and hope to launch in the future.

Episode 14: Ways to Get Involved with Autism Empowerment –

Although April is Autism Acceptance Month, we practice Autism Acceptance every day at Autism Empowerment. We invite you to join us! In this episode, we share ways for you to get involved with and support Autism Empowerment and the work we do with *Spectrum Life Magazine* and our Autism Empowerment Podcast. We'll share virtual volunteer opportunities and talk about ways to be an Ambassador for Acceptance of All Abilities. We're also starting our monthly giveaway to win fun merchandise and prizes.

Episode 15: Autism Acceptance Month 2021 – What does Autism Acceptance look like at Autism Empowerment in 2021? In our world-at-large? What is the difference between acceptance and awareness? Between acceptance and stagnation? How can we promote health, wellness and the human needs of each autistic person with respect and dignity? Join Karen and John Krejcha, Autism Empowerment co-founders for this important discussion.

Where can I find links, Show Notes, transcripts, and your podcast newsletter?

In order to be as accessible to as many people as possible, we have Show Notes, reference links and full transcripts available for each show. These are usually published within a week of each show's release. You can find these, our podcast newsletter, and other features by visiting www.AutismEmpowermentPodcast.org

Welcome to Spectrum Life Magazine's Spring 2021 Reader Survey and Contest


We value your time and feedback. Your answers help us learn more about you and how we can better serve you, your family (when applicable) and the autism community at large.

Answer our survey by **May 1st, 2021** and you will be entered to win a surprise package worth over \$100.00.

If you win, we will contact you via email and mail your prize package to you.

<https://www.surveymonkey.com/r/SLMSpring2021>

On behalf of Autism Empowerment and *Spectrum Life Magazine*, thank you again for your support!



Spectrum Life Magazine is made possible with the support of



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To learn more about how to support Autism Empowerment and *Spectrum Life Magazine*, please visit: www.AutismEmpowerment.org/donate

therapy

THERAPEUTIC OPTIONS AND RESOURCES



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Autism and Consequences

Autistic Brain Functioning and Social Behavior

By Judy Endow, MSW, LCSW

One way people learn is from consequences. For example, if you leave your car parked outside with the windows down and it rains, the natural consequence is that your car seats will get wet. Sometimes a person with authority over another person engineers a consequence for certain behaviors as a way to decrease the frequency of unwanted behaviors. For example, a mother or a caregiver might decide that if hitting occurs at the park, there will be no going to the park for the next two weeks.

This sort of engineered consequence for unwanted behavior works for most people most of the time. It is why we use it to successfully teach our children to become responsible citizens. We teach them to be responsible for themselves, their behavior, their belongings, and beyond. These kinds of consequences rarely work well for individuals with autism.

Underlying Brain Functioning

For consequences to be effective in deterring future behavior, a typically functioning brain needs to be in place. For example, if an individual is prone to hitting others when at the park, we decide that because he very much enjoys going to the park, the consequence of not going to the park for two weeks will help him to not hit or at least hit less when he does go back to the park.

The underlying brain function that causes this consequence to be helpful in reducing hitting is very intricate and is based on the reliability of connections between many areas of the brain. In practical terms, it means that in order for this consequence to change the hitting behavior, at minimum, these elements must all function smoothly for the person receiving the consequence:

- Understand hitting is wrong.
- Love going to the park.
- Understand hitting at the park will mean no park for two weeks.
- Be negatively affected during the two-week park ban (i.e., wishing it wasn't so).
- Dislike the park ban so much that he is willing to not hit.
- Come to learn what he can do instead of hitting.
- Have the skills and ability to carry through with alternative behaviors.
- After returning to the park and finding himself about to hit - his brain quickly and efficiently connects all the dots, gathering up and synthesizing information from multiple areas of the brain in a split second, whereby he can put together an informative and behavior-altering understanding that keeps him from hitting.

Most people have brains that can accomplish all the above bullet points. However, people with autism do not. Autistic

people generally have brains that do not support the last bullet point. Remember, an autistic brain means the connections between areas of the brain are weak, making it difficult for the brain to pull together information from the various brain regions - the very thing needed for consequences to change future behavior.

A confounding factor here is that autistic people, after an incident and when in a calm state, can repeat to you exactly what happened, why it was wrong, and what they will do instead of hitting next time they are in a similar situation. Then, the next situation arises, and the hitting again occurs. After the incident is over, the autistic individual is usually remorseful, knows what he did was wrong, understands what the consequence will be, and promises not to hit next time, reciting all the options he might employ other than hitting. Then, the next situation arises, and the hitting again occurs. Repeat, repeat, repeat, over and over and over.

Regardless of how many times the consequence of the park ban is employed, it never seems to work in terms of stopping the hitting. Many times people assume the consequence of park banning isn't a big enough consequence, so they up the ante. I have seen this get out of hand quickly. Regardless of how big the consequence or how articulately the autistic individual can explain the behavior/consequence sequence, it is not effective in producing the desired behavior change.

After a time of bigger and bigger consequences, parents, teachers, and caregivers start blaming the person with autism as if he wants to be a bad person. They say he is making poor choices and ascribe character flaws such as being stubborn and mean. It doesn't turn out good for anyone, including the autistic.

Ways to Get a Different Outcome

Once you understand autistic brains will most likely be unable to attain the last bullet point in the above list - not because the individual consciously chooses this, but because of the brain functioning available to him - it would make sense to stop using consequences in hopes of changing behavior. But, we still have the hitting behavior. What can we do instead? Here are some ideas that have worked for numerous autistics of all ages whom I have worked with:

Escalating Behavior

If the behavior is escalating in nature, you can predict when it will occur because you can see the build-up. Then you can prevent the behavior by intervening very early on rather than waiting until the last minute when it is impossible to stop the behavior from happening.



In escalating behavior, the physiological fight or flight response kicks in right before the behavior occurs. This means the individual is operating on survival instinct, feeling they are fighting for their life, no matter how small and non-life-threatening the situation actually is in the moment. Thus, intervention when the behavior is occurring fails. A successful intervention is at the beginning stages.

Non-Escalating Behavior

If the behavior is not escalating in nature, remember the reasons an individual gets an autism diagnosis and address those areas – communication, social, specific deep interests, and sensory. In light of this, here is what I do to help prevent unwanted behaviors when out in the community.

1. Proactively Address Sensory Regulation Daily

Strive to make sure autistic individuals are supported daily in sensory regulating activities. As an autistic myself, daily sensory regulation allows me to be employed and go out into the community each day. It is the same for others I've worked with. For the individual in the example, when he was well regulated, he could cope with unexpected events better. This meant he was less likely to hit.

2. Plan Schedule Ahead of Time

It is important for most of us to know what will happen ahead of time. This is true no matter how our autism presents. Very few autistic people can track a verbally recited chain of events that are to happen in the future. Some people need a written list. Some need a picture schedule. Regardless of how autism presents in our bodies, all of us like to know the plans rather than to have continual surprises randomly occurring.

3. Stop Talking

As autistics get overloaded in sensory, social, or emotional aspects of situations, the ability to process and comprehend verbal input decreases. Helpers typically “help” by talking more. This is the opposite of what is actually helpful to autistics in tense situations.

4. Use Alternative Communication

Even for a person who is highly verbal, an alternative way to communicate becomes essential in tense or overloaded situations. For example, one individual I worked with had a keychain with mini pictures of a van, a bag of peanuts (his favorite snack), his house, and his favorite video game. When he was having difficulty in the community, I would hand him this keychain. Offering the keychain was a nonverbal way to communicate our exit plan.

5. Use Positive Reinforcement

In this example, the pictures on the keychain showed the order of events and included two reinforcements. The first picture was the van. The second picture was the bag of peanuts that were in the glove box in the van. The third picture was his house where his favorite video game (fourth picture) would be available upon arriving. Thus, positive

reinforcement got him out of the park when needed to prevent the hitting from occurring.

6. Plan and Practice Exit Strategies

Use preplanned signals or visuals to exit a tense or problematic situation BEFORE any problem behavior can happen. In this example, the keychain with mini photos was our exit strategy. We went to the park on three different occasions specifically to practice using the exit strategy. Once the strategy was practiced, including eating the peanuts on the ride home and playing the favorite video game, we then went back to the park for an hour – our usual park time. It was important for this young man to actually get his park time.

7. Ensure Social Understanding

After a difficult time and the individual is settled down, remember to go back and ensure social understanding of what happened. Most autistics are literal and concrete by nature. Social situations are rarely literal and concrete. Thus, we are prone to have a different take on social situations than most other people.

I have found it helpful to draw out a situation, finding out the autistic person's take on it. I leave space in the stick figure cartoon frames for other people's thought bubbles and work to fill those in.

Often, the way other people think is a surprise to autistics because it makes no sense to a literal and concrete mind. Social constructs and socially accepted behavior in society are based on this thinking style of the majority. Many autistics benefit from learning this social information.

For more information: *Outsmarting Explosive Behavior: A Visual System of Support and Intervention for Individuals With ASD* - bit.ly/outsmartingexplosivebehavior



Judy Endow, MSW, LCSW maintains a private practice in Madison, Wisconsin providing consultation for families, school districts, and other agencies. Besides having autism herself, she is the parent of three grown sons, one of whom is on the autism spectrum. Her newest book, *Autistically Thriving* can be purchased at www.judyendow.com.

SPECTRUM LIFE

resource directory

www.spectrumlife.org

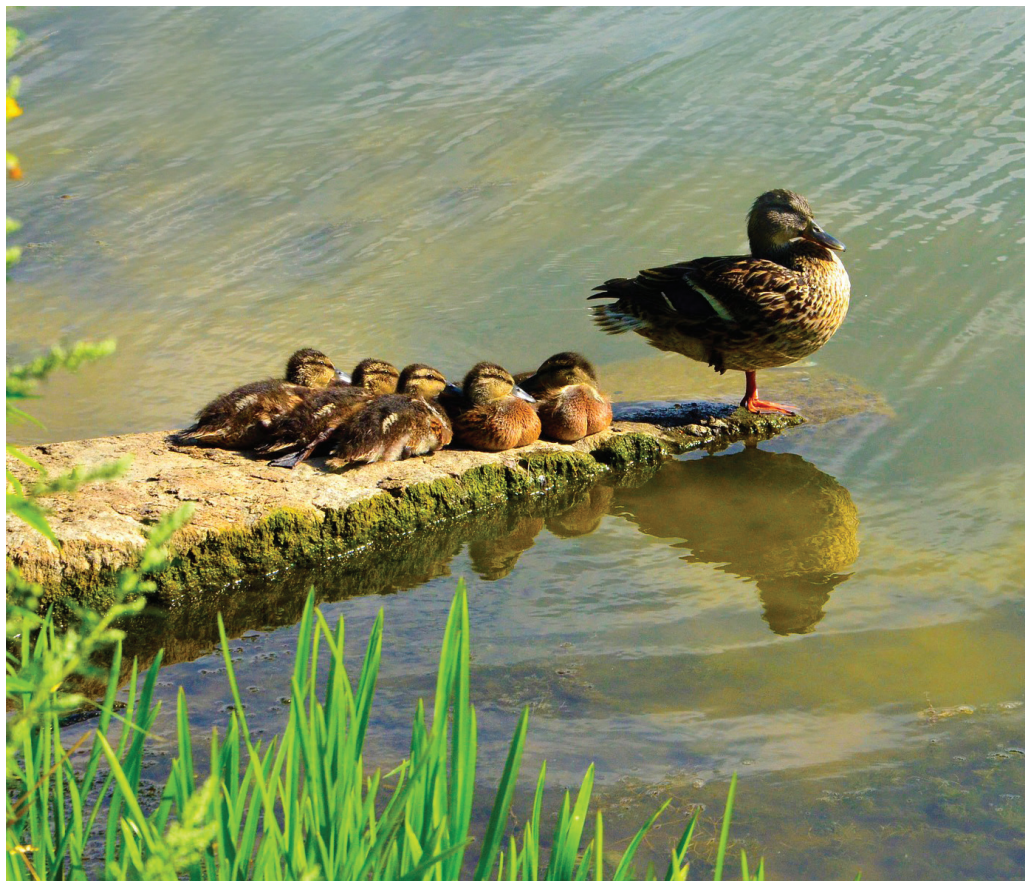
Spectrum Life Magazine serves youth, adults, and families in the autism community. We seek to partner with nonprofit organizations, businesses, support groups, educators and professionals from a variety of fields who desire to support our community in a meaningful way.

If you are an autism-friendly provider who desires to connect with new clients, we can help you make those connections through online directory listings. We also offer advertising and sponsorship opportunities for Spectrum Life Magazine and the Autism Empowerment Podcast. Please contact John Krejcha at spectrumlife@autismempowerment.org or call (360) 852-8369.

Spectrum Life Magazine and Autism Empowerment do not endorse, promote or guarantee the services or outcome of any one provider or type of therapy.

We currently list over 1,300 autism-friendly service providers from Oregon, Washington and throughout the United States. Some of the directory categories where you are able to search for providers in your region include:

Adult Services
Advocacy
Assessment and Diagnosis
Autism-Friendly Businesses
Camps
Caregiving
Chiropractic
Dentists
Educational Support
Employment Assistance
Financial Planning
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Housing
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Medical Professionals
Psychiatrists/Psychologists
Recreation
Safety
Schools
Special Needs Trusts
Sports and Fitness
Support Groups
Therapy and Interventions
Transportation
Travel



The SpectrumLife.org website contains current and past issues of Spectrum Life Magazine, supplemental blog stories, Autism Empowerment Podcast features and a robust autism and disability resource directory. Please share this valuable Autism Empowerment program with your friends, family and colleagues. Thank you for your support!

To learn more about our **Spectrum Life Resource Directory**, please visit and bookmark www.SpectrumLife.org.

If you have a resource you'd like to see added, please contact us at spectrumlife@autismempowerment.org or through our website.

Upcoming Events · www.AutismEmpowerment.org

Due to the pandemic, in-person support, social and service groups are not meeting in the second quarter of 2021. Please visit our website for updated information.

PODCAST PROGRAMMING



Wherever you identify in your autism or autistic journey, Autism Empowerment is here to meet you along the way with acceptance, enrichment, inspiration and empowerment for the road ahead.

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New episodes on most Mondays and some Thursdays with special series to be added.

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MONTHLY

Autism Empowerment offers ongoing Enrichment, Support Groups, Social Clubs and Volunteer Service opportunities. Please see our website for dates, times and Facebook group links.

Ongoing Enrichment:

- Autism Empowerment Podcast
- SpectrumLife.org website
- AutismEmpowerment.org website

Ongoing Service & Volunteerism:

- Autism Serves Kids Care Club
- Autism Serves - Volunteerism for all ages

Online Support Groups:

- Adults on the Autism Spectrum (peer-led)
- AWEtism We Embrace (Adults, Parents, Allies)

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STEPHEN'S PLACE

As an Independent Apartment Community (IAC), Stephen's Place offers positive living options for adults with developmental disabilities.

With forty-one modern apartments, our focus is on community; empowering and enabling each resident to be a productive contributing member of their community.

Call or email us to schedule a tour
(360) 984-3600
info@stephensplace.org

501 SE Ellsworth Road, Vancouver, WA 98664



Apartment rent is inclusive of all meals, supportive services, nursing & ADL assistance and programming including:

Job Skills Training, Placement & Coaching
Life Skills Training
Horticultural Therapy
Group Fitness Classes & Yoga
Arts & Crafts
Movie Nights
Sporting Events
Group Outings to Local Attractions
Transportation Services

We also offer a Day Program to people who live outside of the Stephen's Place community, but would like to build peer relationships and participate in activities.

Learn more about us @ www.stephensplace.org

